

HYPERSEXUALITY IN NEUROLOGICAL DISORDERS

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Declaration of originality

I, Natalie Ahmad Mahmoud Tayim, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Natalie Ahmad Mahmoud Tayim

Abstract

The issue of hypersexuality in neurological disorders is grossly underreported. More research has been done into sexual dysfunction (outside of hypersexuality) in neurological disorders such as erectile dysfunction and hyposexuality (loss of libido). Furthermore, in Parkinson's disease research, most mention of hypersexuality has been in conjunction with other impulse control disorders and has therefore not been examined in depth on its own. Although in recent years hypersexuality has become more recognized as an issue in research, there is still very limited information regarding its manifestations, impact, and correlates. It is therefore important to explore this area in detail in order to broaden understanding associated with this sensitive issue. Perhaps in doing so, barriers will be broken and the issue will become more easily discussed and, eventually, more systematically assessed and better managed.

This thesis aims to serve as an exploratory paper examining prevalence, clinical phenomenology, impact, and potential feasible psychological interventions for hypersexuality in patients with neurological disorders and their carers. The thesis is divided into three main studies:

1. *Study I*: systematic review assessing prevalence, clinical phenomenology, successful treatment modalities, implicated factors contributing to the development, and assessment tools for hypersexuality in specific neurological disorders.
2. *Study II*: systematic investigation using qualitative and quantitative methods assessing prevalence, clinical phenomenology, and impact on both patients with Parkinson's disease and dementia and their carers.
3. *Study III*: investigation of feasible psychological/behavioural management modalities and the development of a public-facing psychoeducational website providing patients and carers with succinct, proper information about hypersexuality in neurological disorders.

The thesis revealed the following:

- a. Prevalence figures regarding hypersexuality in neurological disorders reported in the literature were inconsistent, which might be due to the varied assessment tools used to assess it, lack of insight of patients into their hypersexuality and its consequences, and the inherent challenges and stigma associated with discussing matters relating to sex and/or sexuality that causes some patients to feel embarrassed or shameful, prompting them not to disclose any information.
- b. Hypersexuality did not manifest in the same way among different patients but did appear to overlap across many neurological disorders. Specifically, there was a notable difference in the manifestations of patients with Parkinson's disease and dementia. Hypersexuality in Parkinson's disease was characterized by sexual compulsivity while hypersexuality in dementia was characterized by sexual disinhibition, although there was an overlap in some characteristics.
- c. Hypersexuality did negatively impact areas of patient and carers' daily living, including marital life, family life, social life, health, finances, self-confidence, and quality of life. Specifically, carers appeared very distressed and in despair because of their partners' hypersexuality. The carers' difficulties with coping suggested that they might suffer as much as the patients themselves, if not more because there is no question of insight for the carers as in the case of the patients.

- d. Although cultures and societies have evolved and become more tolerant, the taboos regarding sex are so deep-rooted in that their effects can still be observed in present day and were observed in the patients and carers who took part in the study. This sexual stigma seemed to impede patients/carers' ability to access bodies of help for the hypersexuality, perpetuating their suffering.
- e. The participants expressed their discontent with the services, or lack thereof, that were provided to them regarding the hypersexuality. Professional help-seeking barriers may stem from the stigma associated with sex and the difficulties associated with the discussion of such a sensitive topic for the patients and carers as well as the health professionals. The results showed that neither the patients nor carers were getting the adequate and necessary information and help for the newly-developed hypersexuality.
- f. Many different options for management of hypersexuality were reported in the literature. Most commonly, pharmacological treatment modalities were used: implicated medications believed to contribute to the hypersexuality were reduced/ceased and/or new medication was added to the patients' regimen. There was an evident lack, however, in interventional studies assessing psychological/behavioural management options of the symptoms and consequences of hypersexuality.

The available literature on hypersexuality in neurological disorders will benefit from this thesis as it is the only available in-depth examination. This thesis makes ten contributions:

1. Systematic review examining prevalence, clinical phenomenology, and ameliorating management options of hypersexuality in neurological disorders.
2. Systematic investigation of phenomenology and impact of hypersexuality in patients with neurological disorders and their carers using both quantitative and qualitative methods.
3. Discussion and development of profile of patients with 'insight' into hypersexuality.
4. Inclusion of carers in examination of hypersexuality and its effects, as well as in consideration of feasible psychological interventions.
5. Triangulation of patient and carer accounts of hypersexuality.
6. New semi-structured interview schedules for assessment of hypersexuality developed for hypersexual patients with neurological disorders and their carers.
7. Website as a psychoeducational tool for patients with neurological disorders and their carers providing contact details.
8. Recommended pathways for management of symptoms and effects of hypersexuality for health professionals and clinical researchers to consult.
9. Addressing the challenges associated with the discussion of sex in the neurological disorder setting.
10. Highlighting the possible link between background psychology and psychological side-effects of medications.

Impact statement

The insight and knowledge gained in this thesis has implications both inside and outside academia. Although these implications are addressed at the end of each chapter, the most notable are as follows:

Inside academia, one might consider:

- The potential benefits of including only a small sample size when tackling an issue as sensitive as hypersexuality to grasp the nature and severity of the issue.
- Exploring other recruitment methods that could guarantee a higher sample size such as the use of radio and social media to inform people of potential studies, as was suggested by one of the participants in the study, or providing study leaflets to every patient and carer attending clinics. Home visits could also be of benefit.
- Multi-centre studies to further ensure substantial sample size, potentially benefiting prevalence studies, which are inconsistent.
- Developing a sensitive, standardised hypersexuality-specific tools to be used across all neurological disorders that would make it easier to assess prevalence and/or phenomenology, and may consequently make it simpler to compare between neurological disorders to create a more holistic view of hypersexuality.
- Conducting interventional studies testing the effectiveness of management options on the symptoms and effects of hypersexuality, separate from other impulse control disorders.
- Conducting studies to compare the manifestations and impact of hypersexuality within neurological disorders, such as in dementia between frontotemporal dementia and Alzheimer's disease, and between neurological disorders, such as between Parkinson's disease, dementia, and epilepsy. Such studies could be beneficial as they might uncover distinctions and patterns that have yet to be uncovered.
- Exploring the significance of past experiences and how they affect the nature in which the hypersexuality develops, as is discussed in the findings.
- Not disregarding carers in any assessment of hypersexuality as they can often provide more information than the patients.
- Conducting studies investigating the professional help-seeking barriers and possibly involving general practitioners and consultants and considering reasons why they do not broach the subject.
- Conducting studies testing the recommended pathways for improvement, outlined in this thesis.

Outside academia, health professionals might consider:

- Informing patients and their carers of the possibility of developing hypersexuality and its relationship to the neurological disorder. Lack of information might have negative consequences on the patients' lives and the lives of those around them.
- Educating themselves about hypersexuality and the negative impact it has in order to then educate the patients and their carers/families. Perhaps in doing so (as well as having appropriate communication skills), they can attempt to normalise hypersexuality, explain it, and provide reassurance, if nothing else. This would help alleviate the patient and carer burden of living with hypersexuality and consequently facilitate better help-seeking behaviour.
- Not forgetting to routinely ask patients and their carers about such sexual changes to allow them to keep a close eye on its development and/or progression.
- The need to also include carers in the discussion of hypersexuality, especially since some patients may choose not to disclose information about the changes in their sexuality because of the sensitive nature of the issue or may not realise their sexual changes to begin with.
- That the recommended pathways presented in the thesis should only act as starting points. Further research into hypersexuality will allow for the improvement of these pathways.

Outside academia, carers might consider:

- Educating themselves about hypersexuality and understanding that it is beyond the patients' control. This does not mean that carers must accept however the hypersexuality manifests, but rather to know that they are able access bodies of help that can provide support and advice if needed.

Outside academia, society might consider:

- Taking a step back and reevaluating stigmatised beliefs. Although this is difficult considering the deep-rooted stigmas associated with sex, it is not impossible.

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to mama and baba

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List of abbreviations

Terms

AC-QoL	Adult Carer Quality of Life Questionnaire
AD	Alzheimer's disease
AIDS	Acquired Immune Deficiency Syndrome
ALS	Amyotrophic lateral sclerosis
BAS	Behavioural activation system
BD	Brain disease
BIS	Behavioural inhibition system
BIS-11	Barratt Impulsiveness Scale
BIS/BAS	Behavioural Inhibition System and Behavioural Activation System
BPADRS	Behavioural Pathology in Alzheimer's Disease Rating Scale
BPC	Behavioural Problem Checklist
BSAT	Brixton Spatial Anticipation Task
BSSD	Behavioural Syndromes Scale for Dementia
C	Cohort
CBT	Cognitive behavioural therapy
CC	Case control
CHSQ	Carer Hypersexuality Screening Questionnaire
CR	Case report
CS	Cross sectional/case series
DA	Dopamine agonist
DBS	Deep brain stimulation
DRC	Dementia Research Centre
DRT	Dopamine replacement therapy
DSM-IV	Diagnostic Statistical Manual, 4 th edition
ECH	Edgware Community Hospital
ED	Erectile dysfunction
EPHPP	Effective Public Health Practice Project
FBI	Frontal Behaviour Inventory
FFI	Fatal familial insomnia
FLE	Frontal lobe epilepsy
FSFI	Female Sexual Function Index
FTD	Frontotemporal dementia
GP	General practitioner
Gpi	Globus Pallidus pars interna
HADS	Hospital Anxiety and Depression Scale
HBI	Hypoxic brain injury
HC	Healthy controls
HD	Huntington's disease
HIE	Hypoxic ischaemic encephalopathy
Hipp. Sc.	Hippocampal sclerosis
HIV	Human immunodeficiency virus
HS	Hypersexuality
HSE	Herpes simplex encephalitis
HSCT	Hayling Sentence Completion Task
ICDs	Impulse control disorders
ICD+	With ICDs
ICD-	Without ICDs
ICD-10	10 th revision of the International Statistical Classification of Diseases and Related Health Problems
ICDRC	Impulse Control Disorders and Related Conditions Questionnaire

IIEF	International Index of Erectile Function
IRI	Interpersonal Reactivity Index
IQ	Intelligent quotient
J-QUIP	Japanese version of QUIP
KBS	Kluver-Bucy syndrome
KLS	Kleine-Levin syndrome
LBD	Lewy body dementia
L-dopa	Levodopa
MDC	Movement Disorders Clinic
MIDI	Minnesota Impulse Disorders Questionnaire
MMPI	Minnesota Multiphasic Personality Inventory-2
MMSE	Mini-Mental State Examination
mPOA	Medial preoptic area
MS	Multiple sclerosis
MSA	Multiple system atrophy
NA	Not available
NART	National Adult Reading Test
ND	Neurological disorder
NHNN	National Hospital for Neurology and Neurosurgery
NMSS	Non-motor Symptoms Scale
NPI	Neuropsychiatric Inventory
NR	Not reported
NREC	National Research Ethics Committee
OBS	Overt Behaviour Scale
OSA	Obstructive sleep apnoea
OSEC	Open Sexual Communication
PD	Parkinson's disease
PD-SAST	Parkinson's Disease Sexual Addiction Screening Test
PDE5-I	Phosphodiesterase type 5 inhibitor
PDQ-39	Parkinson's Disease Questionnaire-39
PDQ-39 SI	PDQ-39 summary index
pRBD	Probable rapid eye movement, sleep behaviour disorder
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PSP	Progressive supranuclear palsy
PVN	Paraventricular nucleus
QUIP	Questionnaire for Impulsive-Compulsive Disorders in Parkinson's Disease
QUIP-s	Short version of QUIP
QUIP-rs	QUIP Rating Scale
RCPM	Raven's Coloured Progressive Matrices
RLS	Restless legs syndrome
RMET	Reading the Mind in the Eyes Test
SASBA	St. Andrew's Sexual Behaviour Assessment
SAST	Sexual Addiction Screening Test
SAST-R	Sexual Addiction Screening Test-Revised
SAB	Sexually aberrant behaviour
SCA3	Spinocerebellar ataxia 3
SCI	Spinal cord injury
SCS	Sexual Compulsivity Scale
SD	Standard deviation
SGRS	Stockton Geriatric Rating Scale
SRA	Social Research Association
SSRI	Selective serotonin reuptake inhibitors

STDs	Sexually transmitted diseases
STN	Subthalamic nucleus
STN DBS	Deep brain stimulation of the subthalamic nucleus
TBI	Traumatic brain injury
TLE	Temporal lobe epilepsy
TS	Tourette's syndrome
Tu. Sc.	Tuberous sclerosis
UCL	University College London
UCLH	University College London Hospital
UK	United Kingdom
UPPS-P	UPPS-P Impulsive Behaviour Scale
URICA	University of Rhode Island Change Assessment Scale
VaD	Vascular dementia
VTA	Ventral tegmental area
ZSQ-ICD	Zurich Screening Questionnaire for ICDs

People

CS	Caroline Selai
JF	Jennifer Foley
JNP	Jalesh N. Panicker
NT	Natalie Tayim
PB	Pedro Barbosa

i was made from sex.
there is no shame. in such a creation.

– *nayyirah waheed*

if you're completely honest, what words do come to mind when you think of a sex addict? i suspect, like most people, the words that come to mind are someone who is a bit of a creep or a freak, or maybe someone who is a bit sleazy. or you might think of somebody below moral standards, you might think of someone who's selfish and greedy or worse, you might think that a sex addict was a risk to society, a potential rapist, a child molester, or sexual pervert.

– *paula hall*

Important note

Two types of superscripts were used in this thesis and it is important to draw the distinction between them:

- Text that is followed by ^(x) superscript indicates reference to citation in bibliography.
- Text followed by ^x superscript without the ‘ () ’ indicates a footnote at the bottom of the respective page.

Chapter 1

Introduction

1.1 Background

1.1.1 *Sexuality*

A person's sexuality is a fundamental part of life. A healthy sex life plays an important role in quality of life and quality of relationships. Typically, a healthy sex life generates a good quality of life^(1,2). Sexuality is a process that requires the “functioning of the body's autonomic, sensory and motor systems, and depends upon the neurological, vascular and endocrine systems allowing sufficient blood supply to and from genital organs, a balanced hormonal system and a healthy emotional state”^(3,4). Psychosocial factors, individual factors, and sexual partners all affect expressions of sexuality^(3,4). Sexuality can thus be influenced by life experiences such as abuse, illnesses, and their treatments^(3,4). The human sexual response cycle is a four-phase⁵ model describing the sequence of physical and emotional changes that accompany both male and female sexual arousal and consequent sexual activity^(5,7). The four phases in order of normal occurrence are excitement, plateau, orgasm, and resolution⁽⁷⁾. Although sexual response is fundamentally similar between and within sexes, there may be differences in response intensity and the duration of each phase⁽⁵⁾, as sexuality is generally an individual experience.

1.1.2 *Sexual dysfunction*

Sexual dysfunction refers to any difficulty experienced by an individual or couple during any phase of the sexual response cycle which disrupts their ability to reach optimum satisfaction⁽⁷⁾ and, in turn, can be detrimental to their quality of life and cause extreme distress and personal and/or interpersonal strain^(8,9).

Causes of sexual dysfunction

Causes of sexual dysfunction include interpersonal, psychological, sociocultural, and physical disturbances. Interpersonal and psychological causes include anxiety⁽¹⁰⁾, depression⁽¹¹⁾, relationship or marital problems⁽¹²⁾, feelings of fear and/or guilt⁽¹²⁾, concerns about body image⁽¹³⁾ and/or sexual performance, and effects of past sexual trauma⁽¹²⁾ and/or physical abuse^(14,15). Sociocultural causes may include insufficient education, conflict with religious, personal, and/or family values, and other societal influences^(12,14). Physical causes of sexual dysfunction may include diabetes^(16,17), heart and vascular disease^(17,18), kidney⁽¹⁹⁾ and liver failure⁽²⁰⁾, thyroid disease⁽²¹⁾, hormonal imbalances⁽²²⁾, alcoholism^(23,25), drug abuse^(25,26), pelvic injury or trauma⁽²⁷⁾, pelvic surgery⁽²⁸⁾, side effects of medication⁽²⁹⁻³¹⁾, and neurological disorders^(32,33).

Symptoms of sexual dysfunction

The symptoms of sexual dysfunction in males include erectile dysfunction, a difficulty achieving and maintaining erections suitable for intercourse, delayed or no ejaculation despite adequate sexual stimulation, and/or premature ejaculation, a difficulty controlling timing of ejaculation^(34,35). Females, on the other hand, may experience difficulty achieving orgasm, difficulty relaxing vaginal muscles enough for intercourse, and/or insufficient vaginal lubrication prior to and during intercourse^(34,36). Some symptoms of sexual dysfunction common to both males and females include difficulty in arousal, pain with intercourse, decreased desire for sex termed hyposexuality, and/or a heightened desire for sex^(35,36) termed *hypersexuality*⁽³⁶⁾, which is the primary focus of this dissertation.

¹ Can also be termed “narrative literature review”.

² Some research conveys the human sexual response cycle to consist of five phases including ‘desire’ before ‘excitement’. The ‘desire’ phase can be characterised by sexual urges occurring in response to sexual cues or fantasies.

Sexual dysfunction and neurological disorders

Sexual dysfunction, including hypersexuality, occurs frequently in patients with neurological disorders and is multifactorial, often with different etiologies contributing to the problem. It can be detrimental to the patients and their partner's quality of life⁽³⁴⁾. Nonetheless, thorough evaluation and appropriate use of available therapies can improve sexual function for many patients⁽³⁴⁾. Table 1 summarizes the possible manifestations of sexual dysfunction in neurological disease and potential therapeutic strategies:

Table 1 – Manifestations and potential therapeutic strategies of sexual dysfunction^(3,34,37)

Dysfunction	Symptoms	Potential therapeutic strategies
Sexual arousal dysfunction	Erectile dysfunction	Sildenafil (Viagra) Tadalafil (Cialis) Vardenafil (Levitra) Sublingual apomorphine Intraurethral medication application Intracavernosal injections Vacuum constriction devices Surgical placement of intra-penile prosthesis
Ejaculatory dysfunction	Premature ejaculation	Serotonergic agents: Clomipramine Selective serotonin reuptake inhibitors: Sertraline Paroxetine
	Delayed ejaculation (difficulties reaching orgasm)	Practical therapeutic strategies* Yohimbine Midodrine Increased stimulation (apart from vaginal intercourse) – vibrator use
Sexual desire dysfunction	Hypersexuality (increased libido)	Reduction/cessation of behaviour-inducing drug (in PD) Introduction of new medication
	Hyposexuality (decreased libido)	Practical therapeutic strategies* Hormonal treatment (androgen, oestrogen)

PD: Parkinson's disease

*. Practical therapeutic strategies incorporate psychological therapies including but not limited to counselling, psychotherapy, sex, couple and behavioural therapies.

1.1.3 Hypersexuality

The term *hypersexuality* is not always only used to describe increases in sexual behaviour⁽³⁸⁾. Other expressions that are used include “hyperphilia”⁽³⁸⁾, “hypersexual disorder”⁽³⁹⁻⁴¹⁾, “compulsive sexual behaviour”^(42,43), “impulsive-compulsive sexual behaviour”⁽⁴⁴⁾, “sex addiction”⁽⁴⁵⁾, “hyperlibidinisism”⁽⁴⁶⁾, “sexual disinhibition”⁽⁴⁷⁾, “inappropriate sexual behaviour”⁽⁴⁸⁾, and “out-of-control”⁽⁴⁹⁾ sexual behaviour. This dissertation will use the term *hypersexuality* as it is the most atheoretical and unbiased expression. It will, however, be used interchangeably with the terms “compulsive sexual behaviour”, characteristic of increased sexual behaviour in PD, and “sexual disinhibition”⁽⁴⁷⁾ or “sexual inappropriateness”^(50,51), characteristic of behaviour in dementia, to distinguish them from each other.

Hypersexuality is expressed more frequently in the general male population than in the female population⁽⁵⁸⁾. Only 8.0-40.0% of those affected are female, possibly because, females generally have fewer sexual partners and experiences than males do during their lifetimes⁽⁵⁸⁾. Another reason might be that the stigma associated with sex for women is different than that for men: “a man might be a ‘player’ or a ‘bit of a lad’, but a woman that has many sexual partners is called a ‘slut’ or ‘whore’”⁽⁵²⁾, possibly prompting females not to divulge information about their sexual experiences. The prevalence of hypersexuality in the general US population ranges from 3.0-6.0%⁽⁵³⁾.

Usually, sexual expression and behaviour depend on several dynamics including individual and relationship schemes, societal values, cultural norms, and ethnic and religious principles⁽⁵⁵⁾. The question to be asked is, “How much sex is too much? How much is enough? And who decides?”⁽⁵⁴⁾. It is a challenge to define what sexual behaviour constitutes as normal and what behaviour does not, as sexual expression and identity differ between different individuals, couples, groups, and cultures. The term hypersexual disorder, was excluded from the publication of the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition* despite having been initially considered for inclusion⁽⁵⁵⁾. This may have left clinicians without anchor for diagnosis of such presented increased sexual behaviour. There has thus been debate regarding this lack of consensus; however, it can be argued that “whilst it is true that having a recognised name for a problem can be a relief for many because it normalizes the problem and may offer community support from other sufferers, for others a label increases the feelings of personal shame and can restrict power to change, especially if they believe a label to be fixed and permanent”⁽⁵⁶⁾. The proposed⁽⁵⁷⁾ definition, however, defines hypersexual disorder as “recurrent and intense sexual fantasies, urges, and behaviour over a period of six months or more, leading to adverse consequences and clinically significant distress or impairment in social, occupational, or other important areas of functioning”⁽⁴⁵⁾.

1.1.4 Hypersexuality in neurological disorders

The issue of hypersexuality in neurological disorders is grossly underreported as compared to that in the general population. Most commonly, hypersexuality is reported in patients with Parkinson’s disease (PD)⁽⁵⁷⁾ and dementia^(58, 59). It is necessary to explore hypersexuality further in order to broaden the understanding associated with such a sensitive issue. Perhaps in doing so, barriers will be broken and the issue will become more easily discussed and, eventually, more clearly and better managed.

Currently, there are no validated tools used to assess hypersexuality in neurological disorders⁽⁶⁰⁾. Self-assessment and self-reporting, therefore, are the most reliable methods to date used to diagnose and assess hypersexuality⁽⁶¹⁾. The Voon proposed operational diagnostic criteria for pathologic hypersexuality, however, are commonly used to diagnose hypersexuality⁽⁶²⁾, and are as follows:

“A. The sexual thoughts or behaviours are excessive or an atypical change from baseline marked by one or more of the following:

1. Maladaptive preoccupation with sexual thoughts
2. Inappropriately or excessively requesting sex from spouse or partner
3. Habitual promiscuity
4. Compulsive masturbation
5. Telephone sex lines or pornography
6. Paraphilias

B. The behaviour must have persisted for at least one month

C. The behaviour causes at least one or more of the following:

1. Marked distress
2. Attempts to control thoughts or behaviour unsuccessfully or result in marked anxiety and distress
3. Are time-consuming

4. Interfere significantly with social or occupational functioning

D. The behaviour does not occur exclusively during periods of hypomania or mania

E. If all the criteria except C are fulfilled, the disorder is subsyndromal”⁽⁶²⁾.

For purposes of this dissertation, the term hypersexuality will be defined as the neurological patient’s heightened motivation to pursue sexual reward and an increase in sexual thoughts, urges, and/or behaviour⁽⁶³⁾ reported by the patient and/or their carer.

1.1.5 *Hypersexuality and sex addiction*

Some research has likened hypersexuality to sex addiction. Sexual addiction can be defined as a “condition in which some form of sexual behaviour is employed in a pattern that is characterised by two key features: recurrent failure to control the sexual behaviour, and continuation of the sexual behaviour despite significant harmful consequences”^(64,65). Research shows that “all addictions, both chemical and process, are used as a form of affect regulation. There is, of course, nothing wrong with using sex, to alleviate difficult emotions and to create a sense of wellbeing, but if sex becomes a primary coping mechanism on which a person depends, in spite of negative consequences, then it might be considered an addiction”⁽⁶⁶⁾. Sexaholics Anonymous provides an addiction model for these heightened sexual tendencies:

It begins with an overpowering desire of a high, relief, pleasure, or escape. It provides satisfaction. It is sought repeatedly and compulsively. It then takes on a life of its own. It becomes excessive. Satisfaction diminishes. Distress is produced. Emotional control decreases. Ability to relate deteriorates. Ability for daily living is disrupted. Denial becomes necessary. It takes priority over everything else. It becomes the main coping mechanism. The coping mechanism stops working. The party is over.⁽⁶⁶⁾

Symptoms of sex addiction include: (1) frequently engaging in sexual activities with more partners than planned; (2) a preoccupation with sex; (3) consistent and constant desire to engage in sexual activity; (4) unsuccessful attempts at stopping the behaviour; (5) neglecting other areas of life due to preoccupation with or pursuit of sex; (6) inability to reduce or stop sexual activity despite negative consequences; and (7) irritation when unable to “engage in desired behaviour”⁽⁶⁷⁾. These mirror the reported symptoms associated with hypersexuality. Furthermore, clinical research has in fact shown that dopamine appears to be the “common denominator in all addictions”⁽⁶⁸⁾. It plays a vital role in hypersexuality, as will be discussed in the upcoming section, especially in PD. The similarities between sex addiction and hypersexuality overlap enough to aid health professionals in extrapolating from the sex addiction research on the general population and then modifying it accordingly to the needs of patients with neurological disorders and their carers in the case of lack of information and guidance.

Nevertheless, some have argued that sex addiction does not belong under hypersexual disorder due to the theory that “sex addiction is not the same as a high sex drive... [and that] many of the [sex] addicts... do not get sexual pleasure from what they’re doing and it does not satiate their drive”⁽⁶⁸⁾. However, empirically, it has been observed that individuals with hypersexuality also possibly neither get sexual pleasure from what they are doing nor have their sexual drives satiated⁽⁶⁸⁾. Individuals suffering from hypersexuality have recounted the substantial personal and interpersonal suffering stemming from overthinking about sex, especially since those thoughts might not line up with their personal beliefs and desires⁽⁶⁹⁾, similar to those suffering from sex addiction.

1.1.6 Dopamine and sexuality

Dopamine and reward

Research recognizes dopamine as a fundamental neurotransmitter in networks associated with reward and addiction^(60,70-73) and as the basis of the reward and pleasure circuit⁽⁵⁶⁾. The neuromolecular mechanism of action of dopamine first includes the release of dopamine outside the synaptic cleft, which then diffuses in the extracellular fluid where it is metabolised⁽⁷⁴⁾. The metabolism and reuptake of dopamine thus mediates dopamine receptor action⁽⁷⁴⁾. The firing pattern of dopamine ensues as a response to “motivationally relevant stimuli”⁽⁷⁴⁾.

Furthermore, an individual’s motivation stems from the desire to achieve rewards that have been previously achieved and thus, motivation is produced by cues that lead to such rewards⁽⁷⁴⁾. Dopamine plays a role here in that when the association has been created between the stimuli and rewards, dopaminergic effect on this association may remain potent long after until this motivation-related behaviour possibly becomes extinct⁽⁷⁴⁾. Further, memory processing also involves dopamine which “biases the brain towards events that will produce reward”^(56,75).

Dopamine in sexual behaviour

Studies have realised dopamine as being a pro-sexual neurotransmitter⁽⁷⁶⁾ that is naturally produced by having sex⁽⁵⁶⁾. Studies using both humans and animals have uncovered the association between dopamine and sexual motivation, copulatory proficiency, and genital reflex⁽⁷⁷⁻⁷⁹⁾. Dopamine is involved in three distinct anatomical pathways^(79,80). The nigrostriatal dopamine system is necessary for the sensory-motor coordination, which helps facilitate mount and intromission⁽⁷⁹⁾. The incertohypothalamic system, as well as evidently being involved in sexual motivation^(56,81,82), is essential for “penile erectile and ejaculatory performance”⁽⁷⁹⁾. The mesocorticolimbic system is involved in sexual rewarding⁽⁷⁹⁾, modulation of emotion-related behaviour⁽⁸³⁾, and the preparation phase of sexual behaviour including sexual arousal and motivation⁽⁷⁹⁾.

The nigrostriatal pathway originates in the zona compacta of the substantia nigra, which projects to the caudate nuclei and the putamen of the striatum^(80,84). Only after copulation begins is the dopamine released in the dorsal striatum⁽⁸⁴⁾. This reinforces the necessity of this pathway for motor, rather than motivational, aspects of copulation and intromission⁽⁷⁹⁾.

The incertohypothalamic pathway of the hypothalamus originates from the A12-14 dopaminergic cell groups which project to the medial preoptic area (mPOA) and the paraventricular nucleus (PVN)^(79,80,84). In the PVN, the release of dopamine stimulates oxytogenic neurons, which project to the extra-hypothalamic brain areas (e.g.: hippocampus, medulla oblongata)⁽⁷⁶⁾. These areas are essential for sexual motivation and reward and are essential during the consummatory period^(76,81,82). Research suggests the involvement of the incertohypothalamic pathway in the “anticipatory phase of the copulatory behaviour”⁽⁷⁹⁾. Apart from receiving cues from the olfactory systems, the mPOA is directly connected to the ventral tegmental area (VTA), the source of the mesocorticolimbic dopaminergic pathway⁽⁷⁹⁾.

The mesocorticolimbic pathways involves both the mesolimbic and the mesocortical pathways⁽⁸³⁾. The mesolimbic dopaminergic pathway includes the VTA that projects to the nucleus accumbens, the brain region that has an important role in reward, pleasure and addiction⁽⁸³⁾. This pathway also projects to the amygdala, responsible for emotional reactions, and the hippocampus, which is associated with memory and learning⁽⁸³⁾. The involvement of these areas suggests that sexual activity is rewarding⁽⁷⁹⁾ since dopamine in the mesolimbic area is “recognised as a mediator of reinforcement and is implicated in drug addictions and is also recognised to play an important role in the regulation of hypersexuality”⁽⁵³⁾. The mesocortical pathway, on the other hand, includes VTA projections to the prefrontal cortex, associated with decision-

making, moderating social behaviour, and inhibition. Due to their overlap, these two pathways are often referred to as the “mesocorticolimbic system”⁽⁸³⁾.

1.1.7 Dopamine and Parkinson’s disease

PD is a neurological disorder resulting from the degeneration of the neurons of the substantia nigra, which decreases the amount of dopamine available for neurotransmission in the corpus striatum, affecting movement control⁽⁸⁵⁾. PD patients are consequently required to manage their disorder using dopamine replacement therapy, which may lead to impulse control disorders (ICDs). Hypersexuality has been described as a part of a general loss of control associated with lesions in the prefrontal cortex and is the earliest ICD to be identified^(53,86). Most commonly in dopamine replacement therapy, dopamine agonists are associated with the development of ICDs, possibly due to the dopamine-receptor binding profiles⁽⁸⁶⁾. Dopamine agonists act on dopamine receptors, improving patients’ motor symptoms (D1 and D2 receptors abundant in the dorsal striatum)⁽⁸⁶⁾, but possibly amplifying activation within the reward centre of the brain^(87,88) associated with both behavioural addictions and substance abuse disorders (D3 receptors abundant in the ventral striatum)⁽⁸⁶⁾. Levodopa, however, is also associated with the development of ICDs. Although the mechanism is still unclear, research reports the possibility that levodopa causes dopaminergic dysregulation within the mesolimbic pathway of the brain, consequently leading to the development of impulsive tendencies⁽⁸⁹⁾.

1.1.8 Impulse control disorders and Parkinson’s disease

As mentioned above, dopaminergic drugs taken by patients to manage their PD are subsequently producing “reward-seeking” behaviours^(90,92) called ICDs, which include the hypersexuality as well as pathological gambling, compulsive shopping, binge eating, dopamine dysregulation syndrome, hobbyism, and punding^(92,96). Such behavioural changes in PD patients may result from abnormal dopaminergic stimulation caused by a “combination of disease progression, dopaminergic medication, and environmental and genetic factors”⁽⁸⁶⁾. More research has been done about ICDs in general as compared to just hypersexuality; therefore, it is necessary to discuss ICDs first to better understand the upcoming section. Dopamine agonists are recognised as likely contributing to the development of the ICDs in patients with PD⁽⁹⁷⁾. ICDs can be defined as “the failure to resist an impulse, drive, or temptation to perform an act that is harmful to the person or to the other”⁽⁹⁸⁾ and have been generally linked to “increased impulsivity, decreased ability to learn from negative outcomes, and decreased ventral striatal activation, suggesting loss of inhibitory control”⁽⁵³⁾.

Prevalence

These drug-induced pathological behaviours are not uncommon. The prevalence of ICDs is reported to vary between 8.0-28.0%⁽⁹⁷⁾. The multicentre DOMINION study, which involved 3090 patients, reported a prevalence of 13.6% for ICDs in PD with 5.0% for pathological gambling, 3.5% for compulsive sexual behaviour, 5.7% for compulsive buying, and 4.3% for binge eating⁽⁹⁹⁾. In another study that included 321 PD patients taking dopamine agonists, 69 experienced ICDs: 36.0% exhibited gambling, 35.0% exhibited hypersexuality, 26.0% exhibited compulsive spending and shopping, and 17.0% exhibited binge eating⁽¹⁰⁰⁾.

Risk factors

Researchers have examined other potential risk factors that may increase the chances of developing these aberrant behaviours⁽¹⁰¹⁾. Several of these risk factors now include a history of alcoholism⁽¹⁰¹⁾, substance abuse and smoking^(102,103), as well as premorbid psychiatric symptoms such as depression and anxiety^(101,104). Younger patients appear more likely to develop such behaviours since dopamine agonists are generally prescribed to younger PD patients^(101,104-106). Gender is also a risk factor as males are more likely to develop hypersexuality^(104,107,108) and gambling^(104,108-110), while it seems to be equally divided between males and females regarding binge eating and compulsive shopping^(91,111).

Challenges

Essentially, there are several issues associated with findings regarding ICDs. First, different studies report varying prevalence figures for ICDs. Second, there is a lack of sensitive tools to detect such disorders. However, the Questionnaire for Impulsive-Compulsive Disorders in Parkinson's Disease (QUIP)⁽¹¹²⁾, a validated questionnaire used to screen for the different ICDs in patients with PD, can be used. Third, it is challenging to determine what constitutes a “disorder”, and at what level any changes reach this threshold. Fourth, patients can lack insight into, or wish not to disclose, any changes, and therefore any assessment of prevalence should also consider input from the patients' partners/carers³ as well. Lastly, issues surrounding sexuality can be particularly sensitive, and thus any changes may go undetected, despite potential devastating impacts on relationships and personal functioning.

1.1.9 Hypersexuality and Parkinson's disease

Hypersexuality resulting from neurological disorders is most often reported in patients with PD and yet still underreported. As in the other ICDs, dopaminergic drugs used to manage PD are believed to produce the hypersexual behaviour. There is currently no data regarding sexual conduct in PD patients without medication. Although there is no validated tool to assess hypersexuality specifically in patients with PD⁽⁶⁰⁾, the QUIP is used to screen for hypersexuality in this group⁽¹¹²⁾. This questionnaire can be used alongside self-reporting⁽⁶¹⁾ to help health professionals identify affected patients.

Prevalence

At present, the literature seems to present different prevalence figures with regards to hypersexuality in PD. It has been estimated as being somewhere from 2.0% to approximately 10.0%^(43, 99, 107, 111, 113). A recent systematic review of hypersexuality in PD by Codling et al. (2015) reports the prevalence of hypersexuality in PD to be between 2.0% to 4.0% and between 3.5% and 7.2% among users of dopamine agonists⁽⁵³⁾. Further, in another more recent systematic review conducted by Nakum and Cavanna (2016), average lifetime prevalence of hypersexuality in patients with PD on dopamine replacement therapy has been estimated at 2.7%, while lifetime prevalence for patients on dopamine agonists is estimated at 7.4%⁽⁸⁶⁾. The inconsistency in reported prevalence figures may be due to the stigma⁽¹¹⁴⁾ associated with sex, which may cause patients fear and embarrassment when discussing such a sensitive topic with other people⁽⁵⁶⁾. These feelings may thus complicate the identification and consequent evaluation of the behaviour.

Clinical phenomenology

The behavioural expression associated with hypersexuality involves heightened libido, increased frequency of erection, increased sexually demanding demeanour, seeking sex from prostitutes and use of sex phone lines⁽⁵³⁾, changes in sexual orientation⁽⁵³⁾, which may be coupled with excessive⁽⁵³⁾, compulsive and aggressive masturbation^(60, 103, 107, 115-119), and expression of paraphilias^(120, 121), all associated with disrupted frontal inhibition^(89, 122). Research suggests two possible reasons for the increased libido: First is the disintegration of the reward circuit, and second is the fact that patients are subjected to perpetual and prolonged dopaminergic system stimulation by medication, which might have functional and structural repercussions⁽¹¹¹⁾.

Risk factors

The exact causes of hypersexuality are poorly understood and demarcated. Development of hypersexuality has been associated with either “increased sexual drive or lack of sexual impulse control, both dependent on dopaminergic regulation or neurodegenerative process”⁽⁹⁾. Other reported risk factors include being male, as hypersexuality is exhibited in men more frequently than women^(102, 103), similar to the general population. The literature also suggests other risk factors including younger age at PD onset⁽¹¹¹⁾ and a history of novelty-seeking behaviour⁽¹²³⁾. Since smoking and substance abuse have been identified as risk factors for

³ For purposes of this thesis, the partners of patients with neurological disorders will generally be referred to as carers.

developing impulsive/compulsive behaviours in PD^(102,103), they may be considered as risk factors for hypersexuality also as neither hypersexuality nor any other ICDs were identified by name.

Typically, most hypersexuality cases are associated with dopamine agonists^(62,107,124,125); however, some studies do report other pharmacological etiologies. A study by Shapiro et al. (2006) describes two PD patients who exhibited hypersexual and paraphilic behaviour following selegiline use⁽¹²⁶⁾. These patients then added dopamine agonists to their medication regimes, which caused them to develop obsessive-compulsive behaviours and punding (a fascination with performing mechanical tasks) behaviours⁽¹²⁶⁾. Another case study by Simonet et al. (2016) describes hypersexuality developing following rasagiline use⁽⁹⁷⁾. Rasagiline and selegiline are both monoamine oxidase-B inhibitors⁽¹²⁷⁾. Further, some research reports hypersexuality developing in patients taking levodopa monotherapy^(62,70), as well as combined levodopa and dopamine agonist therapy^(70,128). Although hypersexuality in PD is most closely associated with pharmacology, it has also been reported in cases following deep brain stimulation of the subthalamic nucleus (STN DBS)⁽¹²⁹⁾ and pallidotomy⁽¹³⁰⁾.

Carers

It is necessary to mention that carers of patients with PD may also be negatively affected by the consequences of hypersexuality, on top of the already difficult consequences of the PD itself⁽⁹⁾. For this reason, partners/carers should be considered in the stages of screening, assessment, and management.

1.1.10 Management and Parkinson's disease

Impulse control disorders

Typically, impulse control behaviours are likely to be concealed by patients with PD unless the clinician specifically asks about them⁽¹³¹⁾. Research shows that despite 2-5 years of agonist treatment, these pathological behaviours can remain undetected^(131,133). Clinicians must become aware of this in attempt to alleviate and avert the hurtful effects such behaviours can have on both patients and carers. The existing literature shows that ICDs do cause considerable distress and can devastate marriages, reputations, general health, and family capital^(90,131).

Developing one or more of the impulse control behaviours may require the patient to reduce or stop taking the offending dopaminergic drug^(134,135), which has proven effective^(107,125), although Codling et al. (2015) report that, unlike other ICDs, hypersexuality may persist⁽⁶³⁾. However, in some cases, the medication cannot be reduced or discontinued due to significant worsening of motor function⁽¹²²⁾. One study by Bermejo et al. (2010) demonstrates zonisamide, a drug used in the treatment of seizures, benign essential tremor and parkinsonian tremor, to be effective for managing ICDs in patients with PD as results show a marked reduction in impulsivity⁽¹³⁶⁾. Other research suggests that STN DBS may improve ICDs^(137,138). One study by Kasemsuk and Hattori (2017) shows an improvement of ICDs in 73.8% of 103 patients and no improvement in 26.2% of the patients⁽¹³⁸⁾. Compulsive spending seemed to have the highest percentage of improvement among the ICDs at 88.46%, with hypersexuality coming in second at 85.47%, followed by pathological gambling at 82.22% and binge eating, punding, and dopamine dysregulation syndrome at <80%⁽¹³⁸⁾. The underlying mechanism of how STN DBS improves ICDs, however, remains ambiguous^(137,138). There is still no consensus on the effect of DBS as some studies show improvement of ICDs following DBS while others show worsening of ICDs following DBS⁽¹³⁸⁾.

Consequently, alternative management modalities must be explored. Psychological and behavioural interventions may thus be considered for helping patients manage symptoms in the acute (symptomatic) phase, and manage consequences such as distress and low mood in the post-acute (post-symptomatic) phase.

To date, the studies that empirically use psychological and behavioural intervention management options for ICDs in patients with PD are scarce. Okai et al. (2013) carried out a cognitive behavioural therapy-based intervention in patients with PD with ICDs⁽¹³⁹⁾. The study was significant in that it was the first time such an intervention had been tried in patients with PD. The cognitive-behavioural therapy (CBT) modules used in the study were extensive and included: the assessment of the problem, education and introduction to CBT, motivational interviewing, monitoring of behaviour, pleasant activity scheduling, problem solving, relaxation and mood training, identifying and challenging negative thoughts and feelings related to ICDs, psychoeducation, and, lastly, review and planning for the future⁽¹³⁹⁾. The main limitation of the study, however, is that the CBT was assumed as the appropriate treatment option for all participants. Different patients express behaviours differently and might suffer different consequences, and may, therefore, require patient-specific treatment options. Other limitations include the lack of an adequate control group for determining the impact of the psychological intervention. Moreover, the impact such an intervention had on carers and partners and their quality of life was not assessed. This is relevant as carers and partners may suffer as much if not more than the patients themselves. Therefore, a psychological intervention should not disregard the carers. Lastly, an individual approach involving home visits by a nurse, as was partially adopted in the study, is hugely expensive and time-consuming and would therefore pose a challenge when incorporating into a care pathway.

As mentioned above, the consequences of these behaviours do not only affect the patients but rather their carers as well. This has been termed “caregiver burden”^(140, 141), and therefore signals a duty to health professionals to educate themselves on the topic and then consider optimal methods by which they can help these carers better understand, manage, and cope with the effects.

It is necessary that patients with PD and their carers are made aware of the possibility of developing ICDs following dopamine replacement therapy and that health professionals monitor patients as part of routine clinical care⁽⁸⁵⁾.

Analogous to management of ICDs, research shows that for patients with PD, a reduction of the offending dopaminergic drug may aid in the management of hypersexuality^(6, 134, 135, 142). However, this is not possible for all patients, due to possible significant worsening of motor function⁽¹²²⁾.

Hypersexuality

There is very limited research pertaining to hypersexuality-specific behavioural or psychological management options for patients with PD. Bronner (2011) presents a practical, three-dimensional scheme for treatment of sexual problems in PD⁽¹⁴³⁾. The first dimension involves the “sex talk”, which highlights the importance of health professionals to communicate with the PD patients about the hypersexuality⁽¹⁴³⁾. The “Open Sexual Communication” (OSEC) module can be used to overcome barriers for discussion⁽¹⁴³⁾. The OSEC module aims at: (1) initiating sex talk with patients; (2) identifying concerns; and (3) choosing an adequate intervention⁽¹⁴³⁾. The second dimension involves taking sexual history using various interview techniques⁽¹⁴³⁾. These techniques include open ended questions, and asking for medication and social history to ease the patient into the discussion about sexual history⁽¹⁴³⁾. The third dimension involves some management considerations for hypersexuality, which include: (1) differentiation between desire differences between members of a couple; (2) considering medical treatment; and (3) referral to psychiatrists, psychologists, or sex therapists for diagnosis and treatment⁽¹⁴³⁾. Because of the limited literature regarding psychological/behavioural management options, one might consider consulting the literature regarding management options in sex addiction as behavioural and psychological expression and consequences of hypersexuality in patients with PD are similar to those in sex addiction in the general population. Treatment options for sex addiction include psychoeducation and talking therapy in individual, group, and/or couple settings⁽⁸⁵⁾, which can be considered for managing the hypersexuality. Another pathway to consider if managing the hypersexual behaviour itself is difficult, is to try and manage the

consequences of the hypersexuality. Some individuals may suffer from depression, anxiety, and/or suicidal ideation because of the hypersexuality so it may be beneficial to explore psychological approaches to help manage these consequences that are extensively researched in the psychological literature. Furthermore, it is possible that PD patients will require patient-specific treatments as their cognitive and psychological profiles, as well as their sexual expression and behaviour, may differ from one patient to another.

Nonpharmacological management options will be most beneficial when the patient expresses insight⁽¹⁴⁴⁾, which can be characterised by two key features: (1) recognizing that there is a problem needing resolution; and (2) expressing a desire to resolve the problem. Insight is significant for management as it will affect the patient's cooperation and the subsequent treatment outcomes.

It should become standard protocol for health professionals to inform patients with PD and their carers of the possibility of developing hypersexuality following dopamine replacement therapy and monitor these patients for such changes as part of routine clinical care⁽⁸⁸⁾.

Also, analogous to management of ICDs, it is important to consider appropriate management approaches for partners to help alleviate their caregiver burden. It is important for health professionals to help reassure partners that the sexual changes originate from illness and are not a reflection of their relationship.

1.1.11 Hypersexuality and dementia

Whereas the hypersexuality in PD appears to be sexually impulsive and compulsive in nature, the characteristics of the dementia patients who express hypersexuality are typically sexual inappropriateness and disinhibition^(51, 59, 145, 146). Johnson et al. (2006) describe the hypersexuality as “a disruptive behaviour characterised by a verbal or physical act of an explicit or perceived sexual nature, which is unacceptable within the social context in which it is carried out”⁽¹⁴⁷⁾. Bronner et al. (2015) explain that dysfunction of the right prefrontal, orbitofrontal, and anterior cingulate cortices (areas that are associated with sexual arousal in health) occurring in frontal variant AD and in bvFTD “often result in executive dysfunction and frontal-type behaviours, including impulsivity, disinhibition, anxiety, and hypersexuality”⁽¹⁴⁸⁾.

It is important to note that even though hypersexuality in PD is associated with sexual impulsivity/compulsivity and hypersexuality in dementia is associated with sexual disinhibition/inappropriateness, this does not mean that hypersexual PD patients do not express disinhibition and inappropriateness also and vice versa.

Prevalence

Hypersexuality in dementia is reported less often than in PD and is poorly researched and understood⁽⁴⁶⁾. The prevalence figure of hypersexuality in dementia is still ambivalent. A study by Series and Décano (2005) shows the prevalence of hypersexuality in dementia to be between 2.0% and 17.0%, with equal occurrence in men and women⁽⁵⁹⁾. A more recent study by De Giorgi and Series (2016), however, reports that the prevalence figure ranges from 7.0-25.0%⁽¹⁴⁶⁾, signifying that hypersexuality in dementia is not uncommon.

Clinical phenomenology

Apart from increased sexual desire, the sexual behaviour can include making explicit sexual comments, touching someone other than partner on the breasts or genitals, touching partner on breasts or genitals in public, and/or exposing breasts or genitals in public^(51, 59). One research suggests that features of inappropriate sexual behaviour can include sex talk, sex acts, and/or implied sex acts⁽¹⁴⁶⁾. Despite these suggested manifestations, Bronner et al. (2015) report that some behaviours in cognitively impaired older adults might be mistakenly and hastily branded as sexual when, in actuality, they might not be sexual in motivation⁽¹⁴⁸⁾.

Risk factors

Currently, there is lack of understanding of the reasons why hypersexuality occurs in dementia⁽⁵⁸⁾ as well as a lack of methods to describe and measure hypersexuality in dementia; however, the sexual changes do cause considerable “personal distress or impairment in social occupational or other important areas of functioning and [unlike in PD] are not due to the effects of drugs... medications”⁽⁵⁰⁾. These patients seem to react thoughtlessly to tempting environmental situations involving sexual objects without considering the consequences^(50, 149) that this may have on their own lives and the lives of those around them.

Sexual disinhibition and inappropriateness in dementia may result from lesions in the frontal lobe and the right hypothalamus and periventricular area^(59, 146). Psychotropic drugs such as benzodiazepines, and alcohol have also been linked with hypersexuality in dementia⁽¹⁴⁶⁾. Further, psychosocial factors include “mood instability, premorbid patterns of sexual activity and interest, lack of habitual sexual partner or misidentification of someone else as usual partner, lack of privacy,... [and] misinterpretation of cues...”⁽¹⁴⁶⁾.

A study by Mendez and Shapira (2013) suggests that hypersexuality in patients with frontotemporal dementia (FTD) is not only due to disturbance of the frontal lobe but rather also involves the right temporolimbic area because, unlike Alzheimer’s disease (AD) patients, FTD patients were observed to have increased sex drive, as well as sexual disinhibition⁽⁵⁰⁾.

1.1.12 Management and dementia

There is no empirically established treatment algorithm for hypersexuality in dementia although there are some pharmacological and nonpharmacological suggestions^(59, 145, 146, 150).

In the United Kingdom, there are no licensed drugs used to treat sexual disinhibition in patients with dementia, although off-license drugs have been used^(59, 151). Existing literature suggests the efficacy of some antidepressants, antipsychotics, anticonvulsants, cholinesterase inhibitors, hormonal agents, beta blockers, or a combination of these medications^(59, 146, 151, 152).

Antidepressants

Antidepressants are used for their anti-libidinal effects⁽¹⁴⁶⁾. Research shows that selective serotonin reuptake inhibitors such as fluoxetine, paroxetine, citalopram, and sertraline appear to be effective in reducing the hypersexual behaviour⁽⁵⁹⁾.

Antipsychotics

Although the side effects of antipsychotics can be very significant, they are commonly used for treating behavioural and psychotic symptoms of dementia⁽¹⁴⁶⁾. Haloperidol and quetiapine have both been used successfully⁽¹⁴⁶⁾.

Anticonvulsants

Anticonvulsants, such as gabapentin and carbamazepine, have also been successful in some cases despite the lack of information about underlying mechanism by which they affect sexual function⁽¹⁴⁶⁾.

Cholinesterase inhibitors

Cholinesterase inhibitors could affect sexual function by altering testosterone levels for instance; however, results have been conflicting⁽¹⁴⁶⁾.

Beta-blockers

Beta-blockers, such as pindolol, result in a decrease of adrenergic drive, which can reduce hypersexuality⁽¹⁴⁶⁾.

Hormonal agents

Hormonal agents such as cyproterone acetate, medroxyprogesterone acetate, and gonadotrophin-releasing hormone, help reduce testosterone and thus reduce sexual behaviour⁽¹⁵¹⁾.

Combination therapy

Existing literature presents some reports of combination therapy where more than one of the above drugs were used simultaneously^(59, 146) in hopes of decreasing the patients' sex drives⁽¹⁵¹⁾.

Since the evidence to support the pharmacological treatment pathway is limited, health professionals must carefully consider the appropriate doses and adverse effects associated with each of these options especially for older patients^(145, 146).

Nonpharmacological treatment options

Even though there is a lack of published reports regarding nonpharmacological treatment options for hypersexuality in dementia^(59, 145, 146) and lack of evidence for their efficacy⁽¹⁴⁶⁾, there is consensus that they should be the first line of treatment for the hypersexuality. However, this is not always practiced due to "ease of administration... [and] perceived efficacy [of medication, as well as] a lack of trained staff members"⁽¹⁴⁶⁾.

Some studies show that psychological/behavioural approaches may be beneficial^(146, 151). One approach involves redirection of the patient, either verbally or physically, away from inappropriate stimuli or situations as well as sensitively explaining to the patient why the behaviour is unacceptable^(146, 151). Another approach suggests using distraction methods whereby patients have their focus redirected before placing themselves in compromising situations⁽¹⁴⁶⁾. CBT can involve re-educating the patient about social norms, encouraging the patient to think about the intentions driving their behaviour, and methods of negative conditioning⁽¹⁴⁶⁾. This may prove challenging for dementia patients since they might suffer from substantial cognitive impairment and might consequently be unable to learn necessary behavioural treatment strategies⁽¹⁵¹⁾. Other practical approaches may involve modifying clothing items to include back or no zippers to prevent easy removal^(146, 151, 153) and even having same-sex carers care for the hypersexual patients to limit their sexual desire⁽¹⁵¹⁾.

There is evidence in the literature to suggest that carers might benefit from psychoeducation and support groups^(146, 151).

Similar to management of hypersexuality in ICDs and PD, in order for patients and carers to receive optimal help from health professionals, health professionals must educate themselves and their teams on how hypersexuality manifests and how they are able to help.

1.1.13 Hypersexuality in other neurological disorders

Apart from PD and dementia, hypersexuality has also been reported in: (1) epilepsy; (2) Kluver-Bucy syndrome; (3) Kleine-Levin syndrome; (4) traumatic brain injury; (5) stroke; (6) multiple sclerosis; (7) Huntington's disease; (8) restless legs syndrome; (9) progressive supranuclear palsy; (10) multiple system atrophy; (11) encephalitis; (12) brain disease; (13) hippocampal sclerosis; (14) spinocerebellar ataxia type 3; (15) Tourette's syndrome; and (16) fatal familial insomnia, all of which will be addressed in Chapter 2.

1.2 Thesis development

1.2.1 Overview

The research for this thesis was conducted in four main stages. First, the literature was reviewed narratively (as presented in this chapter) in order to outline the problems in the research area. This helped set the tone and define the research questions/aims for the entire thesis. This stage informed Stages 2 and 3. In the second stage, a systematic review was set up and carried out to provide a complete, exhaustive summary of current literature on hypersexuality in neurological disorders in response to the research questions. The third stage consisted of the main study, which was a systematic investigation, using qualitative and quantitative methods, of prevalence, clinical phenomenology, and impact of hypersexuality in neurological disorders. Stages 2 and 3 were carried out simultaneously and both informed Stage 4, which consisted of an investigation and development of potential psychological/behavioural management options.

1.2.2 Stage 1: Narrative literature review

The narrative literature review presented in this chapter provided the background to the issue of hypersexuality in neurological disorders and allowed to define the problems in the research area, which are as follows:

1. There is a lack of consistency in prevalence figures regarding hypersexuality in different neurological disorders.
2. There is a lack of systematic investigations of clinical phenomenology (manifestations, tools, and correlates) of hypersexuality in different neurological disorders.
3. There is a lack of research into the impact of hypersexuality on patients with neurological disorders and their carers.
4. There is a lack of research into potential psychological/behavioural interventions used to manage the symptoms and consequences of hypersexuality in patients with neurological disorders and their carers.

These problems allowed the development of the research questions for Stages 2 (systematic review) and 3 (empirical study).

1.2.3 Stage 2: Systematic review

Although a narrative literature review was completed and the problems in the research area were identified, it was necessary to conduct a systematic review as it is more rigorous. The main objectives of the review are to highlight the issue of hypersexuality in neurological disorders by “making a case for the importance of the problem... building it into a conceptual framework, and... avoiding duplication of effort”⁽¹⁵⁴⁾, as well as delivering a meticulous summary of *all* the available primary research in response to a research question”⁽¹⁵⁵⁾. The following research questions emerged from the narrative literature review, which the systematic review aimed to answer:

1. What is the prevalence of hypersexuality in specific neurological disorders?
2. What is the clinical phenomenology of hypersexuality in specific neurological disorders?
3. What are successful treatment options (pharmacological and non-pharmacological) used to manage hypersexuality in specific neurological disorders?
4. What are the implicated factors contributing to the development of hypersexuality in different neurological disorders?
5. What are the tools used to assess hypersexuality in specific neurological disorders?

The systematic review was carried out in adherence with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Statement, using the Embase, Medline, and PsycINFO databases.

1.2.4 Stage 3: Systematic investigation (main empirical study)

There has been no research aimed primarily at characterizing hypersexuality in patients with neurological disorders and assessing the impact it has on the lives of the patients and their carers; therefore, the systematic investigation was conducted after the following research questions emerged from the narrative literature review:

1. What is the prevalence of hypersexuality in specific neurological disorders?
2. What is the clinical phenomenology of hypersexuality in specific neurological disorders?
3. What is the impact of hypersexuality on patients with hypersexuality and their carers?

Patients and carers who consented to take part in the study underwent qualitative assessment in the form of a semi-structured interview as well as quantitative assessment in the form of questionnaires and tests (psychological, cognitive, and behavioural). During the interviews, the participants were asked about to reflect on, describe, and/or recount their experience with hypersexuality and its impact on their lives to the best of their abilities considering the sensitive nature of the topic. The questionnaires/tests helped examine the possible relationship that hypersexuality has with clinical, pharmacological, behavioural, psychological, and cognitive factors.

Because Stages 3 and 4 were carried out simultaneously, there was some overlap in findings, which was addressed in the thesis conclusions in Chapter 5.

1.2.5 Stage 4: Investigation/development of psychological/behavioural management options

The investigation/development of psychological/behavioural management options, informed by Stages 2 and 3, aimed to develop feasible recommended pathways of management for patients with neurological disorders and carers affected by hypersexuality, as well as to develop a website as an easily accessible psychoeducational tool that patients, carers, and health professionals could access to get proper information about hypersexuality.

1.3 Thesis structure and aims

The main aim of the entire thesis is to examine prevalence, clinical phenomenology, impact, and potential feasible psychological interventions for hypersexuality in patients with neurological disorders and their carers. It is hoped that the research will help inform the lacking understanding of hypersexuality in neurological disorders.

In summary, the thesis is divided into three separate studies with the aims of each detailed in Table 2.

Table 2 – Structure and objectives/aims of the thesis

Study (Chapter number)	Objectives
<i>Study I</i> (Chapter 2)	Systematic review assessing: <ol style="list-style-type: none"> 1. Primary outcomes <ol style="list-style-type: none"> a. <i>prevalence</i> of hypersexuality in specific neurological disorders b. <i>clinical phenomenology</i> of hypersexuality in specific neurological disorders c. <i>treatment modalities</i> that have been shown to ameliorate symptoms/effects of hypersexuality in these neurological disorders 2. Secondary outcomes <ol style="list-style-type: none"> a. implicated factors contributing to the development of hypersexuality b. tools used to assess hypersexuality in specific neurological disorders
<i>Study II</i>	Systematic investigation, using qualitative and quantitative methods, assessing:

(Chapter 3)	<ol style="list-style-type: none"> 1. Part A <ol style="list-style-type: none"> a. <i>prevalence</i> of hypersexuality in neurological disorders 2. Part B <ol style="list-style-type: none"> a. <i>clinical phenomenology</i> of hypersexuality in neurological disorders and its associated clinical, pharmacological, behavioural, psychological, and cognitive factors b. <i>impact</i> on both patients and carers
Study III (Chapter 4)	<p>Investigation of psychological/behavioural management options:</p> <ol style="list-style-type: none"> 1. Part A <ol style="list-style-type: none"> a. developing feasible <i>recommended pathways of management</i> for patients and carers that health professionals can consult when presented with hypersexual patients and/or their carers 2. Part B <ol style="list-style-type: none"> a. developing a public-facing <i>psychoeducational website</i> that will provide patients and carers with succinct, proper information about hypersexuality in neurological disorders, based on previous research and the findings of this thesis b. requesting feedback about the website from clinicians, therapists, patients, and carers, and consequently modifying the website based on their suggestions

1.4 Ethics

Because the study deals with sexuality, obtaining ethical approval for the study was a long process, taking around a year to complete.

An ethics application (15/LO/0557) was submitted through the Integrated Research Application System on March 25th, 2015 to the London – Hampstead National Research Ethics Committee (NREC). The study was given a favourable opinion on April 28th, 2015 after the Research Ethics Committee meeting took place on April 9th, 2015. R&D approval was then granted on May 28th, 2015.

A first substantial amendment was submitted on August 28th, 2015. Initially, the project did not include blurbs, leaflets, or posters about the study. After realizing challenges surrounding recruitment, the application was amended to include these. The documents and the amendment application was submitted to the London – Hampstead NREC and was given favourable opinion on September 28th, 2015.

A second substantial amendment was submitted on March 30th, 2016. Initially, the project did not include carers in Study III. The necessary documents and amendment application was submitted to the London – Hampstead NREC and was given favourable opinion on May 20th, 2016.

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Chapter 2

Systematic review: Prevalence, clinical phenomenology, and management options for hypersexuality in neurological disorders

2.1 Relevance to overall thesis

To date, there has been no systematic review assessing hypersexuality in neurological disorders, which is why the following review is significant. It will provide *all* available information from primary research in response to the research questions/aims in a systematic and rigorous manner. This will allow for the identification of key areas of weakness in the research area, as well as the presentation of suggestions for future research.

2.2 Introduction

As described in the previous chapter, the issue of hypersexuality in neurological disorders is grossly underreported. It is important to explore this area further in order to broaden understanding associated with this sensitive issue. Perhaps in doing so, barriers will be broken and the issue will become more easily discussed and, eventually, more systematically assessed and better managed.

2.3 Aims

Primarily, this chapter aims to systematically review the prevalence of hypersexuality in specific neurological disorders, clinical phenomenology of hypersexuality in specific neurological disorders, and modalities that have been explored to ameliorate or manage hypersexuality in these neurological disorders.

Secondarily, this chapter aims to systematically review the implicated factors contributing to the development of hypersexuality, and the tools used to assess hypersexuality in specific neurological disorders.

2.4 Methodology

2.4.1 Data sources and searches

The systematic review was performed in adherence with the PRISMA Statement, which provides clear guidance on the methodology by which empirical evidence should be collated.

The protocol for the review detailing the methods of the search, review, and analysis, which was developed by the research student, was registered with the PROSPERO database of systematic reviews (CRD42017036478: <http://www.crd.york.ac.uk/PROSPERO>).

The search was carried out with the help of Kate Brunskill, the Deputy Librarian at the University College London Institute of Neurology, Queen Square Library across the Embase (1974 to 2017 March 10), Medline (1946 to Present), and PsycINFO (1806 to March Week 1 2017) databases. No language restrictions were applied and date restrictions were those pre-embedded within the databases. The search strategy that was used in Ovid¹ in March 2017 was as follows:

¹ The numbers in parentheses at the end of every numbered line corresponds to the number of results that the respective keyword search generated.

- 1 (increase* adj3 libido).ti,ab. (641)
- 2 (sexual* adj3 inappropriat*).ti,ab. (1201)
- 3 impulsive compulsive disorder*.ti,ab. (217)
- 4 exp Paraphilic Disorders/ or exp PARAPHILIAS/ or exp sexual deviation/ or paraphili*.ti,ab. (16663)
- 5 exp hypersexuality/ or hypersexual*.ti,ab. (3272)
- 6 (exp Compulsive Behavior/ or exp COMPULSIONS/ or exp compulsion/ or "Disruptive, Impulse Control, and Conduct Disorders"/ or exp impulse control disorder/) and sex*.ti,ab. (2996)
- 7 ("increased sexual frequency" or "increased sexual desire" or "increased sexual behaviour" or "increased sexual behavior").ti,ab. (227)
- 8 exp sexual addiction/ or (sex* adj3 addict*).ti,ab. (2534)
- 9 (sexual* adj3 disinhibit*).ti,ab. (544)
- 10 (compulsive adj3 sex*).ti,ab. (1178)
- 11 (sex* adj3 impulsiv*).ti,ab. (680)
- 12 (sex* adj3 compulsiv*).ti,ab. (1678)
- 13 ("impulse control" adj3 (behaviour or behavior or behaviours or behaviors)).ti,ab. (479)
- 14 (sex* adj3 inappropriate adj3 (behavior or behaviour or behaviors or behaviours)).ti,ab. (854)
- 15 Selegiline/ or selegiline.ti,ab. (12582)
- 16 rasagiline/ or rasagiline.ti,ab. (2943)
- 17 monoamine oxidase B inhibitor/ or exp monoamine oxidase inhibitors/ or (Monoamine Oxidase-b Inhibitor or Monoamine Oxidase b Inhibitor).ti,ab. or exp Monoamine Oxidase Inhibitors/ (68658)
- 18 exp dopamine/ or dopamine.ti,ab. (350273)
- 19 exp Levodopa/ or levodopa.ti,ab. (69461)
- 20 entacapone.ti,ab. or exp entacapone/ or exp carbidopa plus entacapone plus levodopa/ (3608)
- 21 pramipexole.ti,ab. or exp pramipexole/ (7920)
- 22 rotigotine.ti,ab. or exp rotigotine/ (2587)
- 23 pergolide.ti,ab. or exp Pergolide/ (5980)
- 24 ropinirole.ti,ab. or exp ropinirole/ (5607)
- 25 apomorphine.ti,ab. or exp Apomorphine/ (34198)
- 26 bromocriptine.ti,ab. or exp Bromocriptine/ (30325)
- 27 cabergoline.ti,ab. or exp cabergoline/ (6472)
- 28 lisuride.ti,ab. or exp Lisuride/ (3957)
- 29 piribedil.ti,ab. or exp Piribedil/ (2359)
- 30 quinagolide.ti,ab. or exp quinagolide/ (861)
- 31 tolcapone.ti,ab. or exp tolcapone/ (2071)
- 32 amantadine.ti,ab. or exp amantadine/ (22647)
- 33 deep brain stimulation.ti,ab. or exp Deep Brain Stimulation/ or exp brain depth stimulation/ or dbs.ti,ab. (55540)
- 34 exp Parkinson disease/ or exp Parkinson's disease/ or parkinson*.ti,ab. (286775)
- 35 dementia/ or exp alzheimer disease/ or exp Alzheimer's disease/ or exp frontotemporal dementia/ or exp kluver bucy syndrome/ or exp semantic dementia/ or exp Kleine Levin Syndrome/ or alzheimer*.ti,ab. or "frontotemporal dementia".ti,ab. or "semantic dementia".ti,ab. (500621)
- 36 exp dystonia/ or dystonia.ti,ab. (51564)
- 37 exp tremor/ or tremor.ti,ab. (74164)
- 38 exp multiple sclerosis/ or multiple sclerosis.ti,ab. (195707)
- 39 exp epilepsy/ or epilep*.ti,ab. (445071)

- 40 kluver-bucy.ti,ab. (623)
- 41 kleine levin.ti,ab. (963)
- 42 Nervous System Diseases/ or Nervous System Disorders/ or neurologic disease/ or neurological disease*.ti,ab. or neurological disorder*.ti,ab. (245371)
- 43 Neurodegenerative Diseases/ or (neurodegenerative adj3 (disease or diseases or disorder or disorders or condition or conditions)).ti,ab. (153621)
- 44 Craniocerebral Trauma/ or Head Injuries/ or (head injury or head injuries).ti,ab. (93909)
- 45 Brain Injuries/ or brain injury/ or Traumatic Brain Injury/ or Brain Injuries, Traumatic/ or (brain injury or brain injuries).ti,ab. (230277)
- 46 Cerebrovascular Disorders/ or Cerebrovascular Accidents/ or cerebrovascular accident/ or stroke.ti,ab. or (cerebral vascular accident or cerebrovascular accident).ti,ab. (618505)
- 47 Parkinsonian Disorders/ or parkinsonism/ or (parkinsonism or parkinsonian syndrome or parkinsonian disorder or parkinsonian disorders).ti,ab. (57250)
- 48 Lewy Body Disease/ or Dementia with Lewy Bodies/ or diffuse Lewy body disease/ or (dementia adj2 lewy body).ti,ab. (11941)
- 49 Dementia, Vascular/ or Vascular Dementia/ or multiinfarct dementia/ or vascular dementia.ti,ab. (23397)
- 50 Brain Neoplasms/ or (brain adj2 (tumor or tumors or tumour or tumours)).ti,ab. (183863)
- 51 exp brain surgery/ or (brain adj3 surgery).ti,ab. (59498)
- 52 Glioma/ or (glioma or gliomas).ti,ab. (128488)
- 53 Spinal Cord Injuries/ or spinal cord injury/ or (spinal cord injury or spinal cord injuries).ti,ab. (101045)
- 54 or/1-14 (27603)
- 55 or/15-53 (3251487)
- 56 54 and 55 (3315)
- 57 remove duplicates from 56 (2296)

2.4.2 Study selection

After the search in the chosen databases was completed, all identified abstracts were imported into a bibliography management software (EndNote X8; Thomson Reuters, Pennsylvania, United States of America). Titles and abstracts of all identified studies were independently reviewed by two reviewers, Natalie Tayim[‡] (NT) and Pedro Barbosa[‡] (PB), who each reviewed all the abstracts according to relevance and sorted these into “Accepted”[‡] and “Rejected” folders according to the following criteria:

Inclusion criteria

Studies reporting the (a) prevalence; (b) clinical phenomenology; and/or (c) success of management modalities (either pharmacological or non-pharmacological) of hypersexuality in patients with neurological disorders were included in the review.

Exclusion criteria

(a) Non-original articles[‡]; (b) studies not published in full text; (c) conference abstracts; (d) articles not published in English; (e) non-human studies; (f) studies that do not distinguish hypersexuality from other ICDs; and (g) studies that included patients with hypersexuality predating the onset of neurological disorders were excluded from the review.

[‡] Research student.

[‡] Clinical research fellow at the Reta Weston Institute, UCL Institute of Neurology.

[‡] Accepted refers to relevant abstracts.

[‡] Systematic reviews.

Outcomes

The chosen primary outcomes for the search were (1) prevalence of hypersexuality; (2) clinical phenomenology of hypersexuality; and (3) ameliorating management options for hypersexuality in different neurological disorders. The secondary outcomes were (1) implicated factors contributing to the development of hypersexuality; and (2) tools used to assess hypersexuality in specific neurological disorders.

It is important to note that search results that included only a title and no abstract were not rejected until full text was reviewed.

These results were then compared between reviewers and discrepancies observed were resolved amongst the two reviewers without the need for Jalesh N. Panicker (JNP)⁶, the appointed adjudicator, who would serve to reconcile differences in the case of any discrepancies between the two reviewers.

2.4.3 Data extraction and management

The abstracts that were included in the “Accepted” folder were then retrieved in full text, if available, and assessed by the two reviewers (NT and PB) for possible inclusion according to the same criteria detailed above. The variables assessed included year of publication, study type (design), population, total number of participants, age of participants, gender of participants, underlying neurological disorder, duration of neurological disorder, tools used to evaluate hypersexuality, prevalence of hypersexuality, clinical phenomenology (manifestations) of hypersexuality, implicated factors contributing to the development of hypersexuality, and ameliorating management options for hypersexuality. Data from eligible reports were extracted onto two separate Excel sheets, one for each of the two reviewers (NT and PB). The discrepancies were resolved amongst the two reviewers without the need for the appointed adjudicator.

2.4.4 Risk of bias (quality) assessment

Risk of bias assessment was carried out by both reviewers (NT and PB) for the cross sectional, cohort, and case control studies, and discrepancies were resolved amongst the two reviewers without the need for the adjudicator. The Quality Assessment Tool for Quantitative Studies (The Effective Public Health Practice Project – EPHPP) (Appendix 1) yields a Global Rating score by examining and grading the quality of the each of the studies as either “Strong”, “Moderate”, or “Weak”. This included the assessment of selection bias, study design, confounders, blinding, data collection methods, and withdrawal and drop-outs. Case reports and case series, however, were not assessed for quality and risk of bias as they are study designs that present with inherent bias and issues with quality⁶.

2.4.5 Data synthesis

Meta-analysis of data was not deemed appropriate due to different study designs and clinical and methodological heterogeneity of included studies. For this reason, qualitative synthesis was used. The aim of the synthesis was to develop descriptive themes which can provide new insights and to determine how the studies’ findings are related to each other⁷. Seers (2012) indicates that there are two different ways of carrying out qualitative synthesis⁸, the first of which was implemented in this review:

1. Integrated reviews: data are aggregated or summarised often using themes
2. Interpretative reviews: involve an inductive approach, whereby new conceptual understandings emerge leading to the development of a theory that explains and integrates the concepts.

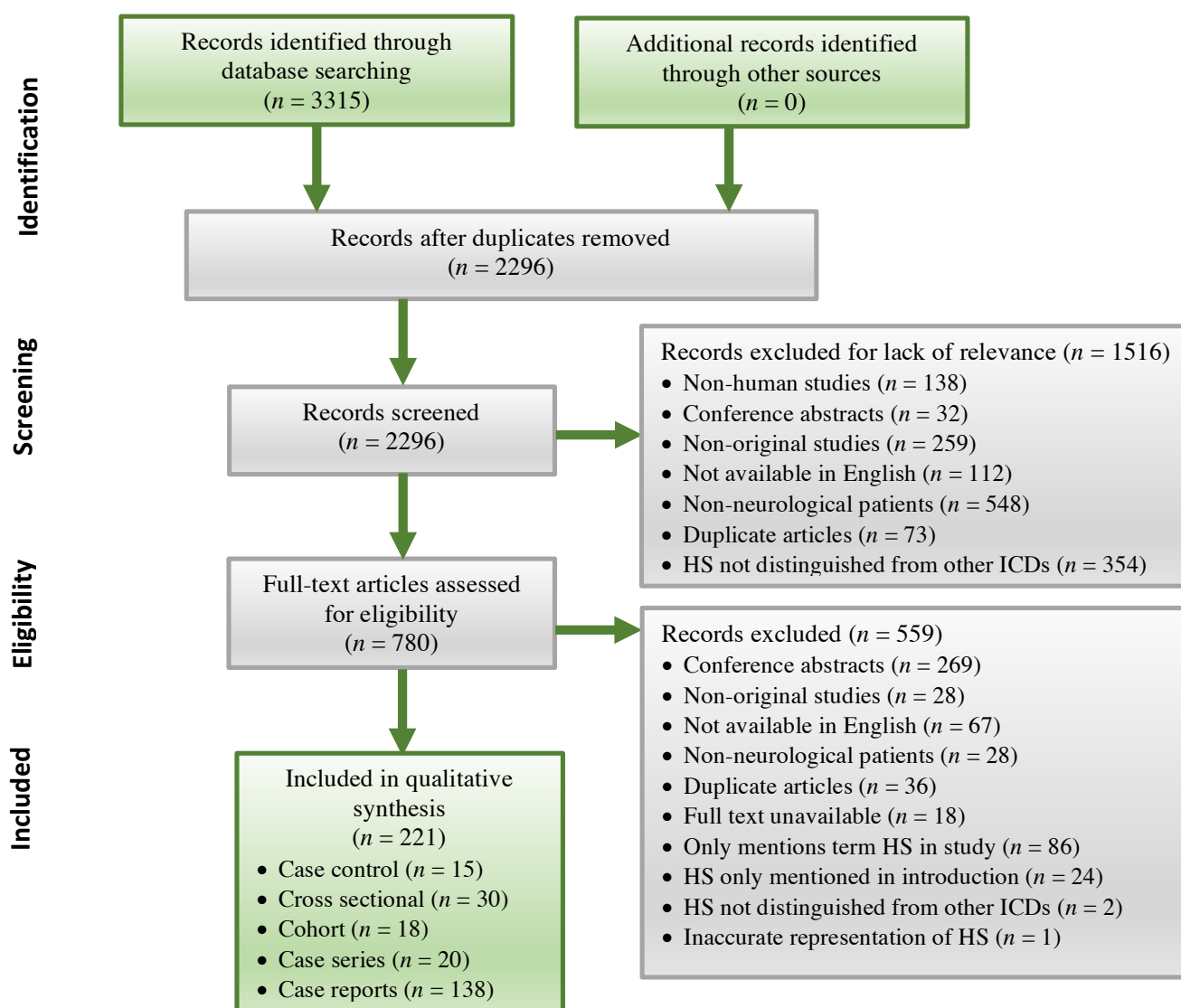
⁶ Consultant neurologist in Uro-Neurology at the National Hospital for Neurology and Neurosurgery, UK.

2.5 Results

2.5.1 Search results

The PRISMA flow diagram of the literature search and results is presented in Figure 1. The electronic database search generated 3315 abstracts (Embase: 1975 results, Medline: 746 results, PsycINFO: 594 results), of which 780 were selected for full-text retrieval for assessment of eligibility. After the full texts were evaluated, 221 studies were included in the narrative synthesis. The remaining 559 were excluded: 269 were conference abstracts, 28 were non-original studies, 67 were not available in English, 28 included non-neurological patients, 36 were duplicate articles, 18 were unavailable in full text, 86 only mentioned the term hypersexuality in the study with no detail into prevalence, phenomenology, or management, 24 only mentioned hypersexuality in the introduction of the studies with no reference to hypersexuality within the actual study or results, 2 studies did not distinguish hypersexuality from other impulse control disorders, and one portrayed an inaccurate representation of hypersexuality⁷.

Figure 1 – PRISMA flow diagram
HS: hypersexuality; ICDs: impulse control disorders



⁷ The article reported walking naked as being a representation of hypersexual behaviour; however, walking naked does not necessarily refer to a heightened motivation to pursue sexual reward but rather generally disinhibited (non-sexualised) behaviour (page 9).

Table 3 summarizes the main findings from the 63 cross sectional, case control, and cohort studies which have been categorised according to date of publication and neurological disorder.

Table 3 – Characteristics of the included cross sectional, cohort, and case control studies

Study	Design	Population	Total number of patients (F/M)	Age of patients, Mean (SD)	Duration of ND, Mean (SD)	Evaluation of HS (tools)	Prevalence of HS % (number of patients)	Clinical phenomenology	Implicated factors contributing to HS	Ameliorating management options of HS
<i>Parkinson's disease</i>										
Merola et al. (2017) ⁶⁰	C	PD treated with STN DBS	150 (64/86)	59.1 (7.2)	12.9	NR	Pre-DBS: 12.0 (18) Post-DBS: 8.0 (12)	NR	DRT	Success with STN DBS (<i>n</i> = 6)
Azmin et al. (2016) ⁶¹	CS	PD	80 (31/49)	64.3 (8.3)	4.0	QUIP	5.0	NR	Higher L-dopa dose	NR
Gescheidt et al. (2016) ⁶²	CS	Young-onset PD and HC	49 (15/34)	47.0	Median: 11.0	MIDI-modified	10.2 (5)	NR	DA	NR
Wang et al. (2016) ⁶³	CS	pwPD	217 (97/120)	67.2 (0.6)	5.8 (4.3)	MIDI, interview, Voon criteria for HS	1.8 (4)	NR	NR	NR
Amami et al. (2015) ⁶⁴	C	PD treated with STN DBS	56 (21/35)	At surgery: 55.5 (7.2)	11.5 (4.2)	Structured interview	Pre-DBS: 10.7 (6) Post-DBS: 3.6 (2)	NR	NR	Success with STN DBS (<i>n</i> = 4)
Baumann-Vogel et al. (2015) ⁶⁵	CS	PD with and without data from carers	150 (57/93) With carer data: 64 (19/45) Without carer data: 86 (38/48)	With carer data: 67.0 (9.0) Without carer data: 69.0 (10.0)	With carer data: 11.3 (5.6) Without carer data: 10.1 (7.3)	ICDRC	pwPD without carer data: 17.0 pwPD with carer data: 55.0	NR	PD	NR
Fantini et al. (2015) ⁶⁶	CC	PD with and without pRBD	216 (86/130) PD-pRBD: 106 (43/63) PD-no pRBD: 110 (43/67)	PD-pRBD: 67.3 (9.0) PD-no pRBD: 66.4 (11.6)	PD-pRBD: 8.1 (5.0) PD-no pRBD: 6.4 (4.4)	QUIP-s	PD-pRBD: 11.3 (12) PD-no pRBD: 5.4 (6)	NR	PD and pRBD	NR

Sharma et al. (2015) ⁽¹¹⁾	CS	PD	299 (75/224)	57.7 (11.4)	6.9 (4.7)	QUIP	11.0 (33)	NR	NR	NR
Politis et al. (2013) ⁽¹²⁾	CC	PD with and without HS	24 (3/21)	58.8	9.9	Voon criteria for HS	NR	<ul style="list-style-type: none"> • Pornography • Sexual fantasies • Heightened sexual urges • Having sex with people whom normally would not associate with • Excessive time obsessing about sex and engaging in sexual activity • Affairs • Prostitutes 	DA	NR
Poletti et al. (2013) ⁽¹³⁾	CS	PD	805 (324/481)	72.5 (9.5)	9.9 (7.2)	QUIP and semi-structured interview	3.0 (24)	NR	Younger current age, DRT, male gender	NR
Tanaka et al. (2013) ⁽¹⁴⁾	CS	PD	93 (47/46)	69.3 (9.8)	9.6 (6.6)	J-QUIP, interview, and Voon criteria for HS	8.9 (45)	NR	Younger current age, younger age of PD onset, longer PD duration, higher DRT dose	NR
Weintraub et al. (2013) ⁽¹⁵⁾	CC	PD and HC	311 (222/98)	61.5 (9.5)	NR	QUIP-s	4.2	NR	NR	NR
Chiang et al. (2012) ⁽¹⁶⁾	CS	PD	278 (101/167)	70.2 (0.6)	8.6	Voon criteria for HS	3.0 (8)	NR	NR	NR
Farnikova et al. (2012) ⁽¹⁷⁾	CC	PD and HC	46 (26/20)	64.6 (8.5)	7.1 (5.2)	MMPI-2	10.9 (5)	NR	Longer disease duration, higher L-dopa dose	NR
Perez-Lloret et al. (2012) ^{*(18)}	CS	PD and patients post-stroke	203 (77/126)	67.0	9.0	QUIP-s	10.0 (20)	NR	Younger current age, DA, higher DRT doses	NR
Solla et al. (2012) ⁽¹⁹⁾	CS	PD	156 (65/91)	69.3 (8.5)	6.3 (4.4)	NMSS	19.8	NR	PD	NR
Avila et al. (2011) ⁽²⁰⁾	C	PD with ICDs	25 (6/19)	74.0 (6.7)	4.0	Structured interview	36.0 (9)	NR	DRT	Success with reduction/cessation

										of DRT
Avila et al. (2011) ⁽²¹⁾	C	PD	432 (233/199)	77.1	6.7	6-item questionnaire designed by psychiatrist for ICDs	2.1 (9)	NR	PD	NR
de Chazeron et al. (2011) ⁽²²⁾	CC	PD and HC	115 (46/69)	66.9 (5.8)	7.4 (4.0)	HS questionnaire (shorter French version of the SAST)	1.7 (2)	NR	NR	NR
Hassan et al. (2011) ⁽²³⁾	CS	PD using DA	321 (107/214)	NR	8.3	NR	7.0 (24)	NR	DA	Success with reduction/cessation of DA
Lim et al. (2011) ⁽²⁴⁾	CS	PD	200 (88/112)	62.7 (9.7)	7.1 (5.8)	QUIP	13.0	NR	Younger age at PD onset, longer disease duration, use of DRT, higher dose of DRT	NR
Solla et al. (2011) ⁽²⁵⁾	C	PD	349 (164/185)	71.7 (9.6)	9.6 (6.1)	Interview and questionnaire based on Voon criteria for HS	4.0 (14)	NR	PD	NR
Zahodne et al. (2011) ⁽²⁶⁾	C	PD	96 (33/63)	66.0	10.0	SCS	1.0 (1)	NR	PD	NR
Kenangil et al. (2010) ⁽²⁷⁾	CC	PD with and without ICDs	98 (19/79) ICD+: 33 (6/27)	ICD+: 57.6 (10.4)	ICD+: 8.4 (5.4)	Semi-structured interview based on DSM-IV criteria for HS	ICD+: 42.4 (14)	<ul style="list-style-type: none"> • Aggressive sexual behaviour • Heightened sexual urge 	DA	NR
Lee et al. (2010) ⁽²⁸⁾	CS	PD	1167 (669/498)	64.9 (9.8)	6.6 (4.3)	MIDI	2.8 (33)	NR	DA	NR
Weintraub et al. (2010) ⁽²⁹⁾	CS	PD	3090 (1109/1981)	63.8 (8.0)	NR	MIDI	3.5	NR	DA	NR
Bostwick et al. (2009) ⁽³⁰⁾	C	PD	267 (92/175)	73.1 (10.4)	NR	NR	1.9 (5)	<ul style="list-style-type: none"> • Excessive sexual urge • Chasing wife when refused sex 	DA	Success with tapering of ropinirole and

Cooper et al. (2009) ⁽³¹⁾	C	PD	141	68.0 (10.2)	6.7 (5.9)	Hypersexual behaviour questionnaire and Voon criteria for HS	4.3 (6)	<ul style="list-style-type: none"> • Pornography • Increased masturbation • Sexual toys • Sadomasochism • Prostitutes • Cross-dressing 	Younger age of PD onset	addition of L-dopa or entacapone NR
Fan et al. (2009) ⁽³²⁾	CC	PD and HC	312 (119/193)	65.8 (10.5)	5.7 (2.9)	Specially-designed HS questionnaire	1.9 (6)	<ul style="list-style-type: none"> • Excessive sexual thought • Pornography 	DA	Success with cessation of DA or changing to another drug
Ondo et al. (2008) ^{*(33)}	CS	PD and RLS taking DA	211 (92/119)	63.8 (10.4)	9.5	Interview	5.2 (11)	NR	Younger current age, larger DA dose, younger age of PD onset	NR
Giladi et al. (2007) ⁽³⁴⁾	CC	PD and HC	193 (71/122)	67.5 (10.9)	9.6 (6.3)	Interview	8.8 (17)	NR	Younger age at PD onset, male gender, longer duration of treatment with DA	NR
Singh et al. (2007) ⁽³⁵⁾	CS	PD using DA	300 (106/194)	65.0	9.0	Questions about changes in sexuality	11.0 (33)	NR	DA	NR
Voon et al. (2006) ⁽³⁶⁾	CS	PD	297 (116/181)	64.8 (11.2)	NR	Specifically designed questionnaire based on DSM-IV and Voon criteria for HS	2.0 (6)	NR	DRT, male gender, younger age at PD onset	NR
Trosch et al. (1998) ⁽³⁷⁾	C	PD treated with clozapine	172 (76/96)	72.5 (8.7)	NR	Standardised 61-item questionnaire	1.2 (2)	NR	PD	Success with clozapine ($n = 2$)
Dementia										
Canevelli et al. (2017) ⁽³⁸⁾	CS	Dementia	195 (95/100)	76.3 (7.8)	NR	Questionnaire inspired by NPI	17.9 (35)	<ul style="list-style-type: none"> • Sexual comments to unfamiliar persons • Unsolicited sexual 	Dementia	NR

								touching/kissing		
								<ul style="list-style-type: none"> • Extramarital encounters • Prostitutes • Excessive reactions when sex refused 		
Mendez et al. (2014) ⁽³⁹⁾	CC	FTD and early-onset AD	30 (16/14) FTD: 15 (8/7) AD: 15 (7/8)	FTD: 59.9 (10.2) AD: 57.1 (4.2)	NR	NR	NR	<ul style="list-style-type: none"> • Walking up to people, including strangers, and kissing their cheeks and hands • Needing to be restrained from pursuing kissing behaviour • Rubbing backs of men encountered • Attempts to kiss others' feet • Telling strangers she liked them and wanted to bring them home 	FTD	NR
Perry et al. (2014) ⁽⁴⁰⁾	C	FTD	103 (45/58)	59.7 (8.4)	NR	NPI	16.5 (17)	<ul style="list-style-type: none"> • Strip clubs up to twice daily • Public masturbation • Extramarital encounters 	Dementia	NR
Mendez et al. (2013) ⁽⁴¹⁾	CS	FTD and early-onset AD	105 (52/55) FTD: 47 (25/22) AD: 58 (27/31)	FTD: 60.4 (8.1) AD: 57.7 (6.6)	FTD: 2.8 (2.1) AD: 3.0 (2.2)	NR	FTD: 12.7 (6) AD: 0.0 (0)	<ul style="list-style-type: none"> • Searching for women to have sex with (including strangers) • Extramarital encounters • Preoccupation with sex • Saying sexually inappropriate things • Frequent and overt masturbation • Soliciting sex on the internet • Asking a 17-year-old girl to have sex in front of spouse and children • Touching woman's breast while touching oneself • Need for more attention 	FTD	Success with aripiprazole ($n = 1$); sertraline, quetiapine, and oxcarbazine ($n = 1$); escitalopram ($n = 1$); haloperidol ($n = 1$); sertraline and memantine ($n = 1$)

								from men and beginning to wear tight, provocative clothing		
Onishi et al. (2006) ⁽⁴²⁾	CS	Dementia aged 65 and older	586 (422/164)	81.1 (8.6)	NR	Questionnaire assessing behavioural, psychological, and physical symptoms	1.9 (11)	Sexually inappropriate behaviour	Dementia	NR
Alagiakrishnan et al. (2005) ⁽⁴³⁾	CS	Dementia	41 (3/38)	78.3 (7.5)	NR	NR	NR	<ul style="list-style-type: none"> • Inappropriate touching • Exhibitionism • Increased masturbation • Saying sexually inappropriate things 	Dementia	NR
Mendez et al. (2005) ⁽⁴⁴⁾	CC	FTD and AD	56 (28/28) FTD: 28 (13/15) AD: 28 (15/13)	FTD: 61.9 (7.1) AD: 66.1 (9.2)	NR	NR	NR	<ul style="list-style-type: none"> • Unsolicited sexual approach/touching • Paedophilia • Exhibitionism 	FTD	NR
Wiseman et al. (2000) ⁽⁴⁵⁾	CS	Dementia with problematic HS	20 (3/17)	73.0	NR	NR	NR	<ul style="list-style-type: none"> • Sexual comments • Unsolicited sexual touching/kissing/hugging • Preoccupation with sex • Public masturbation • Grabbing at genitals or breasts of staff and residents • Sexual hallucinations or delusions of spouses' infidelity • Sexually seducing other residents • Attempts to undress staff or other residents • Chasing other residents for sexual purposes • Exhibitionism 	Dementia	Success with cimetidine ($n = 14$); cimetidine and ketoconazole and/or spironolactone ($n = 6$)

Tsai et al. (1999) ⁽⁴⁶⁾	C	Dementia	133 (35/98)	74.1	NR	NR	15.0 (20)	NR	Dementia	NR
Hwang et al. (1997) ⁽⁴⁷⁾	CS	AD	75 (25/47)	74.3 (6.7)	4.4 (2.8)	Checklist adapted from BPADRS	10.7 (8)	Sexually inappropriate behaviour	Dementia	NR
Zeiss et al. (1996) ⁽⁴⁸⁾	C	Dementia	40 (0/40)	NR	NR	NR	17.5 (7)	<ul style="list-style-type: none"> • Sexually inappropriate behaviour • Public masturbation • Hand to groin (rubbing) 	Dementia	NR
Miller et al. (1995) ⁽⁴⁹⁾	CS	FTD and AD	28 (12/16) FTD: 14 (8/6) AD: 14 (4/10)	FTD: 63.0 AD: 70.5	NR	Questionnaire for dietary changes, carbohydrate craving, compulsions, or altered sexual behaviour (administered to carers)	FTD: 8.0 AD: 8.0	Increased sex drive	Dementia	NR
Devanand et al. (1992) ⁽⁵⁰⁾	CS	probable AD	106 (69/37)	72.1 (9.8)	4.4 (2.2)	BSSD	2.9	Sexual disinhibition	Dementia	NR
Burns et al. (1990) ⁽⁵¹⁾	CS	AD	178 (141/37)	80.4 (6.6)	5.3	SGRS	7.0 (12)	NR	Dementia	NR
<i>Restless legs syndrome</i>										
Schreglman et al. (2012) ⁽⁵²⁾	C	RLS	28 (15/ 13)	69.0	NR	ZSQ-ICD	14.3 (4)	NR	Transdermal rotigotine	Success with reduction/cessation of rotigotine
Dang et al. (2011) ⁽⁵³⁾	CS	RLS	73	58.9 (7.1)	NR	MIDI-modified	4.1 (3)	NR	DA	Success with reduction/cessation of DA
Voon et al. (2011) ⁽⁵⁴⁾	CS	RLS	140 (98/42)	NR	NR	Voon criteria for HS	1.4 (2)	NR	Pramipexole	NR
Cornelius et al. (2010) ⁽⁵⁵⁾	CC	RLS treated with DA, RLS who were never treated with DA, and OSA without RLS or exposure to	152 (75/77) RLS-DA: 100 (48/52) RLS-no DA: 52 (27/25)	RLS-DA: 59.0 (14.6) RLS-no DA: 60.8 (14.9)	NR	Questionnaire based on Voon criteria for HS	Questionnaire: RLS-DA: 8.0 (8) RLS-no DA: 2.0 (1) Phone interview: RLS-DA: 3.0	<ul style="list-style-type: none"> • Sexually inappropriate behaviours involving the internet • Multiple girlfriends who were half patient's age 	DA	Success with cessation of DA

		dopaminergic agents					(3) RLS-no DA: 0.0 (0)			
Ondo et al. (2008) ⁽³³⁾	CS	PD and RLS taking DA	89 (57/32)	60.9 (13.5)	22.4	Interview	0.0 (0)	NR	NR	NR
Driver-Dunckley et al. (2007) ⁽⁵⁶⁾	CS	RLS	99	70.0 (11.0)	24.0 (18.0)	Newly-designed set of 4 questions	4.0 (4)	Pornography	DRT	NR
Traumatic brain injury										
Simpson et al. (2013) ⁽⁵⁷⁾	CS	TBI	507 (257/250)	At injury: 32.7 (14.2)	NR	OBS	8.9 (45)	<ul style="list-style-type: none"> • Sexually inappropriate comments • Genital and nongenital touching • Public masturbation • Exhibitionism • Coercive behaviours 	TBI	NR
Simpson et al. (2001) ⁽⁵⁸⁾	CC	TBI patients with and without SAB	50 TBI-SAB: 25	NR	NR	NR	NR	<ul style="list-style-type: none"> • Overt sexual aggression • Exhibitionism • Frotteurism • Toucherism 	TBI	NR
Simpson et al. (1999) ⁽⁵⁹⁾	C	TBI patients with sexual offences	29	32.0 (10.0)	10.0	NR	NR	<ul style="list-style-type: none"> • Overt sexual aggression • Exhibitionism • Frotteurism • Toucherism • Voyeurism • Touching genitals of animals 	TBI	NR
Emory et al. (1995) ⁽⁶⁰⁾	C	TBI and HS	8 (0/8)	At time of trauma: 17.5	NR	NR	NR	<ul style="list-style-type: none"> • Exhibitionism • Frotteurism • Paedophilia • Rape • Copralalia 	TBI	Success with intramuscular Depo-Provera injections and counselling
Kleine-Levin syndrome										
Wang et al. (2016) ⁽⁶¹⁾	C	KLS	44 (16/28)	18.3 (8.9)	NR	NR	18.0 (8)	NR	KLS	NR
Arnulf et al. (2008) ⁽⁶²⁾	CC	KLS and HC	108 (27/81)	27.0 (11.0)	NR	Questionnaire developed for KLS (due to lack of existing one)	53.0	<ul style="list-style-type: none"> • Heightened sexual urge • Increased masturbation (to the point of bleeding) • Overt masturbation 	KLS	NR
Kesler et al.	CC	Female KLS	16 (8/8)	Age at	NR	NR	56.3 (9)	Heightened sexual urge	KLS	NR

(2000)⁽⁶³⁾ and male
KLS onset:
F: 15.1
(3.5)
M: 15.2
(2.77) F: 50.0 (4)
M: 62.5 (5)

Epilepsy										
Shukla et al. (1979) ⁽⁶⁴⁾	CC	TLE and grand mal epilepsy	140 (44/96) TLE: 70 (24/46) Grand mal: 70 (20/50)	TLE: 20.8 (12.1) Grand mal: 21.7 (9.7)	NR	Interview	TLE: 1.4 (1) Grand mal: 0.0 (0)	<ul style="list-style-type: none"> • Preoccupation with sexual fantasies • Increased masturbation 	TLE	Success with medication (undisclosed)
Saunders et al. (1970) ⁽⁶⁵⁾	C	Epilepsy (idiopathic epilepsy, TLE, cortical fits)	100 (0/100)	NR	NR	NR	1.0 (1)	Exhibitionism (in front of small children)	TLE (seizures)	NR
Stroke										
Perez-Lloret et al. (2012) ^{*(15)}	CS	PD and patients post-stroke	52 (24/28)	69.0	NR	QUIP-s	0.0 (0)	NR	NR	NR
Hainline et al. (1992) ⁽⁶⁶⁾	C	Post-stroke	32 (15/17)	66.0	NR	BPC	0.0 (0)	NR	NR	NR

AD: Alzheimer's disease; BPADRS: Behavioural Pathology in Alzheimer's Disease Rating Scale; BPC: Behavioural Problem Checklist; BSSD: Behavioural Syndromes Scale for Dementia; C: cohort; CC: case control; CS: cross-sectional; DA: dopamine agonist; DBS: deep brain stimulation; DRT: dopamine replacement therapy; DSM-IV: Diagnostic Statistical Manual, 4th edition; F: female; FTD: frontotemporal dementia; HC: healthy controls; HS: hypersexuality; ICDs: impulse control disorders; ICD+: with ICDs; ICD-: without ICDs; ICDRC: Impulse Control Disorders and Related Conditions Questionnaire; J-QUIP: Japanese version of QUIP; KLS: Kleine-Levin syndrome; L-dopa: levodopa; M: male; MIDI: Minnesota Impulse Disorders Questionnaire; MMPI: Minnesota Multiphasic Personality Inventory-2; ND: neurological disorder; NMSS: Non-motor Symptoms Scale; NPI: Neuropsychiatric Inventory; NR: not reported; OBS: Overt Behaviour Scale; OSA: obstructive sleep apnoea; PD: Parkinson's disease; pRBD: probable rapid eye movement, sleep behaviour disorder; QUIP: Questionnaire for Impulsive-Compulsive Disorders in Parkinson's Disease; QUIP-s: short version of QUIP; QUIP-rs: QUIP Rating Scale; RLS: restless legs syndrome; SAST: Sexual Addiction Screening Test; SAB: sexually aberrant behaviour; SCS: Sexual Compulsivity Scale; SD: standard deviation; SGRS: Stockton Geriatric Rating Scale; STN: subthalamic nucleus; TBI: traumatic brain injury; TLE: temporal lobe epilepsy; ZSQ-ICD: Zurich Screening Questionnaire for ICDs

*. Studies with more than one neurological diagnosis were categorised depending upon the neurological disorder implicated in contributing to the development of hypersexuality, or according to the neurological disorder listed in the study aim

Table 4 summarizes the main findings of 158 case series and case reports, which have been categorised according to date of publication and neurological disorder.

Table 4 – Characteristics of the included case reports and case series

Study	Design	Total patients (F/M)	Age of patients, year	ND	Duration of ND	Evaluation of HS (tools)	Clinical phenomenology	Implicated factors contributing to HS	Ameliorating management options of HS
<i>Parkinson's disease</i>									
Cannas et al. (2016) ⁽⁶⁷⁾	CR	1 (M)	79.0	PD	10.0	NR	<ul style="list-style-type: none"> • Priapism • Compulsive sexual behaviour • Harassing wife with uncontrollable and irrepressible sexual urge 	Rotigotine	Success with cessation of rotigotine
Simonet et al. (2016) ⁽⁶⁸⁾	CR	1 (M)	74.0	PD	3.0	NR	Obsessive sexual thoughts and desire	Rasagiline	Success with cessation of rasagiline
Teive et al. (2016) ^{*,(69)}	CS	7 (F = 1; M = 6)	66.7	PD	NR	NR	<ul style="list-style-type: none"> • Anal intercourse • Excessive masturbation • Exhibitionism • Paedophilia 	DA (<i>n</i> = 4), DBS (<i>n</i> = 2), L-dopa high dose (<i>n</i> = 1)	Success with reduction/cessation of DRT doses (<i>n</i> = 5); DBS parameter correction (<i>n</i> = 1); NR (<i>n</i> = 1)
Bonfils et al. (2015) ⁽⁷⁰⁾	CR	1 (M)	55.0	PD	5.0	NR	<ul style="list-style-type: none"> • Compulsive masturbation • Increased pornography • Online sex chat rooms for 6-10 hours a day 	PD	Success with clozapine
Codling et al. (2015) ⁽⁷¹⁾	CS	7 (M)	56.6	PD	13.6	Structured clinical interview for DSM-IV	<ul style="list-style-type: none"> • Fetishism • Phone lines • Change in orientation • Prostitutes • Possible paedophilic tendencies • Incessant demands for sex • Pornography • May have assaulted daughter • Excessive masturbation 	PD and management	NR
Akakin et al. (2014) ⁽⁷²⁾	CR	1 (M)	58.0	PD	NR	NR	Insisting on sex every day and become aggressive if denied	STN DBS	NA (patient did not allow intervention)
Reyes et al. (2014) ⁽⁷³⁾	CR	1 (M)	51.0	PD	NR	NR	<ul style="list-style-type: none"> • Obsessiveness with sexual life • Pornography 	Rasagiline	Success with cessation of rasagiline
Almeida et al. (2013) ⁽⁷⁴⁾	CR	1 (M)	63.0	PD	22.0	NR	Attempts to have sex with donkeys	Selegiline	Success with L-dopa and benserazide and cessation of selegiline

Vitale et al. (2013) ⁽⁷⁵⁾	CR	1 (M)	60.0	PD	4.0	NR	<ul style="list-style-type: none"> • Excessive sexual urge • Obsessed with daily sexual intercourse with wife • Pornography • Extramarital encounters 	Rasagiline	Success with cessation of rasagiline
Bronner et al. (2012) ⁽⁷⁶⁾	CS	4 (M)	55.5	PD	7.5	NR	<ul style="list-style-type: none"> • Daily sexual demands from spouse • Frequent intercourse • Intensive rubbing • Frequent masturbation • Frequently talking about sex with his wife and with movement disorder unit staff • Pornography • Sexual affairs with friends and neighbours • Exhibitionism 	Patients trying to make up for ED ($n = 2$), gap in sexual desire between members of couple ($n = 1$), or neurological disease and dopaminergic medication ($n = 1$)	Success with PDE5-I ($n = 2$), sex therapy ($n = 1$), and STN DBS ($n = 1$)
Raina et al. (2012) ⁽⁷⁷⁾	CR	1 (M)	58.0	PD	20.0	NR	Attempts to have sexual intercourse with a female family dog	Extra doses of pramipexole	Success with quetiapine and clonazepam and cessation of pramipexole
Sawyer et al. (2012) ⁽⁷⁸⁾	CR	1 (M)	75.0	PD and dementia	1.5	NR	<ul style="list-style-type: none"> • Compulsive masturbation • Masturbation during sleep 	Pramipexole	Success with cessation of pramipexole
Singh et al. (2012) ⁽⁷⁹⁾	CR	1 (M)	41.0	PD	NR	NR	Intense sexual urges toward other women	Ropinirole	Success with cessation of ropinirole
Solla et al. (2012) ⁽⁸⁰⁾	CR	2 (F = 1; M = 1)	57.5	PD	9.0	NR	<ul style="list-style-type: none"> • Inappropriately and excessively requesting sex from spouse • New onset of transvestic urges (wearing female clothing) • Klismaphilia (compulsive and unusual requests to spouse for the administration of enemas under the pretence of being constipated) 	L-dopa ($n = 2$)	Success with reduction of L-dopa ($n = 2$)
Hinnell et al. (2011) ⁽⁸¹⁾	CR	1 (M)	66.0	PD	8.0	NR	<ul style="list-style-type: none"> • Staring at women on the street while having sexual thoughts • Pornography 	Increasing rotigotine dose	Success with cessation of rotigotine
Maguire et al. (2011) ⁽⁸²⁾	CR	1 (M)	60.0	PD	8.0	NR	<ul style="list-style-type: none"> • Heightened sexual urge and sexual demands often resulting in aggressive outbursts • Cross-dressing • Frequent masturbation 	Ropinirole	Success with cessation of ropinirole
Mendez et al. (2011) ^{*(83)}	CR	2 (M)	59.0	PD	10.5	NR	<ul style="list-style-type: none"> • Paedophilia • Pornography 	PD and medication	Success with reduction/cessation of

							<ul style="list-style-type: none"> • Sexual preoccupation • Massage parlours • Prostitutes • Pornography • Forcing wife to have sex • Demands for oral sex multiple times a day • Frequent masturbation • Propositioning wife's female friends • Hiring strippers 		DRT (<i>n</i> = 2)
Pineau et al. (2010) ⁽⁸⁴⁾	CR	1 (M)	60.0	PD	27.0	NR	Transvestic fetishism (finding pleasure in being seen as a desirable woman and having sexual intercourse with other men)	DA	Success with cessation of DA
Tschopp et al. (2010) ^{*(85)}	CS	4 (F = 1; M = 3)	62.5	PD	4.5	NR	NR	Piribedil	Success with quetiapine and reduction/cessation of piribedil (<i>n</i> = 3)
Bach et al. (2009) ⁽⁸⁶⁾	CR	1 (M)	81.0	PD	12.0	NR	<ul style="list-style-type: none"> • Repeatedly requesting sexual actions from nurses • Compulsive masturbation 	DRT	Success with carbamazepine
Fernandez et al. (2009) ⁽⁸⁷⁾	CR	1 (M)	48.0	PD	11.0	NR	<ul style="list-style-type: none"> • Sexual disinhibition • Exhibitionism • Compulsive masturbation 	L-dopa abuse	Success with reduction of L-dopa dose
Kataoka et al. (2009) ⁽⁸⁸⁾	CR	1 (M)	81.0	PD	7.0	NR	<ul style="list-style-type: none"> • Demands for sex from wife several times every night • Touching wife's genitals many times per night, even though he could not achieve an erection 	Pergolide	Success with reduction of pergolide
Munhoz et al. (2009) ⁽⁸⁹⁾	CR	1 (M)	67.0	PD	7.0	NR	<ul style="list-style-type: none"> • Increased frequency of sexual intercourse with wife, with an extreme preference for anal intercourse (not present before) • Speaking sexual obscenities 	Pramipexole	Success with cessation of pramipexole
Nielssen et al. (2009) ⁽⁹⁰⁾	CR	1 (M)	29.0	PD	9.0	NR	<ul style="list-style-type: none"> • Exhibitionism • Cross-dressing • Obscene phone calls • Following school girls home 	L-dopa	Success with reduction of L-dopa
Pinggera et al. (2009) ⁽⁹¹⁾	CR	1 (M)	67.0	PD	10.0	NR	Penile strangulation	Possibility of overdose of medication (patient on L-dopa and bromocriptine)	NR
Wingo et al.	CR	1 (M)	44.0	PD	3.0	NR	• Pornography	Rotigotine	Success with cessation

(2009) ⁽⁹²⁾							<ul style="list-style-type: none"> • Nude/exotic dance clubs 		of rotigotine
Doshi et al. (2008) ⁽⁹³⁾	CR	2 (F = 1; M = 1)	64.0	PD	NR	NR	<ul style="list-style-type: none"> • Demands for sexual gratification every night and becoming very aggressive when denied • Uncontrollable sexual urge • Exhibitionism 	STN DBS	Success with clozapine ($n = 1$)
Cannas et al. (2007) ⁽⁹⁴⁾	CS	9 (M)	Age of onset: 50.8	PD	NR	NR	<ul style="list-style-type: none"> • Rape • Incest • Paedophilia • Zoophilia • Frotteurism • Exhibitionism • Obsessive masturbation • Pornography • Voyeurism 	Introduction or increase in DA ($n = 8$) or L-dopa ($n = 1$)	Success with clozapine and suspension of pergolide ($n = 1$); clozapine and reduction of pergolide ($n = 3$), clozapine and reduction of L-dopa ($n = 1$); clozapine and suspension of pramipexole ($n = 1$); quetiapine and suspension of pergolide ($n = 1$); reduction of ropinirole and introduction of clozapine ($n = 1$); suspension of cabergoline ($n = 1$)
McKeon et al. (2007) ^{*(95)}	CR	1 (M)	52.0	PD	11.0	NR	Demands for sex from wife several times a day	DA	NR
Cannas et al. (2006) ⁽⁹⁶⁾	CR	1 (M)	51.0	PD	7.0	NR	<ul style="list-style-type: none"> • Heightened sexual urge • Demands for frequent sexual intercourse or intimate contact • Locked himself in a room with woman and forcing his attentions on her by repeatedly touching her sexually • Sexual fantasies 	Pergolide	Success with quetiapine and reduction of pergolide
Foley et al. (2006) ⁽⁹⁷⁾	CR	1 (M)	56.0	PD	15.0	ICD-10	<ul style="list-style-type: none"> • Avid interest in young boys • Inappropriate touching of boys aged 13 and 14 • Heightened sexual urge • Excessive masturbation 	Cabergoline	Success with SSRI and cessation of cabergoline
Mania et al. (2006) ⁽⁹⁸⁾	CR	1 (M)	54.0	PD	NR	NR	<ul style="list-style-type: none"> • Sexually inappropriate comments • Touching female staff members and male peers 	PD	Success with oestrogen and citalopram

Shapiro et al. (2006) ⁽⁹⁹⁾	CR	2 (M)	40.0	PD	NR	NR	<ul style="list-style-type: none"> • Cross-dressing • Excessive pornography • Increased frequency of trips to adult movie stores • Multiple affairs with colleagues at work 	Selegiline	NR
Solla et al. (2006) ⁽¹⁰⁰⁾	CR	1 (M)	62.0	PD	4.0	NR	<ul style="list-style-type: none"> • Paedophilia (sexual attention towards his granddaughter) 	DRT	Success with clozapine and reduction of DRT
Ivanco et al. (2005) ⁽¹⁰¹⁾	CR	1 (M)	55.0	PD	NR	NR	<ul style="list-style-type: none"> • Internet adult chat rooms • Massage parlours 	DA	Success with donepezil and reduction of DA
Klos et al. (2005)* ⁽¹⁰²⁾	CS	13 (M)	Age of onset: 50.2	PD	NR	NR	NR	PD and DA	Success with cessation of DA ($n = 2$); reduction of DA ($n = 1$); reduction of DA and L-dopa and adding quetiapine and valproate ($n = 1$); olanzapine ($n = 1$); quetiapine ($n = 1$); cessation of DA and adding olanzapine and lithium ($n = 1$); sertraline ($n = 1$); NA (resolved spontaneously) ($n = 2$); NR ($n = 3$),
Mendez et al. (2004) ⁽¹⁰³⁾	CR	1 (M)	59.0	PD	16.0	NR	<ul style="list-style-type: none"> • Demands for oral sex up to 12 times a day from wife • Forcing wife to have sex with him despite her serious cardiac condition • Frequent masturbation • Propositioning wife's female friends for sex • Strippers • Prostitutes • Hours on the internet looking for sex and buying pornographic materials • Masturbating while looking at a photograph of his 5-year-old granddaughter • Touching granddaughter inappropriately and asking her to touch his penis 	Right pallidotomy and DRT	Success with valproate and reduction of DRT

Jimenez-Jimenez et al. (2002) ⁽¹⁰⁴⁾	CR	1 (M)	74.0	PD	18.0	NR	<ul style="list-style-type: none"> • Sexual propositioning of granddaughter • Zoophilia (attempts to maintain sexual intercourse with a female family dog) 	Carbidopa/L-dopa and bromocriptine	Success with reduction of implicated medications
Kanovsky et al. (2002) ⁽¹⁰⁵⁾	CS	7 (M)	52.7	PD	7.1	NR	<ul style="list-style-type: none"> • Frequent and spontaneous penile erections • Asking for intimate contact by touching and endearment • Asking for frequent sexual intercourse with spouse 	Pergolide	Success with sexological treatment and reduction/cessation of pergolide
Riley (2002) ⁽¹⁰⁶⁾	CR	1 (M)	72.0	PD	38.0	NR	<ul style="list-style-type: none"> • Transvestism • Sexual advances towards housekeepers 	Selegiline	Success with cessation of selegiline
Roane et al. (2002) ⁽¹⁰⁷⁾	CR	1 (M)	57.0	PD	20.0	NR	<ul style="list-style-type: none"> • Frequent masturbation • Awakening in the middle of the night demanding sexual intercourse • Threatening to find a prostitute • Sexually inappropriate remarks to strangers and to younger female relatives 	GPI DBS	Success with clozapine
Fernandez et al. (1998) ⁽¹⁰⁸⁾	CR	1 (M)	81.0	PD	21.0	NR	Sexual contact with the family dog (caught placing peanut butter on his penis and then allowing the family dog to lick it)	Pergolide	Success with clozapine
Korpelainen et al. (1998)* ⁽¹⁰⁹⁾	CR	1 (M)	59.0	PD	NR	NR	<ul style="list-style-type: none"> • Heightened sexual urge • Aggressive demands for sexual intercourse several times a day • Sexual arousal by wife wearing short-sleeved garments 	Moclobemide	Success with nortriptylin and cessation of moclobemide
Courty et al. (1997) ⁽¹¹⁰⁾	CS	4 (M)	59.0	PD	NR	NR	<ul style="list-style-type: none"> • Frequent penile erections with serious exacerbation of sexual urge • Persistent excessive sexual urge • Demands that his spouse engage in sexual intercourse several times a day and becoming angry if refused • Sexual advances toward daughter's young female friends • Pornography 	Increased dose of apomorphine	Success with reduction/cessation of apomorphine
Weinman et al. (1995) ⁽¹¹¹⁾	CR	1 (M)	63.0	PD	10.0	NR	<ul style="list-style-type: none"> • Prostitutes • Receiving oral sex in the presence of his 7-year-old granddaughter • Overt masturbation • Exhibitionism • Wandering the halls look in on other patients' rooms with his hand on his groin 	L-dopa dysregulation	Success with lithium carbonate and clonazepam (L-dopa was not reduced/stopped because patient refused)

Uitti et al. (1989) ⁽¹¹²⁾	CS	13 (F = 2; M = 11)	Age of onset: 51.4	PD	NR	NR	<ul style="list-style-type: none"> • Excessive sexual urge • Increased frequency of intercourse • Approaching other women • Propositioning women and girls • Genital preoccupation • Feeling “overly sexy” • Exhibitionism • Preoccupation with sex 	L-dopa (<i>n</i> = 4); L-dopa and pergolide (<i>n</i> = 2); bromocriptine (<i>n</i> = 2); amantadine (<i>n</i> = 1); L-dopa-carbidopa (<i>n</i> = 1); pergolide (<i>n</i> = 1); L-dopa-carbidopa and bromocriptine (<i>n</i> = 1); deprenyl (<i>n</i> = 1)	Success with reduction of implicated medication
Harvey (1988) ⁽¹¹³⁾	CR	1 (M)	64.0	PD	(2.0)	NR	<ul style="list-style-type: none"> • Sending a young female patient a letter in which he made her the object of his fantasies • Nocturnal visits to a 12-year-old neighbourhood girl, encouraging her to visit him by giving her money • Sexual dreams and regular morning erections • Voyeurism • Rape fantasies 	Maximum dose of L-dopa reached	Success with replacing amantadine with benzhexol
Quinn et al. (1983) ⁽¹¹⁴⁾	CR	2 (M)	Age at onset: 39.5	PD	NR	NR	<ul style="list-style-type: none"> • Heightened sexual urge • Exhibitionism (especially in public lavatories) • Brothel • Calling neighbours to suggest arranging orgies • Binding testicles with leather thongs • Arranging to be bound at his home by men whom he had met in lavatories 	Bromocriptine (<i>n</i> = 1) and overusing Sinemet (<i>n</i> = 1)	Success with cyproterone, tiapride, haloperidol, pimozide, metoclopramide, oxyperamide and reduction of bromocriptine (<i>n</i> = 1); success with taking Sinemet as required (<i>n</i> = 1)
Dementia									
Luong et al. (2016) ⁽¹¹⁵⁾	CR	1 (M)	85.0	Dementia	11.0	NR	<ul style="list-style-type: none"> • Fondling himself • Public masturbation • Increased sexual thoughts 	Donepezil	Success with cessation of donepezil
Segrec et al. (2016) ⁽¹¹⁶⁾	CR	1 (F)	79.0	AD	NR	NR	<ul style="list-style-type: none"> • Difficulty controlling ability to not be sexually inappropriate towards others • Heightened sexual urge 	Donepezil	Success with cessation of donepezil
Evrensel et al. (2015) ⁽¹¹⁷⁾	CR	1 (M)	55.0	FTD	NR	FBI	<ul style="list-style-type: none"> • A lot of time online chatting with women • Demands for sexual intercourse with wife 	FTD	Success with risperidone and

Zajac et al. (2015) ⁽¹¹⁸⁾	CR	1 (M)	71.0	VaD and FTD	5.0	NR	<ul style="list-style-type: none"> • Pornography • Frequent masturbation (indifferent to whether wife or anyone else saw him) • Sexual disinhibition • Sexually inappropriate comments • Touching nursing staff • Public masturbation • Seeking out female residents 	Dementia	donepezil Success with nabilone
Gomes-Pinto et al. (2014) ⁽¹¹⁹⁾	CR	1 (M)	87.0	Mixed dementia	2.0	NR	<ul style="list-style-type: none"> • Pleasuring himself in front of daughters • Overt pornography use • Requesting unnecessary genital care • Entering daughter's bedroom at night and requesting sex 	Dementia	Success with citalopram
Othman et al. (2014) ⁽¹²⁰⁾	CR	1 (M)	65.0	FTD	4.0	NR	<ul style="list-style-type: none"> • Sodomizing farm animals such as chicken, goat and cow (squeezing the abdomen of the dead chicken forcing out the faeces and dilating the anus in the process before having sex with them) • Exhibitionism • Touching the breasts and private parts of his granddaughter • Interest in female underwear 	FTD	NR
Burke et al. (2013) ⁽¹²¹⁾	CR	1 (M)	73.0	AD	2.0	NR	<ul style="list-style-type: none"> • Sexually inappropriate comments • Requesting sexual activity 3 to 4 times a week • Obsessive and angry about sex • Talking with people and family members about sex in public settings • Suggesting that he would be better off committing suicide since he felt that he was "no longer a man" 	AD	NR
Canevelli et al. (2013) ⁽¹²²⁾	CR	1 (M)	81.0	AD	1.0	NR	<ul style="list-style-type: none"> • Heightened sexual urge • Sexually inappropriate comments • Excessive kissing 	AD	Success with transdermal rivastigmine
Cross et al. (2013) ⁽¹²³⁾	CS	10 (M)	79.5	Dementia	NR	NR	<ul style="list-style-type: none"> • Grabbing female residents' and female staff members' breasts and genitals • Exhibitionism • Public masturbation • Residing in bed with female residents • Inappropriate sexual talk/verbal language 	Dementia	Success with medroxyprogesterone acetate (70% of patients improved)

Poetter et al. (2013) ⁽¹²⁴⁾	CR	1 (M)	78.0	FTD	3.5	NR	Verbal and physical sexual advances toward staff and patients (both females and males)	FTD	Success with carbamazepine and cessation of paroxetine
Reeves et al. (2013) ⁽¹²⁵⁾	CR	1 (M)	61.0	FTD	2.0	NR	<ul style="list-style-type: none"> • Sexually inappropriate comments • Pornography • Requests for oral sexual activity 	NR	Success with aripiprazole
Gourzis et al. (2012) ⁽¹²⁶⁾	CR	1 (F)	29.0	FTD	5.0	NR	Stopping strangers passing by in order to inform them about her sexual preferences and asking their opinion about them	FTD	NR
Mendez et al. (2011) ⁽¹²⁷⁾	CR	1 (M)	55.0	FTD	2.0	NR	<ul style="list-style-type: none"> • Overt pornography use • Frequent masturbation 	FTD	Success with escitalopram
Mendez et al. (2011)* ⁽⁸³⁾	CS	4 (M)	71.3	FTD (<i>n</i> = 2); AD (<i>n</i> = 1); VaD (<i>n</i> = 1)	NR	NR	<ul style="list-style-type: none"> • Paedophilia • Attempts for sexual intercourse with wife several times a day • Frequently fondling wife in public • Touching the breasts of women in magazines • Uncontrollable sexual urge • Frequent masturbation • Talking about sex 	Dementia	Success with regiment of conjugated oestrogens, divalproex, and paroxetine (<i>n</i> = 1, FTD); NR (<i>n</i> = 3)
Rainero et al. (2011) ⁽¹²⁸⁾	CR	1 (M)	49.0	FTD	1.0	DSM-IV criteria for heterosexual paedophilia	Heightened sexual arousal and urges toward his 9-year-old daughter	FTD	Success with olanzapine and paroxetine
Chen (2010) ⁽¹²⁹⁾	CR	1 (M)	85.0	AD	13.0	NR	Obsessiveness with pornographic materials	AD	Success with citalopram
Katsumata et al. (2010) ⁽¹³⁰⁾	CR	1 (M)	39.0	FTD-like dementia	NR	NR	Unabashed attempts to touch the bodies of female nurses	Dementia	NR
Lo Coco et al. (2010) ⁽¹³¹⁾	CR	1 (M)	71.0	AD	1.0	NR	<ul style="list-style-type: none"> • Sexually inappropriate comments • Touching daughter inappropriately • Frequently asking for sexual intercourse with wife during the day • Public masturbation 	Donepezil	Success with cessation of donepezil
Kile et al. (2009) ⁽¹³²⁾	CR	1 (M)	70.0	AD	7.0	NR	<ul style="list-style-type: none"> • Flirtatiously approaching female parishioner and proceeding to hug and repeatedly kiss her • Sexual fantasies 	AD	NR
Na et al. (2009) ⁽¹³³⁾	CS	11 (M)	77.4	VaD	NR	NR	<ul style="list-style-type: none"> • Sexually inappropriate and obscene comments • Exhibitionism • Fondling or hugging female staff • Public masturbation 	VaD	Success with finasteride (<i>n</i> = 6)

Prakash et al. (2009) ⁽¹³⁴⁾	CR	1 (F)	61.0	LBD	2.0	NR	<ul style="list-style-type: none"> • Expressing sexual wishes to her daughter-in-law, saying in foul language that she wanted to have sex • Attempts to touch the private parts of her daughter-in-law • Asking daughter-in-law to touch her genitals 	Dementia	Success with quetiapine
Shoyama et al. (2008) ⁽¹³⁵⁾	CR	1 (M)	80.0	VaD	NR	NR	<ul style="list-style-type: none"> • Obscene words • Propositioning nurses after which he began pawing their bodies 	Increased dose of fluvoxamine	Success with cessation of fluvoxamine
Tosto et al. (2008) ⁽¹³⁶⁾	CR	1 (M)	54.0	AD	NR	NR	More than 20 sexual outlets (number of orgasms) per week	AD	Success with citalopram
Tune et al. (2008) ⁽¹³⁷⁾	CR	1 (M)	68.0	Dementia	4.0	NR	Touching and grabbing genitalia of female residents and staff	Dementia	Success with behavioural therapy (patient given stuffed animal for distraction)
Anneser et al. (2007) ⁽¹³⁸⁾	CR	1 (M)	53.0	ALS and FTD	NR	NR	<ul style="list-style-type: none"> • Exhausting demands for sexual intercourse in terms of frequency and at unacceptable times • Aggression if sexual needs were not met 	FTD	Success with sertraline
Dhikav et al. (2007) ⁽¹³⁹⁾	CR	1 (M)	70.0	AD	NR	NR	<ul style="list-style-type: none"> • Sexually inappropriate language • Touching and grabbing his wife's genitals in front of family members • Forcing wife to have sexual intercourse with him 3-4 times during the night and whenever he got the opportunity during the daytime • Sexual advances toward other females around him and passing sexually inappropriate comments • Masturbation 	AD	Success with olanzapine
Light et al. (2006) ⁽¹⁴⁰⁾	CS	5 (M)	78.8	Dementia	NR	NR	<ul style="list-style-type: none"> • Grabbing breasts of female staff and residents • Attempts for intercourse with a male resident • Exposing himself to adult daughter • Inappropriately touching female residents/daughter • Attempts for oral sexual relations • Extramarital encounters • Public masturbation 	Dementia	Success with medroxyprogesterone acetate ($n = 4$); quetiapine ($n = 1$); and thioridazine ($n = 1$)

Freymann et al. (2005) ⁽¹⁴¹⁾	CR	1 (M)	78.0	Dementia	3.0	NR	<ul style="list-style-type: none"> • Climbing into female residents' beds • Masturbating in front of his 74-year-old wife several times a day • Repeated demands to let him touch his wife sexually 	Dementia	Success with carbamazepine
Alkhalil et al. (2003) ⁽¹⁴²⁾	CR	1 (M)	76.0	AD	3.0	NR	<ul style="list-style-type: none"> • Sexually inappropriate behaviour • Exhibitionism • Grabbing at the genitals or breasts of his daughter and her female visitors • Public masturbation 	AD	Success with gabapentin
Chemali (2003) ⁽¹⁴³⁾	CR	2 (F)	76.5	Mixed dementia	NR	NR	<ul style="list-style-type: none"> • Obsessive sexual thought • Heightened sexual urge 	Donepezil	Success with cessation of donepezil
Haussermann et al. (2003) ⁽¹⁴⁴⁾	CR	2 (M)	76.5	Dementia	NR	NR	<ul style="list-style-type: none"> • Masturbating in front of female patients and nursing staff several times a week • Sexually inappropriate comments • Heightened sexual urge • Compulsive masturbation with ejaculations in public and private places 	Dementia	Success with cyproterone acetate
Rosenthal et al. (2003) ⁽¹⁴⁵⁾	CR	1 (M)	90.0	AD	NR	NR	<ul style="list-style-type: none"> • Masturbating 3-4 times a day during his hospitalization • Public masturbation • Urethral masturbation (trying to insert a variety of objects including straws, plastic syringe covers, discarded intravenous bag tubes) 	AD	Success with haloperidol and custodianship in nursing home
Stewart et al. (2003) ⁽¹⁴⁶⁾	CR	1 (M)	79.0	FTD	5.0	NR	Sexual disinhibition directed exclusively towards his wife	Dementia	Success with paroxetine
Miller (2001) ⁽¹⁴⁷⁾	CR	1 (M)	62.0	VaD	NR	NR	Sexual inappropriateness with staff and patients	NR	Success with gabapentin and cessation of valproic acid and mesoridazine
MacKnight et al. (2000) ⁽¹⁴⁸⁾	CR	1 (M)	85.0	Dementia	NR	NR	<ul style="list-style-type: none"> • Attempts to have sexual relations with his wife • Increased masturbating (to the point of self-injury) 	Dementia	Success with quetiapine
Mendez et al. (2000) ⁽¹⁴⁹⁾	CR	1 (M)	60.0	FTD	NR	NR	<ul style="list-style-type: none"> • Stalking, accosting, and attempting to molest children • Exhibitionism 	FTD	Success with paroxetine, valproate, and conjugated oestrogen
Shelton et al. (1999) ⁽¹⁵⁰⁾	CR	1 (M)	78.0	AD	NR	NR	<ul style="list-style-type: none"> • Sexual propositioning • Sexual aggression 	Dementia	Success with trial of conjugated oestrogen

Stewart et al. (1997) ⁽¹⁵¹⁾	CR	1 (M)	69.0	Dementia	8.0	NR	<ul style="list-style-type: none"> • Sexually inappropriate comments • Fondling or exposing himself to female patients, staff and visitors at assisted-living facilities • Masturbating in public • Repeated graphic requests for sexual favours 	Dementia	Success with paroxetine
Amadeo (1996) ⁽¹⁵²⁾	CR	1 (M)	86.0	AD	NR	NR	<ul style="list-style-type: none"> • Accosting women indiscriminately including caregivers • Offering money for sexual favours • Sexual attacking • Sexually propositioning adolescent niece 	AD	Success with medroxyprogesterone acetate
Leo et al. (1995) ⁽¹⁵³⁾	CR	2 (M)	60.0	Probable AD	NR	NR	<ul style="list-style-type: none"> • Exhibitionism • Pornography • Public masturbation • Unsolicited repetitive sexual touching of female staff 	Dementia	Success with clomipramine ($n = 2$)
Ott (1995) ⁽¹⁵⁴⁾	CR	1 (M)	43.0	FTD	4.5	NR	<ul style="list-style-type: none"> • Sexually inappropriate advances made toward people • Masturbating in front of family members • Attempts to fondle his mother-in-law's breasts • Constant desire for sexual relations with his wife 	FTD	Success with leuprolide
Alexopoulos (1994) ⁽¹⁵⁵⁾	CR	1 (M)	87.0	VaD	NR	NR	Inappropriately touching females	VaD	Success using cues (spaced-retrieval method)
Nadal et al. (1993) ⁽¹⁵⁶⁾	CR	1 (F)	49.0	Pick's dementia	NR	NR	Uncontrollable masturbation (sometimes in the presence of other people)	Dementia	Success with cyproterone acetate
Traumatic brain injury									
Alnemari et al. (2016) ⁽¹⁵⁷⁾	CR	1 (M)	Early twenties	TBI	0.3	NR	Paedophilia	TBI	NR
Fumagalli et al. (2015) ⁽¹⁵⁸⁾	CR	1 (M)	71.0	TBI	31.0	NR	<ul style="list-style-type: none"> • Paedophilic tendencies (he persuaded 2 boys to perform fellatio on him) • Exhibitionism • Frotteurism • Voyeurism 	TBI	NR
ter Mors et al. (2012) ⁽¹⁵⁹⁾	CR	1 (M)	40.0	TBI	26.0	SASBA	<ul style="list-style-type: none"> • Sexually inappropriate behaviour • Accosting his 4-year-old niece sexually 	TBI	Success with electrical aversion therapy
Kelly et al. (2011) ⁽¹⁶⁰⁾	CR	1 (M)	Forties	TBI	5.0	Semi-structured	<ul style="list-style-type: none"> • Making upsetting sexual comments 	Three possibilities:	Success with environmental controls

							interview with family and staff and discussion with patient	<ul style="list-style-type: none"> • Touching of female genital and nongenital areas • Public masturbation • Exhibitionism • Grabbing a female visitor to a day program and attempts to kiss her 	<ol style="list-style-type: none"> 1. Increased sex drive 2. ND 3. Expression of unmet sexual needs that are poorly formulated because of cognitive and communication impairments 	(behavioural strategies employed to manage disinhibited behaviour such as redirection, cueing inappropriate behaviour, and access to a sex worker (facilitating visits to a sex worker))
Bianchi-Demicheli et al. (2010) ⁽¹⁶¹⁾	CR	1 (M)	34.0	TBI	NR	NR		<ul style="list-style-type: none"> • Sexual arousal from seeing sleeping women • Sexual arousal from taking care of their hands and nails while they were asleep • Giving wife sleeping pills so she could fall asleep to satisfy his sexual urge 	TBI	NR
Bezeau et al. (2009) ⁽¹⁶²⁾	CR	1 (M)	31.0	TBI	NR	NR		<ul style="list-style-type: none"> • Sexually inappropriate and lewd comments • Strip clubs and attempts to touch dancers • Pornography • Sexual harassment • Constantly steering conversation towards sexual matters (stating that young females had been put on Earth because of him) • Leering, approaching, and invading personal space • Attempts to touch women 	TBI	Success with behavioural strategies (empathy training, debating) and thioridazine hydrochloride
Eghwurdjakpor et al. (2008) ⁽¹⁶³⁾	CS	5 (F = 1; M = 4)	28.0	TBI	NR	NR		<ul style="list-style-type: none"> • Strong arousal anytime being attended to by a female ward staff members • Unabashed demand for sex • Grabbing female attendant • Keeping hand inside pyjamas to masturbate • Exposing breasts when having female visitors • Attempting rape 	TBI	Success with reprimands for behaviour ($n = 2$); NA (expectancy) ($n = 2$); NR ($n = 1$)
Fyffe et al. (2004) ⁽¹⁶⁴⁾	CR	1 (M)	9.0	TBI	NR	NR		Touching/attempts to touch others in the area of the groin, buttocks, or breasts	TBI	Success with functional communication training and extinction
Britton (1998) ⁽¹⁶⁵⁾	CR	1 (M)	36.0	TBI	15.0	NR		<ul style="list-style-type: none"> • Touching/grabbing the breast, buttocks, and genital region of female staff, 	TBI	Success with medroxyprogesterone acetate

							residents, and visitors		
Wesolowski et al. (1993) ¹⁶⁶	CS	3 (F = 2; M = 1)	24.7	TBI	NR	NR	<ul style="list-style-type: none"> • Constant masturbation when he lay down • Indiscriminate sex in public • Approaching people and caressing/kissing them • Sexual comments to people and cornering them in wheelchair and touching their breasts and genitals 	TBI	Success with hourly feedback and behaviour contracting
Pandita-Gunawardena (1990) ¹⁶⁷	CR	1 (M)	80.0	TBI	74.0	NR	<ul style="list-style-type: none"> • Exposing self to neighbour • Adopting a baby posture and inviting neighbour to change his nappy and to feed him after which he masturbated 	TBI	NR
deFazio et al. (1987) ¹⁶⁸	CR	1 (M)	32.0	SCI	14.0	NR	<ul style="list-style-type: none"> • Constant sexual arousal • Looking at women on the street and in art class aroused him • Stimulating himself as he was approaching the drive-through window of a fast food chain after ascertaining which lines had pretty women has waitresses • Elements of secrecy added to his excitement • Sexual fantasies that as he was exposing himself that a “strange” women would find his penis attractive, approach him and start a relationship • Prostitutes • Exhibitionism 	NR	NR
Miller et al. (1986) ¹⁶⁹	CS	8 (F = 2; M = 6)	NR	TBI	NR	NR	<ul style="list-style-type: none"> • Public masturbation • Attempts to have intercourse with wife and female nurses in front of his three roommates • Excessive sexual demands • Preoccupation with sex • Propositioning both male and female patients and staff and physicians • Talking incessantly about sexual matters • Pornography • Conversation filled with sexual innuendo • Showing pornographic images to visitors in their home 	TBI	Success with thiothixene and benztropine ($n = 1$); NR ($n = 7$)

							<ul style="list-style-type: none"> • Suggesting him and his wife participate in orgy • Requests from wife to have sex with other men while he watched • Inserting objects in penis • Attempting to fondle nurses in hospital 		
Valentich et al. (1984-1986) ⁽¹⁷⁰⁾	CR	1 (M)	29.0	TBI	NR	Interview	<ul style="list-style-type: none"> • Aggressive sexual talk • Sexually inappropriate overtures to other residents and staff • Sexually aggressive manner to coerce a woman into sexual activity 	TBI	NR
<i>Kleine-Levin syndrome</i>									
Das et al. (2014) ⁽¹⁷¹⁾	CR	1 (M)	16.0	KLS	2.0	NR	<ul style="list-style-type: none"> • Standing very close to the person while talking • Hugging others more than usual, irrespective of gender • Sexual comments to female family members and neighbours • Touching genitalia of female family members • Fondling his genitalia and smelling hand afterwards 	KLS	NR
Lachman (2014) ⁽¹⁷²⁾	CR	1 (M)	14.0	KLS	NR	NR	Sexual disinhibition	KLS	Success with risperidone and sodium valproate
Mohapatra et al. (2014) ⁽¹⁷³⁾	CR	1 (M)	15.0	KLS	2.0	NR	Rubbing penis against pillow ignoring the presence of others	KLS	Success with armodafinil
Frase et al. (2013) ⁽¹⁷⁴⁾	CR	1 (M)	19.0	KLS	1.5	NR	Frequent masturbation	KLS	Success with lithium and risperidone
Aggarwal et al. (2011) ⁽¹⁷⁵⁾	CR	1 (F)	22.0	KLS	6.5	NR	<ul style="list-style-type: none"> • Talking about sex • Fondling with the genitalia of her cousin 	KLS	Success with modafinil
Hirst et al. (2007) ⁽¹⁷⁶⁾	CR	1 (M)	14.0	KLS	NR	NR	<ul style="list-style-type: none"> • Sexually inappropriate toward mother, sister, and housekeeper • Public masturbation 	KLS	NR
Masi et al. (2007) ⁽¹⁷⁷⁾	CR	1 (M)	16.0	KLS	NR	NR	<ul style="list-style-type: none"> • Compulsive masturbation without caring about the presence of other people • Sexually assaulting the nurses 	KLS	NR
Cheung (2006) ^{*(178)}	CR	1 (M)	66.0	KLS post trauma	4.0	NR	<ul style="list-style-type: none"> • Sexually inappropriate remarks to a few women including his elderly sister • Inappropriately touching a pharmacy assistant 	KLS	Success with lithium

Mendhekar et al. (2001) ⁽¹⁷⁹⁾	CR	2 (M)	12.0	KLS	NR	NR	<ul style="list-style-type: none"> • Frequently asking nurses for hugs 	KLS	Success with lithium
Masi et al. (2000) ⁽¹⁸⁰⁾	CR	1 (M)	21.0	KLS	7.0	NR	<ul style="list-style-type: none"> • Lying prone in bed and rubbing genitalia against the bed • Overt masturbation • Repeatedly assaulting the nurses, sister, and friend of hers saying he was sexually attracted to them • Continuous requests to fiancée to have sex with him • Constantly staring or approaching other women when out 	KLS	Success with lithium
Mukaddes et al. (1999) ⁽¹⁸¹⁾	CR	1 (M)	13.0	KLS	NR	NR	Increased interest in sex and masturbation	KLS	Success with carbamazepine
Cawthron (1990) ⁽¹⁸²⁾	CR	1 (M)	15.0	KLS	NR	NR	<ul style="list-style-type: none"> • Public masturbation • Developing thoughts of a sexual nature concerning a neighbour 	KLS	NR
Multiple sclerosis									
Lopez-Meza et al. (2005) ⁽¹⁸³⁾	CR	1 (F)	21.0	MS	10.0	NR	<ul style="list-style-type: none"> • Sexual disinhibition • Sexual jokes • Sexually explicit language • Masturbation • Heterosexual and homosexual intercourse • Prostitutes 	MS	Success with clozapine and valproic acid
Yang et al. (2004) ⁽¹⁸⁴⁾	CR	1 (F)	51.0	MS	9.0	NR	<ul style="list-style-type: none"> • Insatiable sexual appetite • Frequent requests to have sex • Frequent masturbation • Contemplating having an affair 	MS	Success with methoprednisolone and oral prednisone
Frohman et al. (2002) ⁽¹⁸⁵⁾	CR	1 (M)	36.0	MS	NR	NR	<ul style="list-style-type: none"> • Sexually explicit questions to strangers • Masturbating 10-12 times per day • Reaching out and touching women's breasts, accosting several women in group homes and nurses • Propositioning a 12-year-old girl in a movie theatre • Sexually assaulting another minor 	MS	Success with fluvoxamine and medroxyprogesterone acetate
de Assis Aquino Gondim et al. (2001) ⁽¹⁸⁶⁾	CR	1 (F)	45.0	MS	18.0	NR	<ul style="list-style-type: none"> • Frequent sexual intercourse • Frequent masturbation • Heightened sexual urges 	MS	NR
Ortego et al. (1993) ⁽¹⁸⁷⁾	CR	1 (F)	39.0	MS	NR	NR	<ul style="list-style-type: none"> • Seducing her 14-year-old's 17-year-old female lover 	MS	NR

							<ul style="list-style-type: none"> Engaging in oral sex and using a vibrator during mutual masturbation with the 17-year-old girl Offering sex to her son's 15-year-old male friends Requesting that her son and his girlfriend engage in sexual intercourse while she watched Attempts to have the pet German shepherd have intercourse with her in front of her son and his girlfriend Having her dog lick her genitalia in front of minors 		
Huws et al. (1991) ⁽¹⁸⁸⁾	CR	1 (M)	NR	MS	NR	NR	<ul style="list-style-type: none"> Assaultive Foot fetish (fondling and kissing feet of females in ward) 	MS	Success with counselling, behavioural therapy, antilibidinal drugs (cyproterone acetate), neuroleptics, and carbamazepine
Epilepsy									
Boronat et al. (2013)* ⁽¹⁸⁹⁾	CR	1 (M)	2.7	Tu. Sc., KBS-epilepsy	NR	NR	<ul style="list-style-type: none"> Frequent touching and holding of his genitals Rhythmic movements of his pelvis when in prone position Masturbation 	Epilepsy	Success with epilepsy surgery
Metin et al. (2013) ⁽¹⁹⁰⁾	CR	1 (F)	44.0	TLE	29.0	NR	<ul style="list-style-type: none"> Heightened sexual urge without being stimulated visually or tactically Sexual daydreams Increased masturbation 	Levetiracetam	Success with cessation of levetiracetam
Pelin et al. (2012) ⁽¹⁹¹⁾	CR	1 (M)	13.0	TLE	NR	NR	<ul style="list-style-type: none"> Masturbation during sleep Convinced that all women were in love with him, so he asked to have sex with almost all of the women around him without caring who they were Inappropriate sexual behaviour 	TLE	Success with topiramate, carbamazepine, and aripiprazole
Rashid et al. (2010) ⁽¹⁹²⁾	CS	3 (F)	44.3	TLE	18.7	NR	<ul style="list-style-type: none"> Kissing motion toward hospital technician Blowing kisses repetitively at phone Holding and kissing technician's hand in an affectionate manner and then asking technician to kiss her hand in return 	TLE	Success with right temporal lobectomy ($n = 2$); NR ($n = 1$)

Arnedo et al. (2009) ⁽¹⁹³⁾	CR	1 (M)	39.0	TLE	NR	NR	Sexually aggressive toward wife by forcing intercourse	Seizures	Success with lamotrigine and levetiracetam
Pestana et al. (2007) ⁽¹⁹⁴⁾	CR	1 (M)	11.0	KBS-epilepsy	9.0	NR	Unsolicited sexual gestures (bringing face close to a person in a kissing gesture and touching)	Seizures	NR
Grabowska-Grzyb et al. (2006) ⁽¹⁹⁵⁾	CR	2 (M)	52.5	TLE (<i>n</i> = 1); FLE (<i>n</i> = 1)	37.0	NR	<ul style="list-style-type: none"> • Obsessive thoughts about sexual activity • Several erections a day without visual or tactile stimulation • Increased masturbation • Aggression when he could not satisfy his heightened sexual urge 	Lamotrigine	Success with cessation of lamotrigine (<i>n</i> = 1); NR (<i>n</i> = 1)
Ozmen et al. (2004) ⁽¹⁹⁶⁾	CR	1 (F)	14.0	Epilepsy	2.0	NR	<ul style="list-style-type: none"> • Excessive masturbation in inappropriate places (such as in classroom, school bus, and family events) • Sexual arousal by rubbing her genitalia on the edge or corner of objects 	Epilepsy surgery	Success with psychoeducative intervention and citalopram
Baird et al. (2002) ⁽¹⁹⁷⁾	CS	7 (F = 5; M = 2)	35.1	TLE	NR	NR	<ul style="list-style-type: none"> • Change in sexual orientation (heterosexuality to homosexuality) • Frequent sexual thoughts and fantasies • Dramatic increase in sexual urge • Wanting spouse to have temporal lobe resection to have same sex drive • Extramarital encounters 	Temporal lobe resection	NR
El-Badri et al. (1998) ⁽¹⁹⁸⁾	CR	2 (M)	24.5	TLE	NR	NR	<ul style="list-style-type: none"> • Sexual arousal in appropriate situations (the stimulus being the feet of adolescent boys) • Overt masturbation • Found in the local toilets trying to entice people to show him their feet • Becoming sexually aroused by black patent leather shoes 	TLE	Success with carbamazepine (<i>n</i> = 2)
Short et al. (1995) ⁽¹⁹⁹⁾	CR	1 (M)	49.0	Epilepsy	NR	NR	<ul style="list-style-type: none"> • Becoming over familiar toward female staff on the ward • Making inappropriate sexual remarks 	Gabapentin	Success with cessation of gabapentin
Hunter et al. (1963) ⁽²⁰⁰⁾	CR	1 (M)	39.0	TLE	10.0	NR	<ul style="list-style-type: none"> • Obsessiveness with sex murders, cross-dressing and masturbation • Tying blind cord around his genitals 	TLE	Success with lobectomy

<i>Kliver-Bucy syndrome</i>									
Ibrahim et al. (2014) ⁽²⁰¹⁾	CR	1 (F)	69.0	KBS	NR	NR	<ul style="list-style-type: none"> • Undressing inappropriately in front of son • Openly discussing her sexual activities • Openly discussing her desire to have sex with her 25-year-old neighbour • Attempts to invite nurses to engage in sexual relations with her • Masturbating in front of roommate in hospital • Pursuing female nurses in corridor trying to touch their genitals 	KBS and possibly taking more lorazepam than was prescribed	Success with risperidone and reduction of lorazepam
Kwiatkowski et al. (2011)* ⁽²⁰²⁾	CR	1 (M)	16.0	KBS secondary to TBI	NR	NR	Increased masturbation	KBS	Success with carbamazepine
Okur et al. (2011) ⁽²⁰³⁾	CR	1 (F)	14.0	KBS	NR	NR	NR	KBS	Success with haloperidol, valproic acid, and carbamazepine
Devinsky et al. (2010) ⁽²⁰⁴⁾	CR	1 (M)	51.0	KBS	NR	NR	<ul style="list-style-type: none"> • More sexually active with his wife • Frequent masturbation • Obsessiveness with child pornography 	Subdural grip/strip electrode surgery and posterior temporal lobe resection	Success with sertraline and quetiapine
Tuleja et al. (2008) ⁽²⁰⁵⁾	CR	1 (F)	61.0	KBS	NR	NR	Inappropriate sexual advances towards nursing staff	KBS	NR
Auvichayapat et al. (2006) ⁽²⁰⁶⁾	CR	1 (M)	14.0	KBS	NR	NR	<ul style="list-style-type: none"> • Excessive public masturbation • Exhibitionism • Touching the genitalia of those who passed his bed, including his mother 	KBS	Success with roxithromycin
Jha et al. (2005) ⁽²⁰⁷⁾	CS	7 (F = 1; M = 6)	8.6	KBS secondary to HIE	NR	NR	<ul style="list-style-type: none"> • Fondling and squeezing of genitalia • Pelvic thrusting • Rubbing genitals against wall or bed 	KBS	NR
Mendhekar et al. (2005) ⁽²⁰⁸⁾	CR	1 (F)	14.0	KBS	NR	NR	<ul style="list-style-type: none"> • Exhibitionism • Manipulating her genitals • Sexual advances toward her father 	KBS	Success with sertraline
Pradhan et al. (1998) ⁽²⁰⁹⁾	CS	7 (M)	3.6	KBS	NR	NR	<ul style="list-style-type: none"> • Rhythmic hip movements • Rubbing genitals over the bed • Excessive manipulation of genitals 	KBS secondary to HSE	Success with haloperidol ($n = 5$) and pimozide ($n = 2$)

Ghika-Schmid et al. (1995) ⁽²¹⁰⁾	CR	1 (F)	70.0	KBS	1.0	BSSD	<ul style="list-style-type: none"> • Verbal sexual advances to male carers • Investing stories about past affairs • Exhibitionism 	KBS secondary to lobectomy	Success with levopromazine, promethazine, and carbamazepine
Pitt et al. (1995) ⁽²¹¹⁾	CR	1 (F)	12.5	KBS	NR	NR	<ul style="list-style-type: none"> • Moving and dancing suggestively • Increased masturbation • Rubbing against objects • Attempts to sit on adults' lap • Kissing adults of both sexes 	KBS	NR
Wong et al. (1991) ⁽²¹²⁾	CR	1 (M)	13.0	KBS	NR	NR	<ul style="list-style-type: none"> • Inappropriately touching females • Talking about sexual topics 	KBS	NR
Huntington's disease									
Teive et al. (2016) ^{*69)}	CS	2 (F = 1; M = 1)	56.5	HD	NR	NR	Excessive sexual intercourse	NR	Success with clonazepam (<i>n</i> = 1) and olanzapine (<i>n</i> = 1)
Mendez et al. (2011) ⁽⁸³⁾	CR	1 (M)	32.0	HD	2.0	NR	Paedophilia	HD	Success with isolation from children, haloperidol, and sertraline
Tavares et al. (2008) ⁽²¹³⁾	CR	1 (M)	80.0	HD	20.0	NR	<ul style="list-style-type: none"> • Sex only subject of talk • Sexual interest openly directed to younger women • Overtly praising the sexual beauty of his nurses, female physiotherapist, female speech therapist, and even of younger members of his family • Frequent commands to nurses take a bath with him • Putting himself nude in his room and attempting to hold his nurse 	HD	Success with cyproterone acetate
Rich et al. (1994) ⁽²¹⁴⁾	CR	1 (M)	34.0	HD	NR	Questionnaire assessing level of sexual interest	Indecent exposure while masturbating	HD	Success with leuprolide
Janati (1985) ⁽²¹⁵⁾	CR	1 (M)	46.0	HD	8.0	NR	Constant masturbation in front of staff and other patients	HD	Success with increase in haloperidol dose
Stroke									
Chae et al. (2006) ⁽²¹⁶⁾	CR	1 (M)	63.0	Stroke	NR	NR	Demands for sexual intercourse from wife	Stroke	Success with quetiapine
Absher et al. (2000) ⁽²¹⁷⁾	CR	1 (M)	70.0	Stroke	NR	NR	<ul style="list-style-type: none"> • Requests to two of the nurses taking care of him to get in the hospital bed with him 	Stroke	Success with lithium and sodium valproate

							<ul style="list-style-type: none"> • Exhibitionism • Frequent sexual innuendoes in his speech • Soliciting sex from nurses 		
Korpelainen et al. (1998)* ⁽¹⁰⁹⁾	CR	2 (M)	57.5	Stroke	NR	NR	<ul style="list-style-type: none"> • Telephone sex services several times a day even when wife present 	Stroke	Success with cessation of moclobemide
Libman et al. (1996) ⁽¹¹⁸⁾	CR	2 (M)	61.0	Stroke	NR	NR	<ul style="list-style-type: none"> • Heightened sexual urge • Increased sexual thoughts • Frequent sexual intercourse • Demands for sex • Excessively holding and hugging wife 	Stroke	NR
Multiple system atrophy									
Tschopp et al. (2010)* ⁽⁸⁵⁾	CR	1 (F)	68.0	MSA	2.0	NR	NR	Piribedil	Success with quetiapine and reduction of piribedil
McKeon et al. (2007)* ⁽⁹⁵⁾	CR	1 (M)	60.0	MSA	NR	NR	Intense fascination with pornography	DA	NR
Klos et al. (2005)* ⁽¹⁰²⁾	CR	2 (M)	Age of onset: 59.5	MSA	NR	NR	NR	DA	Success with cessation of DA ($n = 1$); NR ($n = 1$)
Progressive supranuclear palsy									
Madhusoodanan et al. (2014) ⁽²¹⁹⁾	CR	1 (M)	63.0	PSP	0.5	NR	<ul style="list-style-type: none"> • Sexually assaulting roommate • Increased masturbation 	PSP	Success with divalproex sodium
Kim et al. (2008) ⁽²²⁰⁾	CR	1 (M)	83.0	PSP	NR	NR	<ul style="list-style-type: none"> • Sexually suggestive remarks • Touching and kissing others • Exhibitionism • Facial flushing • Public masturbation 	Two incidents of HS: 1. Bromocriptine 2. Pramipexole	Success with cessation of bromocriptine (first incident) and pramipexole (second incident)
Encephalitis									
Anand et al. (2007)* ⁽²²¹⁾	CR	1 (M)	30.0	KBS secondary to HSE	NR	NR	<ul style="list-style-type: none"> • Excessive genital fondling • Exhibitionism 	HSE	Success with risperidone
Thomas et al. (1995)* ⁽²²²⁾	CR	1 (M)	47.0	Encephalitis in childhood, sequelae of learning disability and epilepsy	41.0	NR	<ul style="list-style-type: none"> • Stealing female undergarments from fellow residents and found wearing them • Staring at neighbours' washing line where female undergarments were hung for drying • Penile erection when wearing female clothing 	Encephalitis	Success with being given an opportunity to express sexual desires

Brain disease									
Lehne (1984-1986) ⁽²²³⁾	CR	1 (M)	38.0	BD	NR	NR	<ul style="list-style-type: none"> • Inappropriate sexual behaviour involving stepdaughter • Voyeurism (drilled holes in the wall to watch his stepdaughter undress) • Attempts to touch stepdaughter's breasts • Fondling of stepdaughter's breasts 	BD	Success with medroxyprogesterone acetate
Restless legs syndrome									
Sansone et al. (2007) ⁽²²⁴⁾	CR	1 (M)	67.0	RLS	NR	NR	<ul style="list-style-type: none"> • Heightened sexual urge • Increased masturbation • Waking his wife up in the middle of the night to have sex • Excusing himself from the dinner table at home, in restaurants, or at the homes of friends to masturbate 	Pramipexole	Success with cessation of pramipexole
Hippocampal sclerosis									
Mendez et al. (2000) ⁽¹⁴⁹⁾	CR	1 (M)	67.0	Hipp. Sc. (without epilepsy)	NR	NR	Child molestation	Hipp. Sc.	Success with sertraline and supervised environment
Tourette's syndrome									
Teive et al. (2016) ^{*,(69)}	CR	2 (M)	30.0	TS	NR	NR	<ul style="list-style-type: none"> • Sexual promiscuity • Excessive masturbation 	NR	NA (one patient developed AIDS and the other patient died) ($n = 2$)
Spinocerebellar ataxia type 3									
Teive et al. (2016) ^{*,(69)}	CS	4 (M)	36.0	SCA3	NR	NR	Excessive sexual intercourse	NR	Success with buspirone ($n = 1$); NA (expectancy) ($n = 1$); NR ($n = 2$)
Fatal familial insomnia									
de Souza et al. (2016) ⁽²²⁵⁾	CR	1 (M)	48.0	FFI	NR	NR	<ul style="list-style-type: none"> • Sexual disinhibition • Touching family members • Making sexual proposals to them • Public manipulation of genitals with masturbatory movements 	FFI	Success with alprazolam and quetiapine

AD: Alzheimer's disease; AIDS: Acquired Immune Deficiency Syndrome; ALS: amyotrophic lateral sclerosis; BSSD: Behavioural Syndromes Scale for Dementia; BD: brain disease; CR: case report; CS: case series; DA: dopamine agonist; DBS: deep brain stimulation; DRT: dopamine replacement therapy; DSM-VI: Diagnostic Statistical Manual, 4th edition; ED: erectile dysfunction; F: female; FBI: Frontal Behaviour Inventory; FFI: fatal familial insomnia; FLE: frontal lobe epilepsy; FTD: frontotemporal dementia; GPi: Globus Pallidus pars interna; HBI: hypoxic brain injury; HD: Huntington's disease; Hipp. Sc.: hippocampal sclerosis; HS: hypersexuality; HSE: herpes simplex encephalitis; ICD-10: 10th revision of the International Statistical Classification of Diseases and Related Health Problems; KBS: Kluver-Bucy syndrome; KLS: Kleine-Levin syndrome; LBD: Lewy body dementia; L-dopa: levodopa; M: male; MS: multiple sclerosis; MSA: multiple system atrophy; NA: not available; ND: neurological disorder; NR: not reported; PD: Parkinson's disease; PDE5-I: phosphodiesterase type 5 inhibitor; PSP: progressive supranuclear palsy; RLS: restless legs syndrome; SASBA: St. Andrew's Sexual Behaviour Assessment; SCA3: spinocerebellar ataxia type 3; SCI: spinal cord injury; SSRI: selective serotonin reuptake inhibitors; STN: subthalamic nucleus; TBI: traumatic brain injury; TLE: temporal lobe epilepsy; TS: Tourette's syndrome; Tu. Sc.: tuberous sclerosis; VaD: vascular dementia

*. Studies with more than one neurological diagnosis were categorised depending upon the neurological disorder contributing to the development of hypersexuality, or according to the neurological disorder listed in the study aim.

2.5.2 Risk bias and quality assessment

Quality assessment was carried out for the cross sectional, cohort, and case control studies using the EPHPP tool and results are summarised in Table 5.

Table 5 – Risk bias and quality assessment for the cross sectional, cohort, and case control studies
NA: not available

	Selection bias	Study design	Confounders	Blinding	Data collection methods	Withdrawal and drop-outs	Global rating
Canevelli 2017 ⁽⁸⁾	Moderate	Weak	Weak	Moderate	Strong	NA	Weak
Merola 2017 ⁽⁹⁾	Moderate	Moderate	Strong	Moderate	Strong	Strong	Strong
Azmin 2016 ⁽⁹⁾	Moderate	Weak	Weak	Moderate	Strong	NA	Weak
Gescheidt 2016 ⁽⁹⁾	Moderate	Weak	Weak	Moderate	Strong	NA	Weak
Wang 2016 ⁽⁹⁾	Moderate	Weak	Weak	Moderate	Strong	NA	Weak
Wang 2016 ⁽⁹⁾	Moderate	Moderate	Weak	Moderate	Weak	Weak	Weak
Amami 2015 ⁽⁸⁾	Moderate	Moderate	Strong	Moderate	Strong	Strong	Strong
Baumann-Vogel 2015 ⁽⁹⁾	Moderate	Moderate	Weak	Moderate	Weak	Weak	Weak
Fantini 2015 ⁽¹⁰⁾	Moderate	Moderate	Weak	Moderate	Strong	Weak	Weak
Sharma 2015 ⁽¹¹⁾	Moderate	Weak	Weak	Moderate	Strong	NA	Weak
Mendez 2014 ⁽⁹⁾	Moderate	Moderate	Weak	Moderate	Strong	Weak	Weak
Perry 2014 ⁽⁴⁰⁾	Moderate	Moderate	Weak	Moderate	Strong	Moderate	Moderate
Mendez 2013 ⁽⁴¹⁾	Moderate	Weak	Strong	Moderate	Weak	NA	Weak
Politis 2013 ⁽¹²⁾	Moderate	Moderate	Moderate	Moderate	Strong	Moderate	Moderate
Poletti 2013 ⁽¹³⁾	Moderate	Weak	Moderate	Moderate	Strong	NA	Moderate
Simpson 2013 ⁽⁷⁾	Moderate	Weak	Weak	Moderate	Strong	NA	Weak
Tanaka 2013 ⁽⁴⁾	Moderate	Weak	Strong	Moderate	Strong	NA	Moderate
Weintraub 2013 ⁽¹⁵⁾	Moderate	Moderate	Strong	Moderate	Strong	Strong	Strong
Chiang 2012 ⁽¹⁶⁾	Moderate	Weak	Strong	Moderate	Strong	Strong	Moderate
Farnikova 2012 ⁽⁷⁾	Moderate	Moderate	Weak	Moderate	Strong	Weak	Weak
Perez-Lloret 2012 ⁽¹⁸⁾	Moderate	Weak	Weak	Moderate	Strong	NA	Weak
Schreglmann 2012 ⁽⁵²⁾	Weak	Moderate	Weak	Moderate	Weak	Weak	Weak
Solla 2012 ⁽¹⁹⁾	Strong	Weak	Strong	Moderate	Strong	NA	Moderate
Avila 2011 ⁽²⁰⁾	Strong	Moderate	Strong	Weak	Weak	Strong	Weak
Avila 2011 ⁽²¹⁾	Moderate	Moderate	Weak	Moderate	Weak	Weak	Weak
Dang 2011 ⁽⁵³⁾	Weak	Weak	Weak	Moderate	Strong	NA	Weak
de Chazeron 2011 ⁽²²⁾	Moderate	Moderate	Strong	Moderate	Weak	Weak	Weak
Hassan 2011 ⁽²³⁾	Moderate	Weak	Weak	Moderate	Weak	NA	Weak
Lim 2011 ⁽²⁴⁾	Strong	Weak	Weak	Moderate	Strong	NA	Weak
Solla 2011 ⁽²⁵⁾	Moderate	Moderate	Weak	Moderate	Weak	Weak	Weak
Voon 2011 ⁽⁵⁴⁾	Weak	Weak	Weak	Moderate	Strong	NA	Weak
Zahodne 2011 ⁽²⁶⁾	Strong	Moderate	Weak	Moderate	Strong	Weak	Weak
Cornelius 2010 ⁽⁵⁵⁾	Moderate	Moderate	Weak	Moderate	Weak	Weak	Weak
Kenangil 2010 ⁽²⁷⁾	Moderate	Moderate	Strong	Moderate	Weak	Weak	Weak
Lee 2010 ⁽²⁸⁾	Strong	Weak	Weak	Moderate	Strong	NA	Weak
Weintraub 2010 ⁽²⁹⁾	Moderate	Weak	Moderate	Moderate	Strong	NA	Moderate
Bostwick 2009 ⁽³⁰⁾	Moderate	Moderate	Weak	Moderate	Weak	Moderate	Weak
Cooper 2009 ⁽³¹⁾	Weak	Moderate	Weak	Moderate	Weak	Weak	Weak
Fan 2009 ⁽⁵²⁾	Moderate	Moderate	Weak	Weak	Strong	Moderate	Weak
Arnulf 2008 ⁽⁶²⁾	Moderate	Moderate	Moderate	Moderate	Weak	Weak	Weak
Ondo 2008 ⁽³³⁾	Moderate	Weak	Weak	Moderate	Weak	NA	Weak
Driver-Dunckley 2007 ⁽⁵⁶⁾	Weak	Weak	Weak	Moderate	Weak	NA	Weak
Giladi 2007 ⁽³⁴⁾	Moderate	Moderate	Strong	Moderate	Weak	Weak	Weak
Singh 2007 ⁽³⁵⁾	Strong	Weak	Weak	Moderate	Weak	NA	Weak
Onishi 2006 ⁽⁴²⁾	Moderate	Weak	Weak	Moderate	Strong	NA	Weak

Voon 2006 ⁽⁶⁰⁾	Moderate	Weak	Weak	Moderate	Weak	NA	Weak
Alagiakrishnan 2005 ⁽⁴⁵⁾	Weak	Weak	Weak	Moderate	Weak	NA	Weak
Mendez 2005 ⁽⁴⁴⁾	Moderate	Moderate	Strong	Moderate	Strong	Weak	Moderate
Simpson 2001 ⁽⁵⁸⁾	Moderate	Moderate	Strong	Moderate	Weak	Weak	Weak
Kesler 2000 ⁽⁶³⁾	Moderate	Moderate	Strong	Moderate	Weak	Weak	Weak
Wiseman 2000 ⁽⁴⁵⁾	Weak	Weak	Weak	Moderate	Weak	Moderate	Weak
Simpson 1999 ⁽⁵⁹⁾	Moderate	Moderate	Weak	Moderate	Weak	Moderate	Weak
Tsai 1999 ⁽⁴⁶⁾	Moderate	Moderate	Strong	Moderate	Weak	Weak	Weak
Trosch 1998 ⁽⁵⁷⁾	Moderate	Moderate	Weak	Moderate	Weak	Moderate	Weak
Hwang 1997 ⁽⁴⁷⁾	Moderate	Weak	Weak	Moderate	Weak	NA	Weak
Zeiss 1996 ⁽⁴⁸⁾	Moderate	Moderate	Weak	Moderate	Weak	Weak	Weak
Emory 1995 ⁽⁴⁶⁾	Moderate	Moderate	Weak	Moderate	Weak	Moderate	Weak
Miller 1995 ⁽⁴⁹⁾	Moderate	Weak	Weak	Moderate	Weak	NA	Weak
Devanand 1992 ⁽⁵⁰⁾	Moderate	Weak	Weak	Moderate	Strong	NA	Weak
Hainline 1992 ⁽⁴⁶⁾	Moderate	Moderate	Weak	Moderate	Strong	Weak	Weak
Burns 1990 ⁽⁵¹⁾	Moderate	Weak	Weak	Moderate	Strong	NA	Weak
Shukla 1979 ⁽⁴⁶⁾	Moderate	Moderate	Strong	Moderate	Weak	Weak	Weak

Risk of bias and quality were not assessed in case series and case reports, which are regarded as low-level evidence⁽²²⁶⁾, due to inherent risk of bias and issues with quality.

2.6 Discussion

2.6.1 Introduction

The aims of this chapter were to systematically review the prevalence, clinical phenomenology, ameliorating management options, assessment tools, and implicated factors contributing to the development of hypersexuality in neurological disorders.

2.6.2 Prevalence of hypersexuality

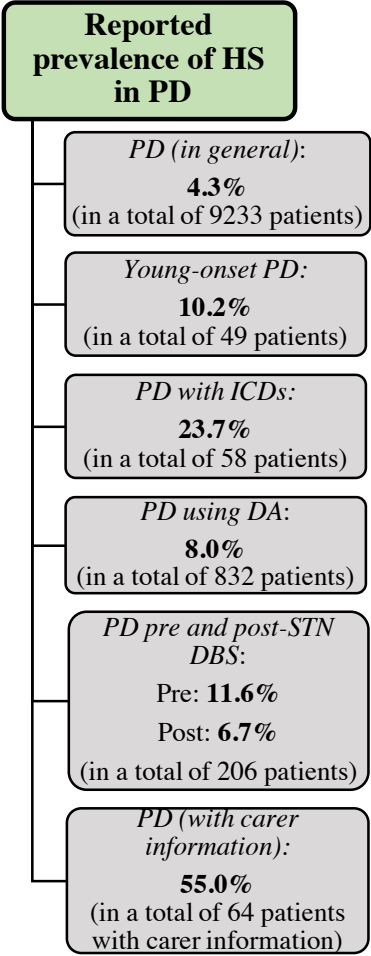
Reported prevalence figures of hypersexuality in specific neurological disorders were presented in Table 3. Average prevalence was calculated by multiplying available percentage prevalence figures by the number of patients in the study and then dividing by the total number of patients for each presented neurological disorder.

2.6.2.1 Parkinson's disease

Prevalence of hypersexuality in PD was reported in 32 of the accepted PD-related studies for the following populations: patients with PD in general (from 23 studies)^(5, 7, 9, 11, 13-19, 21, 22, 24-26, 28-32, 34, 36), PD patients pre and post STN DBS (from 2 studies)^(4, 8), patients with young-onset PD (from one study)⁽⁶⁾, PD patients with ICDs (from 2 studies)^(20, 27), PD patients using dopamine agonists (from 3 studies)^(23, 33, 35), and PD patients with information about hypersexuality from carers (from one study)⁽⁹⁾. Figure 2 represents the average prevalence for each of the above populations:

Figure 2 - Reported prevalence of hypersexuality in Parkinson’s disease

DA: dopamine agonists; ICDs: impulse control disorders; HS: hypersexuality; PD: Parkinson’s disease; STN DBS: deep brain stimulation of the subthalamic nucleus

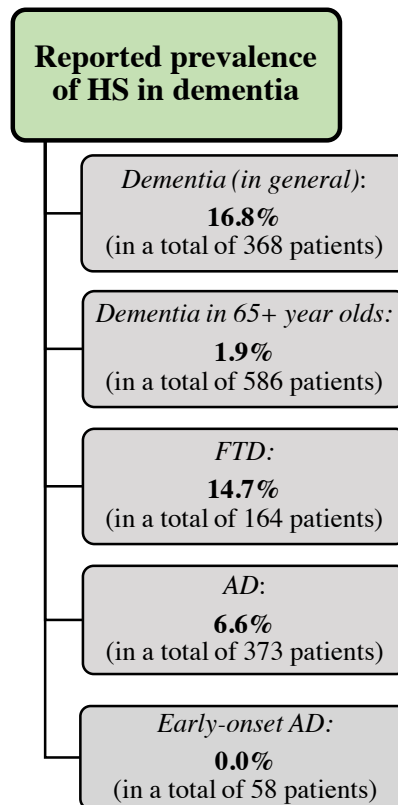


The prevalence of hypersexuality in patients with young-onset PD is significantly higher than PD patients in general. A reason for this may be that younger patients may be more likely to report hypersexuality as there is a stigma surrounding sex in older populations, which may prompt them not to disclose the changes in their sexuality⁽²²⁷⁾. Also, younger patients are more likely to be treated with dopamine agonists, which are closely linked to the development of hypersexuality^(71, 228). This association between hypersexuality and dopamine agonists is evident in the prevalence of PD patients using dopamine agonists, which is greater than PD patients in general. However, despite this, one cannot draw any conclusions regarding causality of hypersexuality. Moreover, PD patients with impulse control disorders also have a higher prevalence of hypersexuality than PD patients in general and this is likely due to selection bias. Results regarding prevalence pre and post STN DBS are suggestive that surgery may help manage hypersexuality, as prevalence was almost halved post-DBS. Furthermore, one study based on carer information suggests that prevalence may be underreported in patient populations possibly due to the sensitivity of the issue and consequent shame and embarrassment prompting patients not to disclose information about the changes in their sexuality, especially if there have been unlawful acts⁽⁹⁾. The prevalence figure in that population, however, appears to be very high and may be influenced by selection bias.

2.6.2.2 Dementia

Prevalence of hypersexuality in dementia was reported in 10 of the accepted dementia-related studies for the following populations: patients with unspecified dementia (from 3 studies)^(38, 46, 48), patients with dementia who are aged 65 and older (from one study)⁽⁴²⁾, patients with FTD (from 3 studies)^(40, 41, 49), patients with AD (from 4 studies)^(47, 49, 51), and patients with early-onset AD (from one study)⁽⁴¹⁾. Figure 3 represents the average prevalence for each of the above populations:

Figure 3 - Reported prevalence of hypersexuality in dementia
AD: Alzheimer's disease; FTD: frontotemporal dementia; HS: hypersexuality

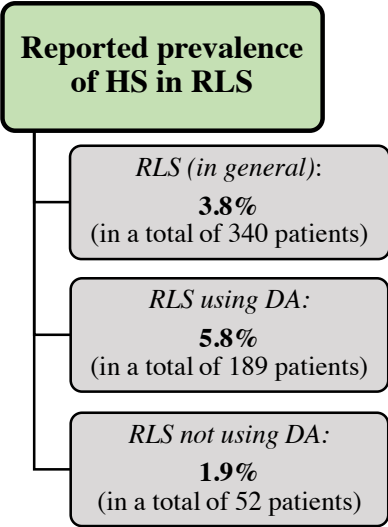


Similar to PD, older patients with dementia report lower prevalence of hypersexuality than patients with dementia in general. The reason for this is also possibly the stigma associated with sexual disclosure and stigma in old age. Moreover, FTD patients reported higher prevalence than AD patients, possibly indicative of direct temporolimbic and frontal involvement in the development of hypersexuality⁽⁴¹⁾.

2.6.2.3 Restless legs syndrome

Prevalence of hypersexuality in RLS was reported in 6 of the accepted RLS-related studies for the following populations: patients with RLS in general (from 4 studies)^(52-54, 56), patients with RLS treated with dopamine agonists (from 2 studies)^(33, 55), and patients with RLS who were never treated with dopamine agonists (from one study)⁽⁵⁵⁾. Figure 4 represents the average prevalence for each of the above populations:

Figure 4 - Reported prevalence of hypersexuality in restless legs syndrome
DA: dopamine agonists; HS: hypersexuality; RLS: restless legs syndrome

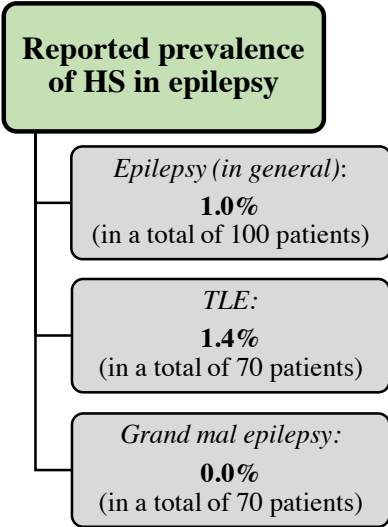


Although prevalence of hypersexuality in RLS is low, exposure to dopamine agonists is predominantly reported as the implicating factor, similar to hypersexuality in PD. RLS patients using dopamine agonists reported a higher prevalence than RLS patients not using dopamine agonists, indicative of dopamine agonist involvement in the development of hypersexuality, although definitive causality cannot be determined.

2.6.2.4 Epilepsy

Prevalence of hypersexuality in epilepsy was reported in 2 of the accepted epilepsy-related studies for the following populations: patients with TLE (from one study)⁽⁶⁴⁾, patients with grand mal epilepsy (from one study)⁽⁶⁴⁾, and patients with unspecified epilepsy (from one study)⁽⁶⁵⁾. Figure 5 represents the average prevalence for each of the above populations:

Figure 5 - Reported prevalence of hypersexuality in epilepsy
HS: hypersexuality; TLE: temporal lobe epilepsy



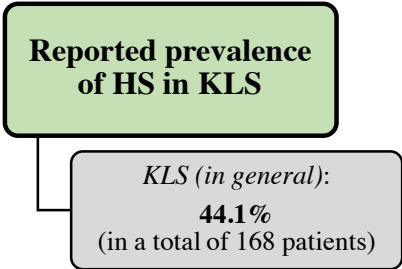
Prevalence of hypersexuality in epilepsy is low, which is consistent with the literature reporting a significantly higher prevalence of hyposexuality (46.7%)^(64,229). Results show that

prevalence of hypersexuality, however, is most common in TLE, possibly due to temporal lobectomies and resections⁽²²⁹⁾, of which the mechanism is poorly understood⁽¹⁹⁷⁾.

2.6.2.5 *Kleine-Levin syndrome*

Prevalence of hypersexuality in KLS was reported in 3 of the accepted KLS-related studies for a population of patients with KLS (from three studies)^(61,63). Figure 6 represents the average prevalence for the above population:

Figure 6 - Reported prevalence of hypersexuality in Kleine-Levin syndrome
HS: hypersexuality; KLS: Kleine-Levin syndrome

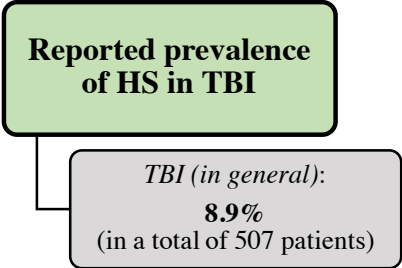


Prevalence of hypersexuality in KLS is high, which is consistent with the literature reporting that the disorder is characterised by a triad of periodic hypersomnia, hyperpolyphagia, and hypersexuality⁽¹⁷⁵⁾.

2.6.2.6 *Traumatic brain injury*

Prevalence of hypersexuality in TBI was reported in one of the accepted TBI-related studies for a population of patients with TBI (from one study)⁽⁵⁷⁾. Figure 7 represents the average prevalence for the above population:

Figure 7 - Reported prevalence of hypersexuality in traumatic brain injury
HS: hypersexuality; TBI: traumatic brain injury

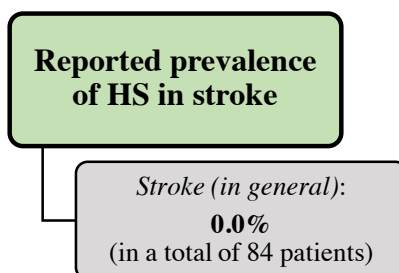


There is nothing notable about the prevalence of hypersexuality in TBI.

2.6.2.7 *Stroke*

Prevalence of hypersexuality in stroke was reported in 2 of the accepted stroke-related studies for a population of patients post-stroke (from two studies)^(18,66). Figure 8 represents the average prevalence for the above population:

Figure 8 - Reported prevalence of hypersexuality in stroke
 HS: hypersexuality



Hypersexuality does not appear to be a main feature of a stroke patient's profile, consistent with the literature reporting that hyposexuality is more common in stroke patients^(230, 231).

Conclusively, hypersexuality has been reported in a wide variety of conditions and, most frequently, in PD and dementia. In PD and dementia, however, the prevalence of hypersexuality is low despite some studies focusing on hypersexuality, suggesting that there is a low propensity for those patients to develop hypersexuality, unlike in KLS. KLS presents with a constellation of symptoms and, as evident, prevalence of hypersexuality is high (>40%), suggesting that in this neurological disorder, the propensity to develop hypersexuality is high.

Furthermore, although hypersexuality has also been reported in HD, MS, KBS, MSA, PSP, encephalitis, Hipp. Sc., FFI, TS, and SCA3 as presented in Table 4, prevalence figures have not been reported as the studies reporting them were case reports and/or case series.

It is important to note that the studies reporting prevalence did not explicitly outline reasons for the difficulties in assessing prevalence.

2.6.3 Clinical phenomenology of hypersexuality

The studies, especially the case reports and case series, showed the many ways in which hypersexuality can manifest. In cross sectional, cohort, and case control studies, little clinical phenomenology associated with hypersexuality is described, especially in the PD population, probably because of very few hypersexuality-specific studies, which is echoed in Codling et al. (2015)'s systematic review. Codling et al. (2015) carried out a systematic review assessing whether there was "emerging evidence that hypersexuality is a distinct entity from other ICDs with more subtle deficits than the category nomenclature implies"; however, they found that "there is yet insufficient evidence to draw this conclusion" as there were "few articles that actively sought to distinguish hypersexuality from hypersexuality umbrella term"⁽²³⁾. This was mirrored in the current review as a total of 356 studies were excluded for not distinguishing hypersexuality from the other ICDs.

The many reported hypersexual behaviours include but are not limited to cross-dressing, paedophilic tendencies, overt/public masturbation, extramarital encounters, penile strangulation, and sexual encounters with animals. Clinical phenomenology is summarised in Figure 9.

Figure 9 – Summary of categories for clinical phenomenology of hypersexuality in neurological disorders

Increased sexual urges/thoughts/fantasies	Self-stimulating sexual behaviour/interests	Compulsive/impulsive sexual behaviour
Verbally and physically inappropriate sexual behaviour (sexual disinhibition)	Excessive reactions when sex refused	Unsolicited sexual acts
New sexual interests/behaviours (e.g. changing in orientation; paraphilias)	Illegal sexual behaviour	Increased frequency of sexual acts

Patterns of hypersexuality were examined across the cross sectional, cohort, and case control studies; however, there did not appear to be a clear distinction in clinical phenomenology across most of the neurological disorders as the above manifestations appeared to overlap across all. Possible reasons for this include the fact that there no uniform assessment scales for manifestations/phenomenology of hypersexuality and there is little research done into phenomenology as most of the studies are prevalence studies.

It is important, however, to point out the possible difference between hypersexuality in PD and dementia as the distinction (sexual compulsivity/impulsivity and sexual disinhibition/inappropriateness, respectively) has already been outlined in the literature^(232, 233), although there have been no studies directly comparing between hypersexuality in the two neurological disorders. Hypersexuality in PD appears to be associated with a heightened desire for sex, generally leading to impulsive and compulsive behaviour. Of the 51 included studies that reported on clinical phenomenology of hypersexuality in PD, 41 (80.4%) indicated sexual impulsivity/compulsivity. Despite a small amount of cases reporting it (10 of 51 studies; 19.6%), sexual inappropriateness alone does not appear to be a primary feature of hypersexuality in PD, although there are some cases where both sexual impulsivity/compulsivity and disinhibition may be present (15 of 51 studies; 29.4%). Dementia, on the other hand, appears to be more closely associated with sexually inappropriate behaviour usually consisting of unsolicited, public displays. Of the 55 included studies that reported on clinical phenomenology of hypersexuality in dementia, 50 (90.9%) indicated sexual inhibition, even though there are some studies (5 of 55 studies; 9.1%) reporting sexual impulsivity/compulsivity alone. As in PD, there are some studies where both sexual impulsivity/compulsivity and disinhibition were present (14 of 55 studies; 25.5%). This is summarised in Table 6. The notion that there is a difference between hypersexuality in dementia and PD is suggested in Bronner et al. (2015)'s work where the difference is outlined in the definitions of hypersexuality in the two neurological disorders⁽²³⁴⁾, although the exact reasons for this are unclear.

Table 6 – Distinction between clinical phenomenology in PD and dementia as reported by included studies

Neurological disorder (<i>n</i> of studies reporting on clinical phenomenology)	Reference number of studies indicating sexual impulsivity/compulsivity	Reference number of studies indicating sexual disinhibition/inappropriateness	Reference number of studies indicating both
PD (<i>n</i> = 51)	12, 27, 30, 31, 32, 67, 68, 70, 72, 73, 75, 78, 79, 80, 81, 82, 84, 88, 91, 92, 93, 95, 99, 101, 105, 109	74, 77, 90, 98, 100, 104, 108, 111, 113, 114	69, 71, 76, 83, 86, 87, 89, 94, 96, 97, 103, 106, 107, 110, 112
Dementia (<i>n</i> = 55)	117, 129, 136, 143, 148	38, 39, 41, 42, 43, 44, 45, 47, 48, 50, 115, 116, 118, 119, 120, 121, 123, 124, 125, 126, 128, 130, 132, 133, 134, 135, 137, 140, 142, 145, 147, 150, 151, 152, 153, 155	40, 49, 83, 122, 127, 131, 138, 139, 141, 144, 146, 149, 154, 156

n: total number; PD: Parkinson's disease

2.6.4 Possible implicating factors contributing to the development of hypersexuality

The findings of the reviewed studies most commonly implicated the neurological disorders and their management in contributing to the development of hypersexuality (211 of the 221 reviewed studies; 95.5%). Management of the neurological disorders included pharmacological options (duration, dosage, and type) and/or surgical options.

Interestingly, as summarised in Table 7, of the total 19 TLE patients that reported hypersexuality in the 10 included studies, 12 patients had not had surgery prior to hypersexuality. This finding contrasts with the traditional teaching in the study of TLE that claims hypersexuality is most commonly reported in the post-operative setting⁽²²⁹⁾.

Table 7 – TLE patients reporting hypersexuality in included studies

Reference number of study	Number of patients	Surgery for epilepsy
64	1	No
65	1	No
190	1	Yes, but long before HS
191	1	No
192	3	No
193	1	No
195	1	No
197	7	Yes
198	2	No
200	1	No

HS: hypersexuality; TLE: temporal lobe epilepsy

Implicated factors, however, are not necessarily causative of the hypersexuality as further research needs to be done into the causes and neurobiology of hypersexuality in neurological disorders.

It is important to note that there are some studies that implicate factors that may not relate to the neurological disorders or their management. Some of these implicated factors include expression of unmet sexual desire⁽¹⁶⁰⁾, trying to make up for erectile dysfunction⁽⁷⁶⁾, and a gap in sexual desire between members of a couple⁽⁷⁶⁾. This suggests that although sexual dysfunction is common in patients with neurological

disorders, one should not be quick in diagnosing hypersexuality as a product of neurological disease and consequent management, as it is multidisciplinary in nature.

The implicated factors that were reported in the reviewed studies are summarised in Table 8.

Table 8 – Possible implicating factors contributing to the development of hypersexuality in specific neurological disorders

ND	ND itself	Pharmacology: duration, type, dosage	Surgery	Demographic characteristics	Expression of unmet sexual desire	Trying to make up for ED	Gap in sexual desire between members of couple
PD	x	x (DRT; most commonly DA)	x (DBS; pallidotomy)	x (Younger current age, younger age of onset, male gender)		x	x
Dementia	x	x (Donepezil; SSRI: fluvoxamine)					
Epilepsy	x (Seizures)	x (Lamotrigine; anticonvulsant: levetiracetam; gabapentin)	x (Temporal lobe resection; lobectomy)				
KBS	x	x (Benzodiazepine dysregulation: lorazepam)	x (Temporal lobe resection; strip electrode surgery)				
TBI	x				x		
RLS	x	x (DA)					
PSP	x	x (DA)					
MSA		x (DA)					
KLS	x						
MS	x						
HD	x						
BD	x						
Stroke	x						
Hipp. Sc.	x						
Encephalitis	x						
FFI	x						
TS							
SCA3							

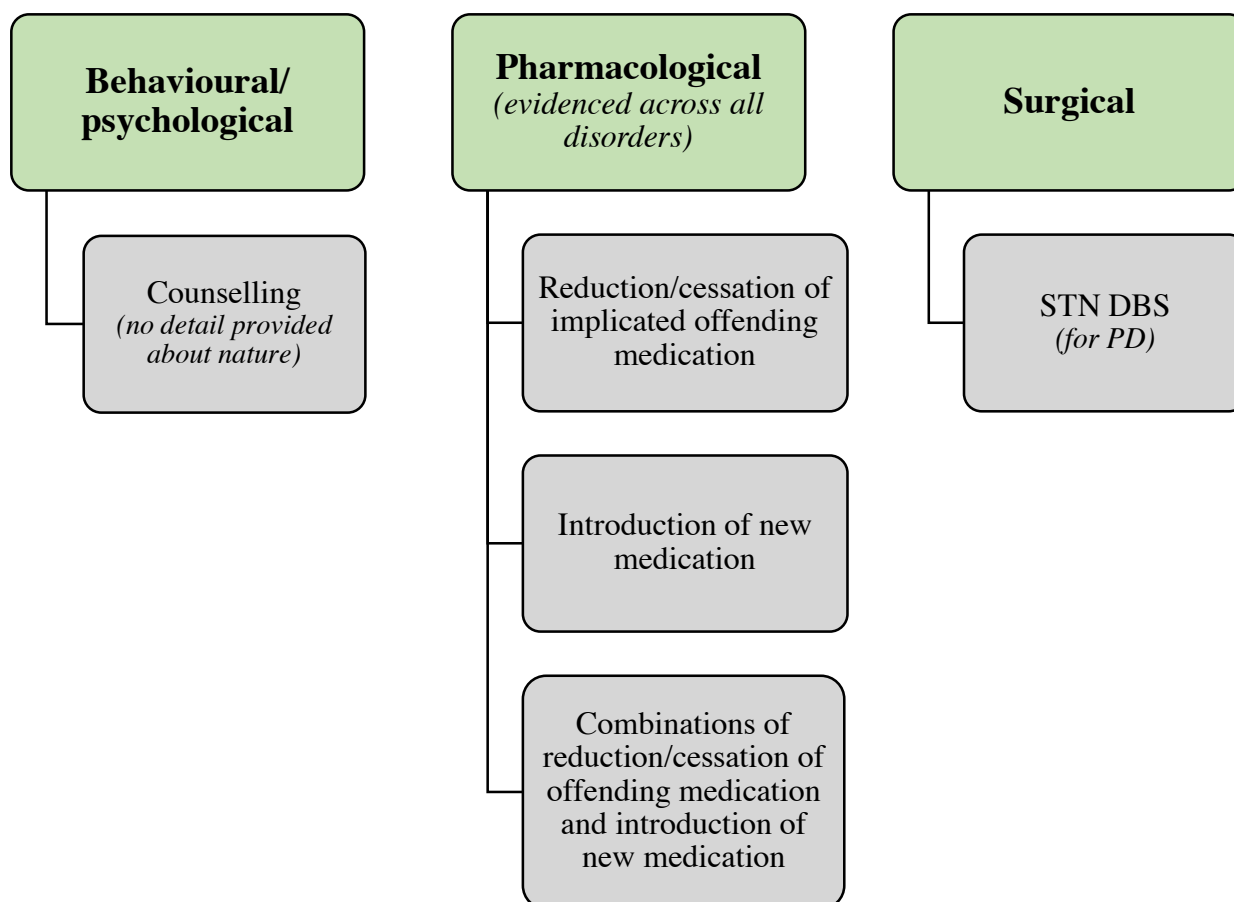
BD: brain disease; DA: dopamine agonist; DBS: deep brain stimulation; DRT: dopamine replacement therapy; ED: erectile dysfunction; FFI: fatal familial insomnia; HD: Huntington's disease; Hipp. Sc.: hippocampal sclerosis; KBS: Kluver-Bucy syndrome; KLS: Kleine-Levin syndrome; MS: multiple sclerosis; MSA: multiple system atrophy; ND: neurological disorder; PD: Parkinson's disease; PSP: progressive supranuclear palsy; RLS: restless legs syndrome; SCA3: spinocerebellar ataxia type 3; SSRI: selective serotonin reuptake inhibitor; TBI: traumatic brain injury; TS: Tourette's syndrome

2.6.5 Ameliorating management options for hypersexuality

Of the 221 reviewed studies, there were no studies primarily evaluating interventions for hypersexuality; however, ameliorating factors were reported. Of the 63 cross sectional, cohort, and case control studies, only 14 reported successful management options*. These options appeared to overlap across all neurological disorders included in the review and, most frequently, the hypersexuality was reduced or remitted following the reduction or cessation of the implicated medications. These management options are summarised in Figure 10*:

Figure 10 – Ameliorating management options reported in the cross sectional, cohort, and case control studies

PD: Parkinson's disease; STN DBS: deep brain stimulation of the subthalamic nucleus



It is important to note that the pharmacological and surgical management options were used to manage the symptoms of the hypersexuality rather than the consequences.

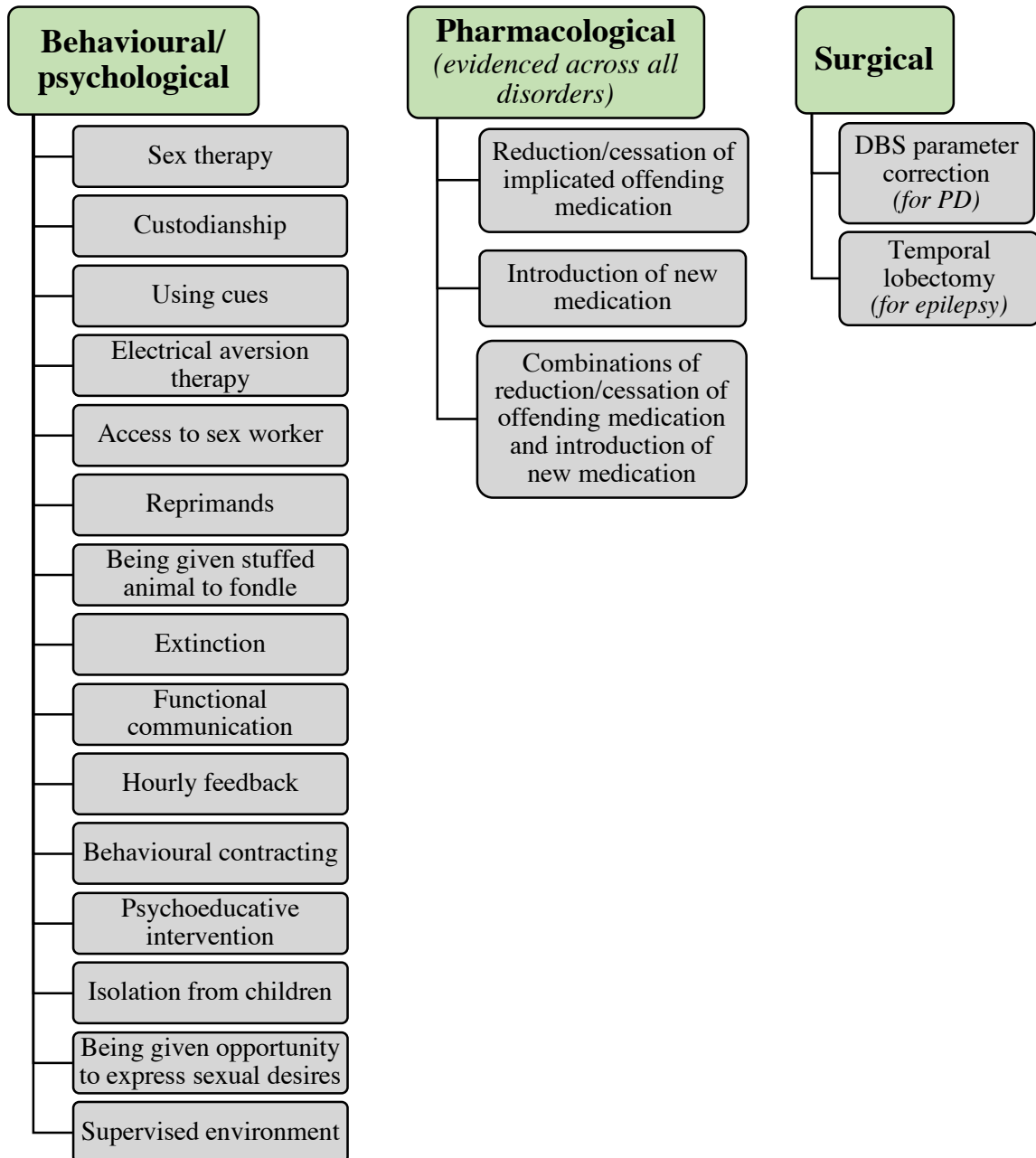
Although case reports and series are regarded as having low level of evidence⁽²³⁶⁾, it is important to include them as there is merit in exploring possible modalities for management that may be considered for use in future larger-scale studies. One must be cautious, however, in drawing conclusions about the effectiveness of these options. Of the 156 case reports and case series, 143 reported ameliorating management options. These options appeared to overlap across all neurological disorders included in the review, and similar to the previously discussed research designs, most frequently the hypersexuality was reduced or remitted

* Being discussed separately to case reports/series because of different level of evidence

* Frequencies for each management option are not included to avoid confusion as some studies used different combinations of management modalities

following the reduction or cessation of the implicated medications. These options are summarised in Figure 11.

Figure 11 – Ameliorating management options reported in case reports and case series
DBS: deep brain stimulation; PD: Parkinson's disease



It is important to note that the pharmacological, surgical, and behavioural/psychological management options, except psychoeducative intervention and sex therapy, were used to manage the symptoms of the hypersexuality rather than its consequences.

2.6.6 Evaluation of hypersexuality

Of the 221 reviewed studies, 58 reported tools that were used to evaluate prevalence and clinical phenomenology of hypersexuality in neurological disorders. There were more than 20 different tools used, which signifies the lack of a single standardised tool and set of diagnostic criteria that are hypersexuality-specific, as well as a lack of consensus about the type of assessment among health professionals and researchers. This prompts them to use questionnaires, although valid and reliable, and criteria suiting their research aims and not necessarily geared towards hypersexuality in a neurological disorder setting, which automatically yields inaccuracies and challenges. The heterogeneity in assessment tools makes it challenging to compare between neurological disorders. Moreover, the included studies reported many different prevalence figures, probably owing to the many different tools used and the possibility that the tools were not sensitive enough to capture prevalence, as well as the full extent of the patients' hypersexuality, particularly if the patients were feeling embarrassed and/or shameful causing them not to disclose such personal information. It is important to note that an appropriate standardised tool for assessment of hypersexuality in neurological disorders would also be necessary in determining options for management, once the extent and nature of the hypersexuality is appropriately and thoroughly examined and assessed.

2.6.7 Risk bias and quality assessment

Quality assessment using the EPHPP predominantly yielded weak studies, which may have biased the results of the review.

Furthermore, case reports and case series were not assessed for risk and quality due to their inherent weaknesses summarised in Table 9:

Table 9 – Merits and limitations of case series/case reports

Merits	Limitations
Detecting novelties (researching rare disorders) ⁽¹⁾	Lack of ability to generalize ⁽¹⁾
Generating new hypotheses ^(1, 235)	Danger of over-interpretation ⁽¹⁾
High applicability when other research designs are not possible to carry out (helps solve ethical limitations due to flexibility and low cost) ^(1, 235)	Observation bias (lack of consecutively selected patients can result in selective reporting favouring outcome) ⁽¹⁾
Allowing emphasis on narrative aspect (allows in-depth understanding) ⁽¹⁾	Publication bias (negative results are often not reported/published) ⁽¹⁾
Educational value ⁽¹⁾	Retrospective design (might yield recall bias) ⁽¹⁾
	Distraction of the reader when focusing on the unusual ⁽¹⁾
	Selection bias (no criteria for patient selection) ⁽²³⁶⁾
	No possibility of establishing cause-effect relationship ⁽¹⁾

Despite the overall weakness in quality associated with this review, results are crucial in shaping this issue and in suggesting directions for future research due to the lack of research into this topic.

2.6.8 Limitations

Because this report represents the first systematic review that aims to assess hypersexuality in neurological disorders, the following limitations should be addressed:

1. Exposure to the relevant literature
Despite best efforts made by the two reviewers, the possibility remains that coverage of literature could be incomplete. Searches in other databases or scientific journals (either electronically or by

hand) and translation of foreign studies may have returned additional studies.

2. Keywords

Although the reviewers and the librarian ensured a comprehensive list of keywords, one may argue that choice of keywords are culturally determined and could influence the search results.

3. Heterogeneity

There was heterogeneity in the aims, methodologies, and designs of the reviewed studies, which may have yielded some inconsistencies and differences in prevalence figures, clinical phenomenology, and management options. Despite the large number of reviewed studies, the heterogeneity may influence the ability to compare between neurological disorders and to formulate conclusions regarding the issue of hypersexuality in neurological disorders.

4. Comorbidities

The information extracted from the studies included only neurological disorders and did not include other non-neurological comorbidities (e.g. psychological disorders) and the options used to manage them that may have, in their own right, had an effect on development and/or progression of the hypersexuality. The scope of this systematic review, however, did not warrant an investigation into this and comorbidities were thus not an outcome of the review.

5. Quality assessment

Although the EPHPP tool is widely used for quality assessment, it does present with its own set of limitations. The global rating score given to each study was easily influenced by the research design of the study being assessed. For instance, cross sectional studies were automatically given a “Weak” rating on the Study design criterion, which immediately lowered the global rating (as it required 2 “Weak” ratings out of a total of 6 criteria to be deemed as globally “Weak”). Furthermore, case reports and case series were not assessed using this scale because of qualitative nature, as well as inherent weaknesses in their design (listed in Table 7). However, it was important to use them in the review as they provided insight into a poorly researched topic, which is necessary for health professionals, researchers, patients, and caregivers to pay attention to in order to properly formulate plans regarding identification, assessment, management, coping, and moving forward with the hypersexuality.

6. Level of evidence of study designs

Following from the previous point, there was a difference in level of evidence associated with the included study designs. For instance, the level of evidence (‘weight’) of cross sectional, cohort, and case control studies is different than that of case reports and case series. This makes it challenging to draw conclusions from case reports and series, although more frequent, especially since they are underpowered and not statistically significant.

7. Tools used to evaluate hypersexuality

As discussed earlier, the multiple different tools used to assess prevalence and/or clinical phenomenology may lead to inconsistencies within and between neurological disorders.

8. Lack/inconsistency in prevalence figures of hypersexuality

As discussed earlier, there was both a lack and inconsistency in prevalence figures reported for hypersexuality in neurological disorders, as different studies report varying prevalence figures. This is possibly owing to three different reasons: (1) the different tools used within and between neurological disorders and their sensitivity, (2) the sensitive nature of the topic, which causes some patients to feel embarrassed or shameful, prompting them not to disclose any information,

and (3) the possibility that patients with neurological disorders may not realize/acknowledge their sexual changes. This limitation suggests that until a standardised, sensitive tool for evaluation of hypersexuality in neurological disorders is developed, the assessment of prevalence will be challenging and it will thus be difficult to provide true prevalence figures.

9. Implicated factors contributing to the development of hypersexuality

No direct causes of hypersexuality have been established. Reported data examines possible risk factors, all of which are still only speculation. This makes it a difficult phenomenon to manage as causes have not been pinpointed. This may explain the many different management options that do exist in the reviewed data. It is also interesting to note that only a couple of the studies that were reviewed have attributed the hypersexuality to non-medical factors including a gap in sexual desire between members of a couple⁽⁷⁶⁾, trying to make up for erectile dysfunction⁽⁷⁶⁾, and expression of unmet sexual needs⁽¹⁶⁰⁾, which suggests the multidisciplinary nature of this issue potentially requiring a multidisciplinary team to manage. Moreover, in cohort studies, for instance, medications used by the patients may have changed throughout the duration of the study, possibly leading to a loss of crucial information regarding the effect of medication on hypersexuality.

10. Management options for hypersexuality

The extracted data showed the many different management options that clinicians used to manage hypersexuality in different neurological disorders, none of which were randomised control trials. There is no guide available for management of the hypersexuality that clinicians and researchers can consult and it will be challenging to create one due to the heterogeneity in the data.

11. Hypersexuality not distinguished from other ICDs

Studies not distinguishing hypersexuality from other ICDs were not included in the review and thus information about management options may have been overlooked. A study by Okai et al. (2013), for instance, aimed to test the effects of a 12-session cognitive behavioural therapy-based intervention delivered to PD patients with ICDs⁽²³⁶⁾. Although the study finds that the intervention was clinically effective in the treatment of ICDs, it does not specify the effect on each of the ICDs although it may very well have influenced the hypersexuality. For this reason, no conclusion could be drawn as it may be faulty and misleading.

12. No interventional studies

Following from the above point, there were no interventional studies aimed at systematically assessing possible management options for hypersexuality in neurological disorders. All data reported (excluding case reports and case series) appeared to mention management options as a by-product of the studies. More information and controlled trials are thus required for health professionals and clinical researchers to develop management strategies.

13. PD and dementia most researched

The overwhelming majority of the search results were associated with PD and dementia. There has been much less research into the other neurological disorders and therefore less information. A reason for this may be that clinicians and researchers do not or choose not to recognize hypersexuality as an issue in other neurological disorders and have therefore not ventured to explore it.

2.6.9 Implications

An important implication is for health professionals to inform patients and their carers of the possibility of developing hypersexuality and its relationship to the neurological disorder. Lack of information might have negative consequences on the patients' lives and the lives of those around them. Health professionals

must also not forget to routinely ask patients and their carers about such sexual changes to allow them to keep a close eye on its development and/or progression. Health professionals could also consider the need to also include carers in the discussion of hypersexuality, especially since some patients may choose not to disclose information about the changes in their sexuality because of the sensitive nature of the issue or may not realise their sexual changes to begin with.

2.6.10 Link to upcoming chapters

The problems in this research area that were initially identified after the introduction/narrative literature review in Chapter 1 were mirrored in this chapter:

1. There is a lack of consistency in prevalence figures regarding hypersexuality in different neurological disorders.
2. There is a lack of systematic investigations of clinical phenomenology (manifestations, tools, and correlates) of hypersexuality in different neurological disorders.
3. There is a lack of research into the impact of hypersexuality on patients with neurological disorders and their carers.
4. There is a lack of research into potential psychological/behavioural interventions used to manage the symptoms and consequences of hypersexuality in patients with neurological disorders and their carers.

These problems gave rise to the following research questions, which will be tackled in Chapters 3 and 4:

1. What is the prevalence of hypersexuality in specific neurological disorders?
2. What is the clinical phenomenology of hypersexuality in specific neurological disorders?
3. What is the impact of hypersexuality on patients with hypersexuality and their carers?
4. What are some non-pharmacological management modalities to consider when faced with hypersexual patients with neurological disorders and their carers?

Although the systematic review and the main empirical study were carried out simultaneously, one cannot undermine the function of this systematic review in setting up the remainder of this thesis.

2.6.11 Recommendations for future research

Due to the preliminary nature of this review, there are several directions to consider for future research (that will not be explored in this dissertation). Some of these recommendations include:

1. Conducting studies exploring the exact causes of hypersexuality in neurological disorders, which would pave the way for suitable management options.
2. Developing a sensitive, standardised hypersexuality-specific tool to be used across all neurological disorders that would make it easier to assess prevalence and/or phenomenology, and may consequently make it simpler to compare between neurological disorders to create a more holistic view of hypersexuality.
3. Conducting interventional studies testing the effectiveness of management options on the hypersexuality, separate from other ICDs.
4. Conducting studies to compare the manifestations and impact of hypersexuality within neurological disorders, such as in dementia between FTD and AD, and between neurological disorders, such as between PD, dementia, and epilepsy. Such studies could be beneficial as they might uncover distinctions and patterns that have yet to be uncovered.

5. Conducting studies assessing the demographic risk factors (e.g. gender) contributing to the hypersexuality in neurological disorders such as has been done in PD and comparing to see if there are any similarities or differences between neurological disorders.

2.7 Conclusions

The results of this literature review show that research into hypersexuality in neurological disorders is still in its infancy and more research is required before definitive conclusions can be drawn.

There are still a lot of inconsistencies regarding prevalence figures of hypersexuality in neurological disorders. Reasons for this include the myriad of assessment tools used and the sensitive nature of the topic, which causes some patients to feel shame or embarrassment, prompting them not to disclose any information, especially if there have been any unlawful acts. This suggests that prevalence of hypersexuality is underreported, making it difficult to report true prevalence figures. Despite these inconsistencies, results preliminarily indicate that patients with PD, dementia, TBI, epilepsy, RLS, and stroke have lower propensity in developing hypersexuality (<20%) than do patients with KLS (>40%). Furthermore, prevalence of hypersexuality in PD and RLS appears to be higher in patients who are taking dopamine agonists, suggestive of an association between hypersexuality and dopamine agonists, although definitive causality cannot be established. Results also show that prevalence of hypersexuality is higher in FTD than in AD, and higher in TLE than in grand mal epilepsy, most likely due to frontal and temporal lobe involvement.

The manifestations of hypersexuality can be categorised under the following larger headings: increased sexual urges/thoughts/fantasies, self-stimulating sexual behaviour/interests, compulsive sexual behaviour, verbally and physically inappropriate sexual behaviour (sexual disinhibition), excessive reactions when sex refused, unsolicited sexual acts, new sexual interests/behaviours, illegal sexual behaviour, and increased frequency of sexual acts. Results show no clear distinction in clinical phenomenology across most of the reported neurological disorders as the hypersexual manifestations appear to overlap across all possibly due to the lack of uniform assessment. However, it is important to point out the evident difference between the expression of hypersexuality in PD and dementia (sexual compulsivity/impulsivity and sexual disinhibition/inappropriateness, respectively), although the reason for this remains ambiguous.

Furthermore, most commonly implicated in the contribution of hypersexuality are the neurological disorders themselves, as well as the options used to manage them (i.e. either pharmacological or surgical). Implicated factors, however, are not necessarily causative of the hypersexuality as further research needs to be done into the causes and neurobiology of hypersexuality in neurological disorders.

Because of the lack of knowledge regarding the exact causes of hypersexuality, studies report many different options that have been successful in the management of hypersexuality. Most commonly, patients' implicated medication is reduced or stopped. Other successful management options include behavioural/psychological and/or surgical options. It is important to note, however, that studies reporting psychological options are more frequently case reports and case series. Because case reports and case series are regarded as having low level of evidence, one must be cautious in drawing conclusions about the effectiveness of these options. This has demonstrated the need for well-designed, adequately-sampled, and powered interventional studies for any definitive conclusions to be drawn.

Additionally, results show more than 20 different tools used to assess prevalence and clinical phenomenology of hypersexuality in neurological disorders. This signifies the lack of a single standardised tool and set of diagnostic criteria that are hypersexuality-specific, as well as a lack of consensus about the type of assessment among clinicians and researchers. An appropriate standardised tool for assessment of hypersexuality in neurological disorders would also be necessary in determining options

for management, once the extent and nature of the hypersexuality is appropriately and thoroughly examined and assessed.

The overall quality of the evidence in the review was weak; however, the results are crucial in shaping the issue of hypersexuality and allowing brainstorming into future directions for research.

2.8 Funding

This review did not receive any funding.

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Chapter 3

Assessment of prevalence, clinical phenomenology, and impact of hypersexuality on patients with neurological disorders and their carers

3.1 Relevance to overall thesis

The previous chapter was useful in both highlighting the extent to which quantitative and qualitative research has examined the problem of hypersexuality in neurological disorders, and identifying gaps in the scientific knowledge concerning this issue. The systematic review showed either a lack or an inconsistency in the literature with regards to prevalence of hypersexuality in neurological disorders, as well as a lack of research aimed primarily at characterizing hypersexuality in patients with neurological disorders and assessing the impact it has had on the lives of the patients and their carers.

3.2 Introduction

This chapter and study, therefore, seek to explore the prevalence, clinical phenomenology, and impact of hypersexuality in patients with neurological disorders and their carers to answer some of the questions raised by the narrative and systematic reviews for a more comprehensive and holistic view on hypersexuality in neurological disorders. This empirical study will therefore use a variety of assessment tools to investigate the relationship that hypersexuality has with clinical, pharmacological, behavioural, psychological, and cognitive factors. It is hoped that this research will help inform the lacking understanding of hypersexuality in neurological disorders.

3.3 Aims

The present chapter has two aims and is thus divided into two main parts:

Part A aims to assess the prevalence of hypersexuality in neurological disorders.

Part B aims to explore the clinical phenomenology of hypersexuality in neurological disorders and its associated clinical, pharmacological, behavioural, psychological, and cognitive factors, and to assess its impact on both the patients and carers.

3.4 Methods

This study is a systematic, exploratory investigation of hypersexuality in neurological disorders using principally qualitative research methods with an added quantitative component.

Part A

3.4.1 Research design

3.4.1.1 Overview

Part A is a descriptive quantitative study, in which screening questionnaires were used to assess the prevalence of hypersexuality in patients with neurological disorders.

3.4.1.2 Rationale

Considering the lack and inconsistencies in prevalence figures of hypersexuality in neurological disorders that were highlighted in the previous chapter, one might argue the purpose of venturing to assess prevalence as part of this study. Although the research team were aware of the possible difficulties, they thought it interesting/important to attempt it first-hand and see what challenges might arise in the process of assessing prevalence, which have not been outlined explicitly in previous research.

3.4.2 Participants

3.4.2.1 Recruitment

PD patients were originally intended to be screened through the Movement Disorders Clinic (MDC) at the National Hospital for Neurology and Neurosurgery (NHNN), and were screened through Edgware Community Hospital (ECH).

FTD and AD carers¹, on the other hand, were originally intended to be screened through the Dementia Research Centre (DRC) at the NHNN.

3.4.2.2 Selection of subjects

The participants were either included or excluded in Part A of the study based on the following inclusion and exclusion criteria.

a. Inclusion criteria

Any patient/carer who was willing to fill out the screening tools.

b. Exclusion criteria

Difficulty understanding English.

3.4.3 Materials

The following two screening questionnaires were used:

1. **Name of Instrument:** Questionnaire for Impulsive-Compulsive Disorders in Parkinson's Disease (QUIP)⁽¹⁾ (Appendix 2)

Brief Description/Purpose: The QUIP was used in Part A to screen for hypersexuality in patients with PD. The QUIP will be discussed in further detail in the materials section of Part B as it was used for Part B also.

¹ FTD/AD patients were not recruited for prevalence study due to research fatigue and will be discussed in section 3.4.4.2.

2. **Name of Instrument:** Carer Hypersexuality Screening Questionnaire (CHSQ) (Appendix 3)

Brief Description/Purpose: The CHSQ is a custom-developed² questionnaire used to screen for hypersexuality in carers of patients with dementia. It was developed by the research student and Jason Warren, a Professor of Neurology at the Institute of Neurology at UCL and a consultant neurologist at the NHNN who is based at the DRC.

3.4.4 Procedure

3.4.4.1 PD patients

It was originally intended that the QUIP would be distributed to PD patients attending a tertiary level MDC at the NHNN, and at ECH over a period of six months. A protocol was developed in conjunction with the respective team leads; however, because of operational challenges raised by the clinical team, distribution and collection of the questionnaire did not prove feasible at the NHNN. The MDC had initially decided that the QUIP would become part of routine assessment in clinic and that it would be given to every patient attending; however, the consultants and research nurses later decided that the QUIP was too intrusive and could make the patients uncomfortable³. As a result, the research team was no longer able to assess prevalence of hypersexuality using the QUIP at the MDC.

During meetings held with the Parkinson's Service Lead and the rest of the Parkinson's Day Unit team at ECH, the necessary protocol was developed and the QUIP was considered, approved, and circulated at the Parkinson's Day Unit over a period of six months⁴ from March 2016 to September 2016. A leaflet (Appendix 4) briefly describing the study was attached to each questionnaire. Patients were informed that they could choose not to fill out the questionnaires. Each patient required 5-15 minutes to complete it. The patients were asked to complete the questionnaires themselves, but were informed that they could ask for assistance from a member of the clinical staff, if they so desired. Patients were also able to take the questionnaire home with them if they wanted more privacy, required more time to consider filling it out, or required more time to read through it. In that case, the patients were provided pre-stamped, pre-addressed envelopes which could be mailed back to the research student at the Department of Uroneurology at the NHNN, if the patients so chose. Otherwise, the research student collected the completed questionnaires from the ECH site at the end of every month. Each of the questionnaires included a section at the end where the patients could indicate if they were interested in discussing the hypersexuality issue further by providing their contact details.

The patients were expected to fill out the questionnaire only once throughout the duration of the study.

3.4.4.2 AD/FTD carers

As advised, due to the vulnerability and research fatigue of patients with dementia, only the carers were intended to be screened for hypersexuality at the DRC. During initial meetings held with a consultant neurologist at the DRC, the CHSQ, also attached to a leaflet (Appendix 5) briefly describing the study, was considered, modified, approved, and was then intended to be circulated by members of the clinical staff to the carers over a period of one year. However,

² Because no such questionnaire exists for these purposes.

³ They are now using the Non-Motor Symptoms Questionnaire, which does not directly screen for hypersexuality in the way the QUIP does and was, therefore, not considered for use in this study.

⁴ To try and avoid the possibility of the same patient filling it out more than once.

a slight concern was raised at the DRC's Research Adoption Committee that some carers might feel a little challenged by the questionnaire and the research team was thus advised that it would not be possible to assess prevalence of hypersexuality in dementia at the DRC.

3.4.4.3 *Informed consent*

Returning completed screening questionnaires implied consent.

3.4.4.4 *Confidentiality*

Patients were not required to include any identifiable data and were assured that their participation was completely confidential unless they chose to leave their contact details at the end of the questionnaire.

3.4.4.5 *Data analysis*

Frequency and percentage analysis of the data was performed using IBM SPSS Statistics software (Version 24) for Macintosh.

Part B

3.4.5 Research design

3.4.5.1 Overview

Part B constitutes both qualitative and quantitative approaches and, therefore, consists of primarily phenomenological qualitative and secondarily descriptive and non-experimental correlational quantitative research design in which a semi-structured interview, questionnaires, and psychological tests were used to characterise hypersexuality in neurological disorders and to assess its impact.

The primary difference between qualitative and quantitative research design is that quantitative refers to a reductionistic objective approach to obtaining information while qualitative refers to a holistic subjective approach⁽²⁾. Qualitative research, which often relies on observations and open questions and thus a deductive process⁽³⁾, is used to systematically gain insight into a phenomenon by exploring its inherent richness and complexity through the analysis of words⁽²⁾. It is “flexible, emergent, and iterative”⁽³⁾. Quantitative research, on the other hand, which often relies on an inductive process⁽³⁾, is used to systematically test the hypothetical relationships between variables and is used to describe and examine cause and effect relationships through the analysis of numbers⁽²⁾.

3.4.5.2 Rationale

This study examined hypersexuality using a primarily qualitative research approach as it is a personal, individual experience requiring information-rich data from a sample appropriate enough to address the research questions. Individuals may view and experience sexuality differently, the depth and essence of which would not be captured using a quantitative approach alone. It is evident, therefore, that a mixed methods research approach is best suited for this research, “because no single research method can tap all dimensions of a complex research problem”⁽³⁾, which hypersexuality is.

The rationale for combining quantitative and qualitative approaches includes triangulation, complementarity, expansion, and completeness⁽⁴⁾. Triangulation refers to “seeking convergence, corroboration, correspondence... between quantitative and qualitative data”⁽⁴⁾, which potentially offers “broader perspectives on the problem and more persuasive findings for policymakers”⁽³⁾. Complementarity refers to seeking “elaboration, enhancement, illustration, [and] clarification of the results from one method with the results from another”⁽⁵⁾. Expansion refers to seeking “to extend the breadth and range of enquiry by using different methods for different enquiry components”⁽⁵⁾. Completeness refers to seeking “a more comprehensive account of the area of enquiry in which... both quantitative and qualitative research are employed”⁽⁴⁾.

3.4.6 Philosophical considerations for qualitative component

Discussion of the key concepts of ontology, epistemology, and theory should precede the discussion of the use of phenomenological research methods, as these form the overall research paradigm or ‘worldview’⁽⁶⁾ that influences the choice of methods.

3.4.6.1 Ontological approach

In brief, ontology refers in broad terms to the perceived nature of reality⁽⁷⁾ – whether social phenomena are regarded as being objective realities which can be investigated in ways similar to the physical world (realism), or whether these are seen as socially constructed and subject to differing interpretations and perspectives (relativism)⁽⁶⁾. Considering the highly sensitive and

personal nature of this research, as well as the researcher's background in psychology, a relativist ontological approach will be assumed, which argues that reality is a result of individual consciousness and cognitions⁽⁶⁾. This reality cannot exist independently from human action and observation⁽⁸⁾, as is assumed in the realist ontological approach.

3.4.6.2 *Epistemological approach*

Epistemology refers to the study of knowledge and, more specifically, the consideration of what knowledge is "legitimate and accurate"⁽⁷⁾. Typically, a researcher's epistemological approach will reflect their ontological beliefs⁽⁹⁾. The epistemological approach assumed in this research is that of constructivism. Constructivism argues that reality and human meaning are constructed or built by individuals through processes of interaction with the world and between individuals, rather than by 'discovery' of objective truths^(7, 10-12). This approach also assumes a connection between reality and language, whereby "language simultaneously reflects reality and constructs it to be a certain way"⁽¹³⁾. Consequently, individuals are not "creatures of determinism, whether natural or cultural, but are socially constructed and constructing"⁽¹⁴⁾. The constructivist epistemological approach is therefore best suited for this research as the patients and carers' experiences and views of hypersexuality cannot be objectively determined and rely heavily on the participants' constructed views and cognitions surrounding sex, sexuality, and what is considered socially and individually acceptable, and the primary way in which these can be communicated and determined by participants and researcher is through the use of language.

3.4.6.3 *Theoretical approach*

The theoretical approach, which is typically informed by both the ontological and epistemological perspectives, provides the "philosophical stance lying behind the methodology"⁽¹⁵⁾. The main two theoretical perspectives are positivism and interpretivism⁽⁷⁾. Positivist researchers, who generally use quantitative research methods, believe that "empirical facts exist apart from personal ideas or thoughts... [and] are governed by laws of cause and effect"⁽¹⁶⁾. According to the interpretivist paradigm, on the other hand, the "nature of enquiry is interpretive and the purpose of inquiry is to understand a particular phenomenon, not to generalise to a population"⁽¹⁶⁾ or provide explanations⁽¹⁵⁾, and aims to study behaviours and motives that are not easily quantifiable⁽¹⁷⁾. Interpretivism assumes that experiences, realities, and meanings vary from individual to individual based on differences in their cognitions, attitudes, and the overall meanings they associate with the studied phenomenon, as well as their "interactions with each other and wider social systems"⁽³⁾. This approach is used in this exploratory research because the intention is to understand (using questions that address why, how, and under what circumstances⁽³⁾) the experiences and lived perspectives of patients and their carers regarding hypersexuality. It is assumed that although there may be identifiable common experiences which provide understanding of the fundamental nature or essence of this phenomenon, it can only be properly understood through the first-hand experience and personal interpretations of the individuals directly involved⁽³⁾.

3.4.7 *Methodological approach for qualitative component*

Within the constructivist epistemological approach and interpretivist theoretical approach, phenomenological research methods are generally used to examine the lived experiences of individuals⁽¹⁸⁾ "as they spontaneously occur in the course of daily life"⁽¹⁹⁾. The use of a phenomenological approach allows the researcher to obtain insights and understanding of 'how it feels' to experience a particular phenomenon and to investigate the context of these experiences⁽²⁰⁾. Creswell (2009) defines phenomenology as "a research strategy of enquiry in which the researcher identifies the essence of human experiences about a phenomenon as described by participants"⁽²⁾. A phenomenological methodological

approach, therefore, aims to provide a comprehensive description and understanding of the themes and patterns as portrayed in the perspectives of the study participants, which is considered most appropriate for the current study since the intention of the qualitative component is to understand the patients and carers' personal experiences of the phenomenon of hypersexuality, and how these individuals view and interpret their experiences.

3.4.8 Participants

3.4.8.1 Recruitment

The PD patients and carers were recruited from the MDC at the NHNN, ECH, as well as from Parkinson's UK. It was intended to recruit 10 PD patients and 5 PD carers.

AD and FTD carers were recruited from the DRC at the NHNN, as well as from the Frontotemporal Dementia Support Group seminar. It was intended to recruit 5 dementia carers.

3.4.8.2 Selection of subjects

The participants were either included or excluded in the study based on the following inclusion and exclusion criteria.

a. Inclusion criteria

PD

Patients: (a) clinically diagnosed PD according to the UK Brain Bank Criteria⁽²¹⁾; (b) indicated hypersexuality either in the past or present since developing PD; (c) no cognitive impairment; (d) ability to provide informed consent.

Carers: (a) spouses or partners of patients with clinically diagnosed PD according to the UK Brain Bank Criteria; (b) indicated hypersexuality either in the past or present since developing PD; (c) ability to provide informed consent.

AD/FTD

Carers: (a) spouses or partners of clinically diagnosed FTD and AD patients; (b) indicated hypersexuality either in the past or present since developing dementia; (c) ability to provide informed consent.

b. Exclusion criteria

PD

Patients: (a) hypersexuality predating the onset of PD; (b) co-existing neurological disorders as determined by clinical history; (c) secondary causes of Parkinsonism⁵; (d) difficulty understanding/speaking English.

Carers: must have partners who do not have (a) hypersexuality predating the onset of PD; (b) co-existing neurological disorders as determined by clinical history; (c) secondary causes of Parkinsonism; (d) difficulty understanding/speaking English.

AD/FTD

Carers: must have partners who do not have (a) hypersexuality predating onset of FTD or

⁵ Secondary causes of Parkinsonism include brain injury, encephalitis, HIV/AIDS, meningitis, multiple system atrophy, stroke, brain damage caused by anesthesia drugs, carbon monoxide poisoning, narcotics overdose, etc.

AD; (b) co-existing neurological disorders as determined by clinical history; (c) difficulty understanding/speaking English.

3.4.9 Materials

3.4.9.1 Rationale

The results of the systematic review, available literature on sex addiction, and the MSc Clinical Neuroscience service evaluation of hypersexuality completed by the research student in 2013⁽²²⁾ provided the research team preliminary understanding of the issue of hypersexuality and these preliminary findings were able to inform the direction in which the researcher team went with regards to interviews, questionnaires, and testing in this study.

The researcher used a combination of an interview and questionnaires/tests to collect data from the patients and carers. The primary focus of the study, however, is on the interviews with the quantitative testing as a complementary method to help establish a more comprehensive and holistic view of hypersexuality, a research area that has been poorly investigated.

Because this is the first study to systematically investigate hypersexuality in neurological disorders, the researcher had to ensure that the battery of questionnaires used assess a wide range of constructs from sex addiction to executive functioning to ensure breadth and depth of the research into hypersexuality and its manifestations. The results from those questionnaires are important in (1) highlighting possible correlations and connections between hypersexuality and different constructs for future researchers; (2) trying to place hypersexuality in cognitive, psychological and behavioural frameworks; (3) and triangulating with the findings from the interviews.

It is important to note that input about which questionnaires to use was provided by specialist neuropsychologist at the Department of Neuropsychology at the NHNN, Jennifer Foley (JF), one of the supervisors of this study.

3.4.9.2 Patients

Patients with hypersexuality underwent qualitative assessment in the form of a semi-structured interview, as well as quantitative assessment in the form of questionnaires and tests, requiring them to spend up to four hours with the researcher. The materials/instruments that were used, in the order that they were given to the patients, are presented below.

1. **Name of Instrument:** Patient Assessment Interview (Appendix 6)

Brief Description/Purpose: Phenomenological research may use a diversity of tools; however, this study will use open-ended interview questions to address the research aims qualitatively. The interview questions will help “provide a description of human experience as it is experienced by the person allowing the essence to emerge”⁽²³⁾. The Patient Assessment Interview, custom-developed by the research student, is a semi-structured thirty-item interview used to assess patients’ experiences with hypersexuality and its impact. This interview can be used to assess patients who currently have hypersexuality or who have had hypersexuality in the past.

This is the only instrument that will inform the qualitative data analysis for patients.

More information about the interview and interview techniques are presented in section 3.3.10.4.

2. **Name of Instrument:** Mini-Mental State Examination (MMSE) (Appendix 7)

Brief Description/Purpose: The MMSE, developed by Folstein et al. (1975)⁽²⁴⁾, is an instrument

that assesses mental status. It tests five areas of cognitive functioning: orientation, registration, attention and calculation, recall, and language. It is effective as a screening tool to help separate patients with cognitive impairment from those without, which is one of the inclusion criteria. This test is part of routine assessment at the NHNN.

Scoring and Classification: The minimum score is 0 and the maximum score is 30. The total score is calculated by summing the points awarded for each of the 11 items. A score of 23 or lower is indicative of cognitive impairment, as presented in Table 10.

Table 10 - Scoring for the Mini-Mental State Examination

Score	Classification
24-30	No cognitive impairment
18-23	Mild cognitive impairment
0-17	Severe cognitive impairment

Psychometric properties: The MMSE is reliable and valid and has been extensively used in clinical practice and research. Tombaugh and McIntyre (1992) found that the scale had adequate to excellent internal consistency (Cronbach's $\alpha = .54$ to $.96$), across four samples⁽²⁵⁾. They also reported excellent concurrent validity between the MMSE scores and other measures of cognitive impairment (correlations ranging from $.70$ to $.90$) and adequate to excellent construct validity between MMSE and Activities of Daily Living scales (correlations ranging from $.40$ to $.75$)⁽²⁵⁾. Furthermore, Agrell and Dehlin (2000) reported significant correlations between MMSE scores and the Barthel Index (a measure of functional disability), Montgomery-Asberg Depression Rating Scale, and Zung Depression Scale ($p < 0.05$) in a sample of stroke patients⁽²⁶⁾. The MMSE also showed excellent correlations with the Wechsler Adult Intelligence Scale Verbal and Performance IQ scores ($r = .78$ and $.66$, respectively)⁽²⁴⁾.

Permission to use: Permission was requested on 18 February 2016 and 29 March 2017; however, this questionnaire is routinely used at the NHNN and is readily available online.

3. **Name of Instrument:** Questionnaire for Impulsive-Compulsive Disorders in Parkinson's Disease (QUIP) (Appendix 2)

Brief Description/Purpose: The QUIP, which was also indicated in Part A, was developed by Weintraub et al. (2009)⁽¹⁾ and is a 12-item self-assessment instrument used to screen for impulse control disorders and other compulsive behaviours in patients with PD. The questionnaire comprises three sections. Section A screens for four ICDs: gambling, sexual, buying, and eating behaviours. Section B screens for other compulsive behaviours, namely hobbyism, punning, and walkabout. Section C screens for compulsive medication use which is termed dopamine dysregulation syndrome. This test is significant for this study as it determines which patients are hypersexual (as part of inclusion criteria) and what other ICDs they have.

Scoring and Classification: Table 11 summarizes the items required for a positive screen for each respective behaviour.

Table 11 – Scoring for the Questionnaire for Impulsive-Compulsive Disorders in Parkinson’s Disease

Full Instrument	Number of endorsed items for <i>positive screen</i>
A. Impulse Control Disorders	
Compulsive gambling	Any 2 of the 5 gambling items
Compulsive sexual behaviour	Any 1 of the 5 sexual behaviour items
Compulsive buying	Any 1 of the 5 buying items
Compulsive eating	Any 2 of the 5 eating items
B. Other Behaviours	
Hobbyism	Item #B1
Punding	Item #B2
Walkabout	Item #B3
C. Medication Use	Items #C1 and #C4

Psychometric properties: Weintraub et al. (2009) showed the discriminant validity of the QUIP was high (ranging from adequate to excellent) for each disorder or behaviour (receiver operating characteristic area under the curve: gambling = .95, sexual behaviour = .97, buying = .87, eating = .88, hobbyism = .93, punding = .78, walkabout = .79)⁽¹⁾. When disorders and behaviours were combined, the sensitivity of the QUIP to detect an individual with any disorder was 96%⁽¹⁾.

Permission to use: Permission was granted by Daniel Weintraub on March 29, 2017.

4. **Name of Instrument:** Sexual Addiction Screening Test-Revised (SAST-R) (Appendix 8)

Brief Description/Purpose: The SAST-R, developed by Carnes (2010)⁽²⁷⁾, is a 45-item instrument used to assess sexually compulsive behaviour indicative of sexual addiction. This test helps separate individuals with sexually addictive tendencies from those without. The SAST-R assesses three different categories: First is the core item scale which tests for sexual addiction in general, which is significant for this study. The second assesses four subscales: Internet items, Men’s items, Women’s items, and Homosexual men, all of which are not of interest in this study and have therefore been disregarded. The third assesses addictive dimensions including Preoccupation, Loss of control, Relationship disturbance, and Affect disturbance which are also significant for this study. This questionnaire is significant for this study as it will help demonstrate the possible correlation, if any, between hypersexuality and sex addiction, as some research has likened hypersexuality to sex addiction. This could in turn lead to clearer views regarding hypersexuality and extrapolation from the sex addiction data.

Scoring and Classification: Each “Yes” answer is given 1 point, whereas a “No” answer is given 0 points. The sum of the points for each scale and dimension is compared to the cut off score which then determines if there is a concern in the given area. A score of 6 or more on the core item scale shows that the patient fits the profile of individuals who have taken this assessment and are sexually addicted. A score of 2 or more on each of the Addictive dimension scales indicates a concern in the respective area. This is summarised in Table 12.

Table 12 – Scoring for the Sexual Addiction Screening Test-Revised

Scale	Item number	Cut off (number of “Yes” responses)
<i>Core*</i>	1-20	6 or more
<i>Subscales</i>		
Internet items	22-27	3 or more
Men’s items	28-33	2 or more
Women’s items	34-39	2 or more
Homosexual men	40-45	3 or more
<i>Addictive dimensions*</i>		
Preoccupation	3, 18, 19, 20	2 or more
Loss of control	10, 12, 15, 17	2 or more
Relationship disturbance	6, 8, 16, 26	2 or more
Affect disturbance	4, 5, 11, 13, 14	2 or more
*. Of interest in this study.		

Psychometric properties: This version of the test used is still in its developmental stages so scoring may be adjusted with more research⁽²⁷⁾. As such, psychometric properties have not been established for the full instrument. The SAST-R Core scale was developed by expanding the original 25-item version (SAST) developed by Carnes in 1989⁽²⁸⁾. The Core scale has demonstrated good internal consistency, which compares favourably to the original test⁽²⁷⁾. The sensitivity of the Core scale to detect sexual addiction was reported to be high at 81.7%⁽²⁷⁾.

The original SAST demonstrated excellent internal consistency (Cronbach’s $\alpha = .89$ to $.95$) across four samples⁽²⁹⁾. Moreover, the test was correlated with the Sexual Dependency Inventory-Revised, Garos Sexual Behaviour Index, and the Internet Sex Screening Test which established convergent validity⁽²⁹⁾.

It is important to note that a short, adapted version of the SAST for PD exists (PD-SAST) and has satisfactory psychometric properties, but requires further testing⁽³⁰⁾.

Permission to use: Permission was granted by Corrine Casanova on April 3, 2017.

5. **Name of Instrument:** University of Rhode Island Change Assessment (URICA) (Appendix 9)

Brief Description/Purpose: The URICA, developed by DiClemente and Hughes (1990)⁽³¹⁾, is a 32-item self-report measure used to assess an individual’s readiness and motivation for change and what stage the individual is at. This test is significant for this study as it will demonstrate patient insight and patient willingness to change/overcome their hypersexuality. The four stages of change, in order, are precontemplation, contemplation, action, and maintenance. Precontemplation (PC) is the first stage which shows that the patient does not recognise their behaviour as a problem and does not intend on working on it. Patients in this stage are often in denial that their behaviour is affecting not only themselves but those around them. They also do not recognise any negative consequences. Contemplation (C) is the second stage where patients can recognise that their behaviour is causing negative consequences and can spend time reflecting on their problem. These patients are aware of the problem behaviour and have an initial desire to change/overcome it. Action/preparation (A) make up the third stage where patients have actually made a commitment to change, try to overcome their problem behaviour, and make significant changes to their lives. Maintenance (M) is the fourth and final stage where patients are able to resist temptation to revert

to the problem behaviour after they have made the necessary changes.

Scoring and Classification: Each of the four subscales consists of 7 items. Responses are given along a 5-point Likert scale ranging from 1 (Strongly disagree) to 5 (Strongly agree). First, the scores for each subscale are calculated by summing the points for each item and then dividing by 7 to get the mean for each subscale ranging from 1 to 5. Next, the means from the C, A, and M subscales are summed and then subtracted by the PC mean: mean (C + mean A + mean M) – mean PC to get the Readiness for Change score. Lastly, the Readiness for Change score is then compared with the proposed cut off points, presented in Table 13 below, indicating in which stage of change the patient is. Summary of scoring is available in Appendix 10.

Table 13 – Scoring for University of Rhode Island Change Assessment Scale

Readiness for change score	Stage
8 or lower	PC
8 – 11	C
11 – 14	A
14 or more	M
A: action; C: contemplation; M: maintenance; PC: precontemplation	

Psychometric properties: Dozois et al. (2004) reported excellent internal consistency for the total URICA (Cronbach's $\alpha = .83$)⁽³²⁾. Cronbach's α for each of the subscales ranged from .73 to .90⁽³²⁾. The URICA was also reported to have adequate convergent and divergent validity⁽³²⁾.

Permission to use: Permission was granted by Carlo DiClemente on February 17, 2017.

6. **Name of Instrument:** International Index of Erectile Function (IIEF) (Appendix 11)

Brief Description/Purpose: The IIEF is a multidimensional 15-item self-report measure, developed by Rosen et al. (1997)⁽³³⁾, used to evaluate male sexual function over the past 4 weeks and its relevant domains, which are erectile function, orgasmic function, sexual desire, intercourse satisfaction, and overall satisfaction. Only the erectile function domain will be considered for this study⁶. This test is significant for this study as it will help demonstrate the possible connection, if any, between sexual functioning and hypersexuality in males.

Scoring and Classification: Domain scores are calculated by summing the scores for each item in each domain. The maximum score for the Erectile function domain is 30. The score obtained is then compared to the proposed cut off scores presented in Table 14. Generally, a score of <14 out of 30 on the Erectile function domain indicates a possible need for the patient to try a course of therapy with erectile function improvement drugs⁽³³⁾. Although there are no available cut off scores or categorical measures for the remaining domains, it is proposed that higher scores are indicative of less dysfunction. Summary of scoring is available in Appendix 12.

⁶ One might suggest the use of the desire and satisfaction domains in a study regarding hypersexuality; however, each of these two domains consist of only two questions which might not be accurate, sensitive, or thorough enough to reflect their relationship with hypersexuality and its phenomenology. Also, the questionnaire requires the participant to answer based on the past four weeks, possibly not an accurate reflection of how desire and satisfaction have been throughout the course of the hypersexuality

Table 14 – Scoring for Erectile function domain of International Index of Erectile Function

Score	Classification
1-10	Severe erectile dysfunction
11-16	Moderate dysfunction
17-21	Mild to moderate dysfunction
22-25	Mild dysfunction
26-30	No dysfunction

Psychometric properties: Adequate to excellent internal consistencies were established for each of the domains as well as the total scale (Cronbach's $\alpha \geq .73$ and $\geq .91$, respectively) in the populations studied by Rosen et al. (1997)⁽³³⁾. Test-retest reliability was reported as relatively high for the total scale scores ($r = .82$) and adequate construct validity was demonstrated⁽³³⁾, which was also high for erectile function and intercourse satisfaction domains ($r = .84$ and $.81$, respectively)⁽³³⁾. The other domains were observed to have moderately high correlations ($r = .64$ to $.77$)⁽³³⁾.

Permission to use: Permission was requested on 18 February 2016 and 29 March 2017; however, this questionnaire is routinely used at the NHNN and is readily available online.

7. **Name of Instrument:** Female Sexual Function Index (FSFI) (Appendix 13)

Brief Description/Purpose: Similar to the IIEF, the FSFI, developed by Rosen et al. (2000)⁽³⁴⁾, is also a multidimensional 19-item self-report instrument used to evaluate female sexual function over the past four weeks and its relevant domains, which are desire, arousal, lubrication, orgasm, satisfaction, and pain. Only the full scale score measuring sexual function will be considered for this study⁷. This test is significant for this study as it will help demonstrate the possible connection, if any, between sexual functioning and hypersexuality in females.

Scoring and Classification: Domain scores are calculated by summing the scores for each item in the domain and then multiplying the sum by the respective domain factor. The full score is then calculated by summing the domain scores. The higher the score, the better the function in the domain. The original developers of the FSFI do not provide categorical measures or cut off scores for domains or the full scale; however, a study by Rouzi et al. (2005) proposes a cut off score of 26.55 for the total scale score⁽³⁵⁾. A score less than 26.55 indicates that a female is at risk for sexual dysfunction. Summary of scoring is available in Appendix 14.

Psychometric properties: Rosen et al. (2000) reported excellent internal consistency for the FSFI (Cronbach's $\alpha \geq .82$) as well as high test-retest reliability coefficients for each of the individual domains ($r = .79$ to $.86$)⁽³⁴⁾. Moreover, good construct validity for each of the domains ($p < 0.001$) was observed by highly significant mean difference scores between females with female sexual arousal disorder and control groups⁽³⁴⁾.

Permission to use: Permission was requested on 18 February 2016 and 29 March 2017; however, this questionnaire is routinely used at the NHNN and is readily available online.

⁷ One might suggest the use of the desire and satisfaction domains in a study regarding hypersexuality; however, each of these two domains consist of only two questions which might not be accurate, sensitive, or thorough enough to reflect their relationship with hypersexuality and its phenomenology. Also, the questionnaire requires the participant to answer based on the past four weeks, which might not reflect how desire and satisfaction have been throughout the course of the hypersexuality

8. **Name of Instrument:** Barratt Impulsiveness Scale (BIS-11) (Appendix 15)

Brief Description/Purpose: The BIS-11, developed by Patton et al. (1995)⁽³⁶⁾, is a 30-item self-report measure used to assess impulsiveness. Impulsiveness is a multidimensional construct which is reflected in the factor structure of the questionnaire. The BIS-11 yields six first-order factors (attention, cognitive instability, motor, perseverance, self-control, cognitive complexity), three second-order factors (attentional, motor, and non-planning impulsiveness), and a total score. Attentional impulsiveness involves making quick decisions and relates to an inability to concentrate^(37, 38). Motor impulsiveness involves acting without thinking^(37, 38). Non-planning impulsiveness involves a lack of “futuring”⁽³⁹⁾ or forethought and relates to lack of premeditation^(37, 38). For purposes of this study, only the total score will be considered to avoid a problem of multiple comparisons between the second-order and first-order factors. This test is significant for this study as it will help demonstrate the possible connection, if any, between impulsivity and hypersexuality, as research has suggested a possible link⁽⁴⁰⁾.

Scoring and Classification: Responses are given on a 4-point Likert scale ranging from 1 (Rarely/never) to 4 (Almost always/always), 4 indicating the most impulsive response. Eight items are reverse scored. First-order factor and Second-order factor scores are calculated by summing the scores for each item. The total score, ranging from 30 to 120, is then calculated by summing the scores for each of the three second-order factors. The BIS-11 does not provide second order factor or total score categorical measures or cut off scores; however, Stanford et al. (2009) propose that a total score of ≥ 72 should be used to classify an individual as highly impulsive, total scores between 52 and 71 should be thought of as within normal limits for impulsiveness, and scores ≤ 52 are usually representative of an individual that is extremely controlled or who has not honestly completed the questionnaire⁽⁴¹⁾. Summary of scoring is presented in Table 15.

Table 15 – Scoring for the Barratt Impulsiveness Scale

Second-order factor	First-order factor	Number of Items	Items	Minimum score	Maximum score	Scoring
Attentional	Attention	5	5, 9*, 11, 20*, 28	5	20	Rarely/never = 1 Occasionally = 2 Often = 3
	Cognitive instability	3	6, 24, 26	3	12	Almost always/always = 4
Motor	Motor	7	2, 3, 4, 17, 19, 22, 25	7	28	Items denoted with (*) are reverse scored: Rarely/never = 4 Occasionally = 3 Often = 2
	Perseverance	4	16, 21, 23, 30*	4	16	
Nonplanning	Self-control	6	1*, 7*, 8*, 12*, 13*, 14	6	24	Almost always/always = 1
	Cognitive complexity	5	10*, 15*, 18, 27, 29*	5	20	Higher scores = higher impulsiveness
<i>Total score</i> ⁺				30	120	

+. Of interest in this study.

Psychometric properties: Patton et al. (1995) reported adequate to excellent internal consistency coefficients for the BIS-11 total score that range from .79 to .83 for separate populations of undergraduate, substance abuse patients, general psychiatric patients, and prison inmates⁽³⁶⁾. Stanford et al. (2009) demonstrated the BIS-11 to have reasonable test-retest reliability over one

month (Spearman's $\rho = .83$) as well as high correlations with similar self-report measures indicating convergent validity ($p < 0.01$)⁽⁴¹⁾.

Permission to use: Permission was granted by Jim Patton on March 29, 2017.

9. **Name of Instrument:** UPPS-P Impulsive Behaviour Scale (UPPS-P) (Appendix 16)

Brief Description/Purpose: The UPPS-P, a revised version of the UPPS⁽³⁷⁾, is a 59-item self-report measure, developed by Lynam et al. (2006)⁽⁴²⁾, which assesses for both impulsiveness and risk-taking. Impulsiveness is a multidimensional construct which is reflected in the five subscales of the UPPS-P. The subscales are (positive and negative) Urgency, (lack of) Premeditation, (lack of) Perseverance, and Sensation-seeking. Negative urgency involves experiencing strong impulses under conditions of negative affect. Positive urgency involves hasty action in response to positive affect. (lack of) Premeditation involves challenges in the ability to consider an action and its consequences before engaging in it. Sensation-seeking involves the propensity to enjoy and pursue exciting activities and an openness to trying new experiences that may or not be dangerous. Apart from its involvement in impulsivity, sensation-seeking is the only subscale that predicts risk-taking tendencies⁽⁴³⁾. For purposes of this study, only the total score and sensation-seeking score will be considered to avoid a problem of multiple comparisons between the subscales. This test is significant for this study as it will help demonstrate the possible connection, if any, between impulsivity and sensation-seeking, and hypersexuality.

Scoring and Classification: Patients are asked to reflect on their behaviour and inclinations during the last six months and the responses are given on a 4-point Likert scale ranging from 1 (Agree strongly) to 4 (Disagree strongly), 4 indicating the most impulsive response. Twenty-five items are reverse scored. Scores for each subscale are calculated by summing the individual item scores. The total score, ranging from 59 to 236, is then calculated by summing the scores of all the subscales. The UPPS-P does not provide categorical measures or cut off scores for the subscales or for the total score; therefore, a single sample t-test was used to determine if a statistically significant difference existed between the mean score of the study sample and scores available in the literature. Summary of scoring is available in Appendix 17.

Psychometric properties: Verdejo-García et al. (2010) established adequate reliability values in a Spanish adaptation developmental sample for all five subscales (Cronbach's α ranging from .78 for (lack of) Perseverance scale to .93 for (positive) Urgency scale)⁽⁴⁴⁾, which mirrored the values demonstrated in the original validation study⁽³⁷⁾ and the French adaptation of the UPPS⁽⁴⁵⁾. Verdejo-García et al. (2010) also reported that the UPPS-P had construct validity as the different dimensions were moderately correlated⁽⁴⁴⁾. Moreover, Sohn et al. (2014) reported a positive correlation between the sensation-seeking subscale and the Balloon Analogue Risk Task, a measure of risk-taking behaviour ($r = .27$, $p = 0.02$)⁽⁴³⁾.

Permission to use: Permission was requested on 18 February 2016 and 29 March 2017. The instrument, however, is readily available online.

10. **Name of Instrument:** Behavioural Inhibition System and Behavioural Activation System (BIS/BAS) (Appendix 18)

Brief Description/Purpose: The BIS/BAS scale, developed by Carver and White (1994)⁽⁴⁶⁾, is a 24-item self-report measure assessing sensitivity to punishment and sensitivity to reward, respectively. Gray (1987) proposed that the behavioural activation and the behavioural inhibition

systems underlie much of our behaviour and personality^(47, 48). The behavioural inhibition system is activated by cues of potential threat, punishment, non-reward, or novel stimuli⁽⁴⁸⁾ and its function “is to suppress behaviour that is expected to lead to punishment”⁽⁴⁹⁾. In contrast, the behavioural activation system is activated by the expectation of pleasure, reward, and nonpunishment⁽⁵⁰⁾. The questionnaire includes one BIS scale, one BAS scale, and three subscales within the BAS scale, which are drive (BAS-DR), fun seeking (BAS-FS), and reward responsiveness (BAS-RR). The BAS-DR subscale refers to the continuous pursuit of desired goals^(46, 51). The BAS-FS subscale refers to the desire for new rewards and an impulsive approach to potentially rewarding events^(46, 51). The BAS-RR subscale relates to the anticipation or occurrence of reward^(46, 51). For purposes of this study, only the BIS and BAS total scales are considered to avoid a problem of multiple comparisons of the three subscales. This test is significant for this study as it will help demonstrate the possible connection, if any, between behavioural activation and inhibition, and hypersexuality.

Scoring and Classification: Responses are given along a 4-point Likert scale ranging from 1 (Strongly disagree) to 4 (Strongly agree), 4 indicating high sensitivity. Two items are reverse scored. Scores for each scale are calculated by summing the individual item scores. The total BAS score is calculated by summing the scores for each of the three subscales. The BIS/BAS does not provide categorical measures or cut off scores for the scales; therefore, a single sample t-test was used to determine if a statistically significant difference existed between the mean score of the study sample and scores available in the literature. Summary of scoring is available in Appendix 19.

Psychometric properties: Carver and White (1994) reported adequate to excellent internal consistencies for all the scales (Cronbach’s α ranging from .66 for BAS-FS subscale to .76 for BAS-DR subscale)⁽⁴⁶⁾. A more recent study by Abdollahi Majarshin et al. (2013) showed adequate internal consistencies for the scales (Cronbach’s α ranging from .62 for BIS scale to .74 for BAS-DR subscale)⁽⁵²⁾. Test-retest reliability was also high ($r = .82$ for BAS-RR, .75 for BAS-DR, .86 for BAS-FS, and .78 for BIS)⁽⁵²⁾. The scale was demonstrated as having concurrent validity as there was a significant positive correlation between the BIS scale and the Beck Depression Inventory, Neuroticism (one of the Big Five personality traits), and negative affect, whereas a significant positive correlation was demonstrated between the BAS scale and positive affect and Extraversion (another of the Big Five personality traits)⁽⁵²⁾.

Permission to use: Permission was granted by Charles Carver on 29 March 2017.

11. **Name of Instrument:** Interpersonal Reactivity Index (IRI) (Appendix 20)

Brief Description/Purpose: The IRI, developed by Davis (1983)⁽⁵³⁾, is a 28-item self-report measure assessing four dimensions of empathy. The Empathic Concern subscale assesses emotional empathy⁽⁵⁴⁾, or feelings of concern about the misfortune of others⁽⁵⁵⁾. The Perspective Taking subscale assesses cognitive empathy or the ability to see things from others’ point of view⁽⁵⁴⁾. The Personal Distress subscale assesses self-oriented feelings of anxiety and discomfort at the suffering of others^(54, 55). The Fantasy subscale assesses empathy for fictional characters⁽⁵⁴⁾ in books or movies⁽⁵⁵⁾, for example. The IRI is not intended to measure overall empathy but rather the multidimensionality of empathy⁽⁵⁴⁾. The subscales should therefore be examined separately, allowing researchers to use the scales best suited for their research. This test is significant for this study as it will help demonstrate the possible connection, if any, between empathy and hypersexuality.

Scoring and Classification: Each of the four subscales consists of 7 items. Responses are given along a 5-item Likert scale ranging from A (Does not describe me well) to E (Describes me very well). Nine items are reverse-scored. Scores for each subscale, ranging from 0 to 28, are calculated by summing the individual item scores. Higher scores indicate better functioning. Because the IRI is regarded as a continuous measure, it does not provide categorical measures or cut off scores⁽⁵⁴⁾; therefore, a single sample t-test was used to determine if a statistically significant difference existed between the mean score of the study sample and scores available in the literature. Summary of scoring is available in Appendix 21.

Psychometric properties: The original scale development paper reported adequate internal reliability for the four subscales (Cronbach's α ranging from .70 to .78)⁽⁵⁴⁾. Test-retest reliability was also adequate for males with correlations with between .61 to .79 and for females between .62 and .81⁽⁵⁴⁾. In the original scale validation paper, the scale was established to have both convergent (correlated with other empathy measures) and concurrent validity (subscales associated with self-esteem and interpersonal functioning)⁽⁵³⁾.

Permission to use: Permission was granted by Mark Davis on April 7, 2017.

12. **Name of Instrument:** Reading the Mind in the Eyes Test (RMET)

Brief Description/Purpose: The RMET, originally developed by Baron-Cohen et al. (1997)⁽⁵⁶⁾, is a test to measure social sensitivity and emotional perception. The test requires patients to look at 36 images of eyes after which they are to choose from a set of 4 words which one best describes the emotion of the individual in each of the pictures. It is routinely used in the Department of Neuropsychology at the NHNN. This test is significant for this study as it will help demonstrate the possible connection, if any, between social sensitivity and emotional perception, and hypersexuality.

Scoring and Classification: Responses are individually scored as correct or incorrect. The total number of correct answers, ranging from 0 to 36, is then considered. The RMET does not provide categorical measures or cut-off scores; therefore, a single sample t-test was used to determine if a statistically significant difference existed between the mean score of the study sample and scores available in the literature.

Psychometric properties: Although the RMET is extensively used in clinical practice and research, its psychometric properties remain ambiguous. Little is known about its reliability and validity⁽⁵⁷⁾. Poor internal consistency has been reported in several studies, which may be attributed to several features of the test itself and its administration, such as the angle of the face and the ratio of dark to light of each image⁽⁵⁷⁾. The RMET has shown some correlation with other measures of theory of mind such as the Strange Stories Test and the Faux-Pas Test suggesting convergent validity, although other studies did not find the same correlations⁽⁵⁷⁾. Moreover, despite heterogeneous validity reports, the test does seem to be able to separate groups with and without autism^(56, 57).

Permission to use: Permission was granted by Anna-Louise Crofts on March 31, 2017; however, did not extend to appending the test to the dissertation.

13. **Name of Instrument:** Parkinson's Disease Questionnaire-39 (PDQ-39) (Appendix 22)

Brief Description/Purpose: The PDQ-39, developed by Jenkinson et al. (1995)⁽⁵⁸⁾, is a 39-item

self-report measure used to assess PD patients' quality of life over the last month. The PDQ-39 assesses the impact of Parkinson's disease on eight dimensions of functioning and well-being: Mobility, Activities of daily living, Emotional well-being, Stigma, Cognition, Communication, and Bodily discomfort. For purposes of this study, only the total score called the PDQ-39 Summary Index (PDQ-39 SI) will be considered to avoid a problem of multiple comparisons between the eight dimensions. This test is significant for this study as it will help demonstrate the possible connection, if any, between quality of life and hypersexuality, although it does not include any sex-specific questions.

Scoring and Classification: Responses are given along a 5-point Likert scale ranging from 0 (Never) to 4 (Always), 4 indicating highest impact. Each dimension is calculated as a scale from 0 to 100, 0 indicating no problem at all and 100 indicating a maximum level problem. The formula for scoring each dimension is as follow:

$$\frac{\text{sum of scores of each item in dimension}}{4 \times \text{number of item in dimension}} \times 100$$

The PDQ-39 SI is then calculated by summing the scores of each dimension and then dividing by 8 (the total number of dimensions in scale). Lower scores are indicative of better quality of life. The PDQ-39 does not provide categorical measures or cut off scores; therefore, a single sample t-test was used to determine if a statistically significant difference existed between the mean score of the study sample and scores available in the literature. Summary of scoring is available in Appendix 23.

Psychometric properties: The PDQ-39 is reliable and valid and is extensively used in clinical practice and research. Excellent internal reliability for the PDQ-39 SI was established (Cronbach's α ranging from .84 to .94)^(59, 60). Construct validity for the PDQ-39 has also been reported as it better represents the impact on quality of life in Parkinson's disease patients than a more generic measure (36-Item Short Form Health Survey) and has been used as a benchmark measure for determining psychometric properties of other outcome measures^(59, 61-63). Furthermore, excellent convergent validity was reported for the PDQ-39 and the Hoen and Yahr scale score, PDQ-39 and Schwab and England Scale, PDQ-39 SI and EuroQuol five dimensions questionnaire, and the PDQ-39 and Beck Depression Inventory ($r = .60, .66, .75, .68$ respectively)⁽⁶⁴⁻⁶⁶⁾.

Permission to use: Permission was requested on 18 February 2016 and 29 March 2017; however, this questionnaire is routinely used at the NHNN and is readily available online.

14. **Name of Instrument:** National Adult Reading Test (NART) (Appendix 24)

Brief Description/Purpose: The NART, developed by Nelson (1982)⁽⁶⁷⁾, is widely used to estimate an individual's premorbid level of intellectual ability⁽⁶⁸⁾ by calculating estimated Full Intelligence Quotient (IQ), Verbal IQ, and Performance IQ. For purposes of this study, only the estimated Full IQ score will be considered. This test is significant for this study as it will help demonstrate the possible connection, if any, between intellectual ability and hypersexuality.

Scoring and Classification: Patients are required to read 50 words out loud. The responses are individually scored as correct or incorrect, according to the correct pronunciation⁽⁶⁸⁾. Consequently, the total number of errors, ranging from 0 to 50, is used to calculate estimates for Full IQ, Verbal IQ, and Performance IQ, which then allows to categorise the subjects according to the cut off scores provided in Table 16. The formulas used for calculation of each premorbid IQ

estimate are as follows:

Estimated Full Scale IQ = $127.7 - (0.826 \times \text{NART error score})$

Estimated Verbal IQ = $129.0 - (0.919 \times \text{NART error score})$

Estimated Performance IQ = $123.5 - (0.645 \times \text{NART error score})$

Table 16 – Scoring for the National Adult Reading Test

IQ	Classification
>130	Very gifted
121-130	Gifted
111-120	Above average intelligence
90-110	Average intelligence
80-89	Below average intelligence
70-79	Cognitively impaired
IQ: intelligence quotient	

Psychometric properties: The NART demonstrated high construct validity as a measure of general intelligence⁽⁶⁹⁾, as well as good criterion validity⁽⁷⁰⁾. The test has also been established as reliable due to excellent internal consistency (Cronbach's $\alpha = .90$)⁽⁷¹⁾, inter-rater reliability ($r = .96$ and $.98$) and test-retest reliability ($r = .98$)^(72, 73).

Permission to use: Permission was requested on 18 February 2016 and 29 March 2017; however, this test is part of routine assessment at the Department of Neuropsychology at the NHNN and is readily available online.

15. **Name of Instrument:** Raven's Coloured Progressive Matrices (RCPM)

Brief Description/Purpose: The RCPM, developed by Raven (1938)⁽⁷⁴⁾, is a 36-item test used to measure current intellectual ability. It consists of three sets of problems: A, AB, and B, each containing 12 items. This test is significant for this study as it will help demonstrate the possible connection, if any, between current intellectual ability and hypersexuality.

Scoring and Classification: Patients are required to identify missing elements that complete increasingly difficult patterns. Responses are individually scored as correct or incorrect. The total number of correct answers, ranging from 0 to 36, is then used to determine intellectual ability. The RCPM does not provide categorical measures of cut-off scores; therefore, a single sample t-test was used to determine if a statistically significant difference existed between the mean score of the study sample and scores available in the literature.

Psychometric properties: The only psychometric properties that have been established exist in populations of children. Martin and Wiechers (1954) reported correlations of .94, .84, and .83 between RCPM scores and the Wechsler Intelligence scale for children Full scale, Verbal and Performance IQ scores, respectively⁽⁷⁵⁾. A study by Cotton et al. (2005) reported excellent internal consistency averaging around .80⁽⁷⁶⁾. A more recent study by Kazem et al. (2007) reported sound construct validity for the RCPM, as well as internal consistency (Cronbach's α ranging from .64 to .89)⁽⁷⁷⁾.

Permission to use: Permission was requested on 18 February 2016 and 29 March 2017; however, this test is part of routine assessment at the Department of Neuropsychology at the NHNN. It is

not readily available online and has, therefore, not been appended to this dissertation to avoid copyright infringement.

16. **Name of Instrument:** Hayling Sentence Completion Task (HSCT)

Brief Description/Purpose: The HSCT, developed by Burgess and Shallice⁽⁷⁸⁾, is a measure assessing the capacity to suppress/inhibit a habitual response⁽⁷⁹⁾. The test consists of two parts: Hayling 1 and Hayling 2. Hayling 1 assesses automatic response initiation and the Hayling 2 assesses non-automatic response suppression/inhibition⁽⁷⁹⁾. Hayling 1 and 2 are each comprised of fifteen incomplete sentences that are read aloud to the patients in which the final word of each sentence is missing. In Hayling 1, titled Sensible Completion, patients are required to complete the incomplete sentences with the omitted word. In Hayling 2, titled Unconnected Completion, patients are required to complete the incomplete sentences with words that are entirely unrelated to the sentences. “Performance on the Hayling requires not only response suppression, but also strategy implementation is also needed to generate semantically-unrelated alternative sentences”⁽⁸⁰⁾. Patients are asked to reply as quickly as possible as scoring is partially dependent on the time (measured in whole seconds) taken to respond to each sentence. This test is part of routine assessment at the Department of Neuropsychology at the NHNN. This test is significant for this study as it will help demonstrate the possible connection, if any, between these aspects of executive functioning and hypersexuality.

Scoring and Classification:

There are several steps associated with scoring outlined below. The tables required for conversion of the scores for each step are located in Appendix 25.

- 1) The total response time (in whole seconds), labelled raw score, is recorded for each Hayling 1 and Hayling 2. The obtained raw score for Hayling 1 is converted to a **Scaled score A**, which ranges from 1 (Impaired) to 7 (High average).
- 2) Using the same method, the raw score for Hayling 2 is converted to a **Scaled score B**, which ranges from 1 (Impaired) to eight (Good).
- 3) Each response for the Hayling 2 is also classified as being either unconnected, somewhat connected (Category B error), or directly connected (Category A error). The total number of Category A errors is then converted to an **A score**.
- 4) Using the same method, the total number of Category B errors is converted to a **B score**.
- 5) The converted score is then calculated by adding the obtained A score and B score after which it is converted into a **Converted scaled score** ranging from 1 (Impaired) to 8 (Good).
- 6) Next, the **Total scaled score** for each patient is calculated by summing Scaled score A (found for Hayling 1) and Scaled score B (found for Hayling 2) and the Converted scaled score (found for Hayling 2 error): **Total scaled score = Scaled score A + Scaled score B**.
- 7) Finally, the obtained Total scaled score is then converted to a **Hayling overall scaled score**, after which performance of each patients, ranging from 1 (Impaired) to 10 (Very superior), can be classified accordingly using Table 17.

Table 17 – Scoring for Hayling Sentence Completion Task

Total scaled scores	Hayling overall scaled score	Classification
23	10	Very superior
22	9	Superior
21	8	Good
20	7	High average
17-19	6	Average
15-16	5	Moderate average
13-14	4	Low average
11-12	3	Poor
10	2	Abnormal
<10	1	Impaired

Psychometric properties: Burgess and Shallice (1997) reported adequate test-retest reliabilities for the Hayling overall score and the Hayling 2 response time (.76 and .78, respectively) and reported poor reliabilities for the Hayling 1 response time and the Hayling 2 errors score (.62 and .52, respectively)⁽⁸¹⁾. Burgess and Shallice (1997) also reported reliabilities in impaired groups ranging from .72 to .93, as well as internal consistency ranging from .62 to .76 in normals⁽⁸¹⁾. Moreover, Bielak et al. (2006) reported good inter-reliability at 96%⁽⁸²⁾. Adequate concurrent validity was demonstrated between the HSCT and the Six Elements Test (correlations ranging from .40 to .65)⁽⁸³⁾ and the Tower of London Task ($r = .40$)⁽⁸⁴⁾.

Permission to use: Permission to describe the test, its function, scoring, and how it is administered was granted by Sarah Weinberg on April 3, 2017; however, permission was not granted for appending the test to the dissertation.

17. **Name of Instrument:** Brixton Spatial Anticipation Task (BSAT)

Brief Description/Purpose: The BSAT, developed by Burgess and Shallice (1996)⁽⁸⁵⁾, is a tool used to assess the capacity to abstract logical rules⁽⁷⁹⁾. The test contains both elements of rule detection and rule adherence⁽⁸⁶⁾. The test consists of 56 items, each on a separate page with the same basic template: a 2x5 arrangement of circles numbered from 1 to 10⁽⁷⁹⁾. The only difference between the items is the position of a single filled circle, which changes position and thus fills a different circle on every page. Patients are required to predict which number the circle would fill on the following page. This test is part of routine assessment at the Department of Neuropsychology at the NHNN. This test is significant for this study as it will help demonstrate the possible connection, if any, between these aspects of executive functioning and hypersexuality.

Scoring and Classification: The performance on this task is measured by the total number of errors made (raw score), ranging from 0 to 56. The raw score is then converted to a scaled score and classified accordingly from 1 (Impaired) to 10 (Very superior) using Table 14:

Table 18 – Scoring for Brixton Spatial Anticipation Task

Raw score (total number of errors)	Scaled Score	Classification
0-7	10	Very superior
8	9	Superior
9-10	8	Good
11-13	7	High average
14-17	6	Average
18-20	5	Moderate average
21-23	4	Low average
24-25	3	Poor
26-31	2	Abnormal
>31	1	Impaired

Although performance on the test is essentially interpreted in the method describe above, two different types of errors exist: rule detection and rule adherence errors⁽⁸⁶⁾. Rule detection errors are the errors made following a rule change. Rule adherence errors, on the other hand, are the errors following two or more consecutive correct responses where the rule had not been changed⁽⁸⁶⁾.

Psychometric properties: Burgess and Shallice (1997) reported adequate test-retest reliability for the BSAT (.71) and modest internal consistency (.62)⁽⁸¹⁾. Crawford and Henry (2005) reported large effect size ($r = .50$) and a moderate effect size ($r = .34$) between healthy controls and patients with frontal and posterior lesions, respectively⁽⁸⁷⁾.

Permission to use: Permission to describe the test, its function, scoring, and how it is administered was granted by Sarah Weinberg on April 3, 2017; however, permission was not granted for appending the test to the dissertation.

18. **Name of Instrument:** Hospital Anxiety and Depression Scale (HADS) (Appendix 26)

Brief Description/Purpose: The HADS, developed by Zigmond and Snaith (1983)⁽⁸⁸⁾, is a two-dimension, 14-item measure used to identify depression and anxiety. The test consists of seven questions assessing depression and seven assessing anxiety. This test is part of routine assessment at the NHNN. This test is significant for this study as it will help demonstrate the possible connection, if any, between mood and hypersexuality.

Scoring and Classification: Responses are given along a 4-point Likert scale ranging from 0 (Absence) to 3 (Extreme presence). Scores for each dimension, ranging from 0 to 21, are calculated by summing the individual item scores. Higher scores indicate higher severity of problem. Cut off scores and severity are presented in Table 19 below. Summary of scoring is available in Appendix 27.

Table 19 – Scoring for Hospital Anxiety and Depression Scale

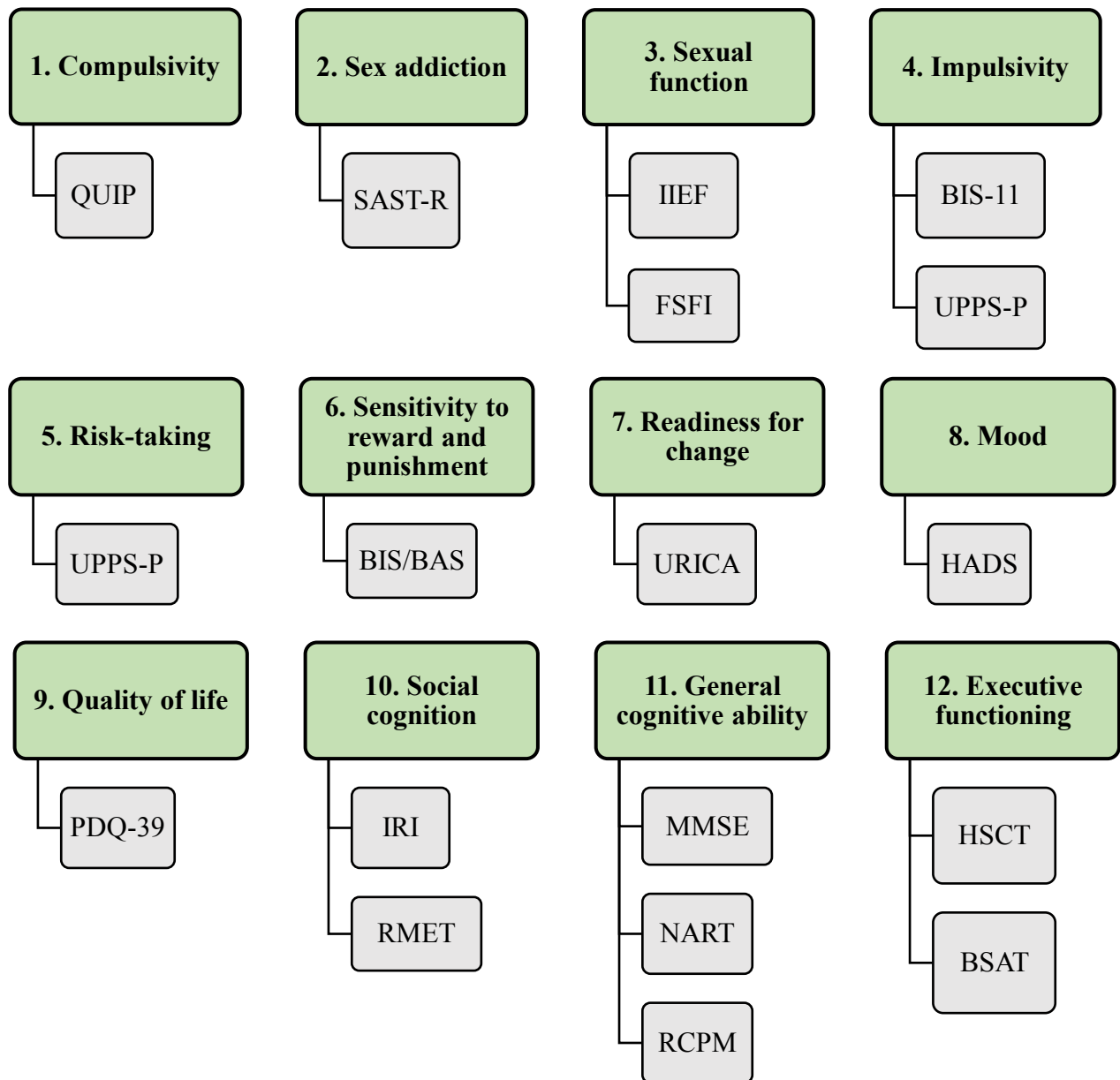
Total score	Severity
0-7	Normal
8-10	Borderline abnormal
11 – 21	Abnormal

Psychometric properties: Adequate to excellent test-retest reliability has been reported for the HADS (r ranging from .70 to .85)⁽⁸⁹⁾. There are several studies that have demonstrated adequate to excellent internal consistencies (Cronbach's α ranging from .67 to .90)⁽⁹⁰⁾, but a study primarily with Parkinson's disease patients established excellent internal consistency for anxiety and depression ($\alpha = .81$ and .83, respectively)⁽⁹¹⁾. Bjelland et al. (2002) reported excellent correlations between the Anxiety subscale and the Beck Depression Inventory and the Clinical Anxiety Scale, as well as between the Depression subscale and the Beck Depression Inventor and the Montgomery-Asberg Depression Rating Scale⁽⁹⁰⁾. Aben et al. (2002) showed the HADS to have excellent convergent validity ($r = .67$) between the Anxiety and Depression subscales⁽⁹²⁾.

Permission to use: Permission was granted by GL Assessment on April 7, 2017.

The quantitative assessment tools were grouped into the following 12 domains presented in Figure 12, determined a priori according to the constructs the tools assess.

Figure 12 – Twelve domains assessed in hypersexual patients with neurological disorders



It is important here to note several points regarding these determined domains:

1. Sex addiction shares some components with compulsivity; however, for the purposes of this study they have been separated as SAST-R also measures addictive dimensions such as preoccupation with sex, loss of control over sex, and relationship disturbances because of sex, which are all not necessarily related to compulsivity but rather addiction.
2. The UPPS-P assesses for two separate constructs and has, therefore, been included under two separate domains.
3. One might argue that the tests used to determine executive functioning can also be used to assess cognitive ability; therefore, the term 'General' has been added to the Cognitive Ability to distinguish between the two domains

3.4.9.3 Carers

The carers of patients with hypersexuality also underwent qualitative assessment in the form of a semi-structured interview as well as quantitative assessment in the form of questionnaires requiring the carers to spend up to two hours with the researchers. The materials/instruments that were used, in the order that they were given to the carers, are as follows:

1. **Name of Instrument:** Carer Assessment Interview (Appendix 28)

Brief Description/Purpose: The interview is a semi-structured custom-developed thirty-four item interview, developed by the research student, used to assess patients' experience with hypersexuality and its impact. This is the only instrument for carers that will inform the qualitative data analysis for carers. This interview can be used to assess carers of patients who currently have hypersexuality or who have had hypersexuality in the past.

This is the only instrument that will inform the qualitative data analysis for carers.

2. **Name of Instrument:** Hospital Anxiety and Depression Scale (HADS)⁽⁸⁸⁾ (Appendix 26)

Brief Description/Purpose: The HADS was already discussed in detail in the previous section pertaining to the patients.

3. **Name of Instrument:** Adult Carer Quality of Life Questionnaire (AC-QoL) (Appendix 29)

Brief Description/Purpose: The AC-QoL, developed by Elwick et al. (2010), is a 40-item self-report instrument used to measure the quality of life of adult, unpaid carers⁽⁹³⁾. The questionnaire consists of 8 subscales: Support for caring, Caring choice, Caring stress, Money matters, Personal growth, Sense of value, Ability to care, and Carer satisfaction. The Support for caring subscale measures the extent of emotional, professional, and personal support carers think they receive⁽⁹³⁾. The Caring choice subscale measures the extent to which carers feel that they have control over their own life, and can choose ventures outside caring such as social activities⁽⁹³⁾. The Caring stress subscale measures physical and mental stress caused by caring, such as exhaustion and depression⁽⁹³⁾. The Money matter subscale measures how carers feel about their financial situation⁽⁹³⁾. The Personal growth subscale measures the extent to which carers feel they have grown and developed⁽⁹³⁾. The Sense of value subscale measures the extent to which the carer feels they are valued and respected, and the positive relationship between them and the person they are caring for⁽⁹³⁾. The Ability to care subscale measures the extent to which the carer is able to provide care for the person they care for, how they cope with the caring role, and how they feel about their competency to care⁽⁹³⁾. The Carer satisfaction subscale measures the extent to which the carer is satisfied with their life and role as a carer, and how they feel about being a carer⁽⁹³⁾. For purposes

of this study, only the overall quality of life score will be considered to avoid a problem of multiple comparisons between the eight dimensions. This test is significant for this study as it will help demonstrate the possible connection, if any, between quality of life and hypersexuality.

Scoring and Classification: Each of the eight subscales consists of 5 items. Responses are given along a 4-point Likert scale ranging from 0 (Never) to 3 (A lot of the time), 3 indicating a better quality of life on that subscale. Fourteen items are reverse-scored. Scores for each subscale, ranging from 0 to 15, are calculated by summing the individual item scores. Higher scores indicate greater quality of life on the respective subscale. Cut off scores and classifications are presented in Table 20 below. Summary of scoring is available in Appendix 30.

Table 20 – Scoring for the Adult Carer Quality of Life Questionnaire

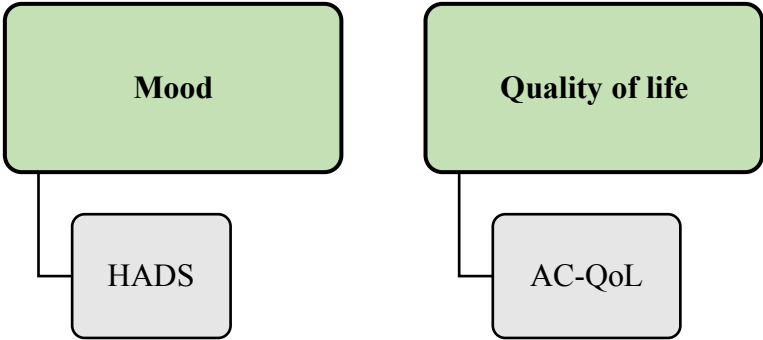
Score	Classification
0 – 40	Indicates a low reported quality of life, and may suggest problems or difficulties
41 – 80	Indicates a mid-range reported quality of life
81+	Indicates a high reported quality of life

Psychometric properties: A study by Joseph et al. (2012), reported excellent internal consistency reliability for the AC-QoL ($\alpha = .94$) and adequate to excellent internal consistency for the eight subscales ranging from .78 to .89⁽⁹⁴⁾. The study also reported a moderately strong correlation between participants’ pre- and post-intervention differences suggesting convergent validity⁽⁹⁴⁾.

Permission to use: Permission was granted by Saul Becker on March 12, 2015.

The carer questionnaires were grouped into the following 2 domains presented in Figure 13, determined a priori according to the constructs the questionnaires assess:

Figure 13 – Two domains assessed in carers of hypersexual patients with neurological disorders



3.4.10 Procedure

3.4.10.1 Pre-screening

PD

Patients attending the MDC at the NHNN who indicated hypersexuality as being an issue during their clinical appointments, and patients at ECH who indicated hypersexuality in the QUIP, who were prepared to discuss it in further detail were contacted over the phone by the research student. These patients as well as the patients who read about the study from the leaflets (Appendix 4) circulated by Parkinson's UK to their Research Support Network in November 2015 and May 2016 who contacted a member of the research team themselves, were all further informed about the study's aims, methods, potential risks and benefits, and confidentiality over the phone.

Spouses of the PD patients who indicated hypersexuality as being an issue during clinical appointments with the patients and who were prepared to discuss it in further detail with a researcher were contacted by the research student. These carers as well as the carers who contacted the researchers after reading the leaflets (Appendix 31) about the study circulated by Parkinson's UK were further informed about the study's aims, methods, potential risks and benefits, and confidentiality over the phone.

AD/FTD

Interested carers of patients with FTD or AD who were informed about the study by the clinical staff at the DRC, through the newsletter that was sent out periodically which contained blurbs (Appendix 32) about the study and the contact details of the members of the research team, or through the carer leaflets (Appendix 5) passed out at the Frontotemporal Dementia Support Group (FTDSG) March 5th, 2016 Seminar, which took place at 33 Queen Square, were further informed about the study's aims, methods, potential risks and benefits, and confidentiality over the phone.

Interested patients and carers were then asked to come into the Department of Uroneurology at the NHNN where any of the available rooms on the scheduled dates was used to provide the participants with written information about the study, obtain written consent, and consequently complete assessment.

The participants were first provided with written information about the study. The participants were given Participation Information Sheets (Appendix 33-35) to read describing the study's aims, methods, potential risks and benefits, and confidentiality assurances, after which they were required to sign and date an Informed Consent Form (Appendix 36-38).

3.4.10.2 Informed consent

As the research is focused on sexual behaviour and sexuality, the participants were informed that the interviews may focus on topics felt to be sensitive and/or potentially embarrassing. All participants were only asked about such topics after providing full, informed consent, and were advised that they could refuse answering any of the questions or stop participating at any time, without affecting their routine medical care. The participants were also informed that in the case of any unforeseen disclosures which were deemed to be a risk to the patient and/or criminal behaviour, the information would be shared with the patients' consultants, as is good clinical practice. The participants were therefore advised, before signing the informed consent form, not to report any sexual activities which involved threatening others or sexual relationships with minors. Furthermore, the participants were informed that the interview

portion of the study was going to be audio-recorded using a Dictaphone and that the recorded material was only to be used in writing up the transcripts, which was completed almost immediately after assessment. Participants were assured that the recorded material would not be passed on and that it would be deleted at the end of transcription. Participants, however, who did not consent to the use of the Dictaphone were informed that they were still eligible to take part in the study. Moreover, if the participant, who had given informed consent, chose to withdraw from the study at any point for any reason, was informed that the data already collected with consent would be retained and used in the study.

The patients were informed that their general practitioners (GPs) would be sent a letter (Appendix 39) informing them about their participation in the study. Patients who did not consent to this, however, were still eligible to take part in the study.

Next, if agreed to proceed with the study, the participants were then asked to sign and date the Informed Consent Forms. The signed informed consent forms are retained at the study site in the Department of Urology at the NHNN (Appendix 36-38).

3.4.10.3 *Screening*

Patients

After signing the informed consent forms, the PD patients were then assessed using the semi-structured interviews, questionnaires, and tests detailed above. In total, PD patient interview and assessment took around three to four hours to complete with as many breaks as required.

Carers

The carers were also assessed using the semi-structured interview and the questionnaires detailed above. The carer interview and assessment took around two hours to complete with as many breaks as required.

In the case that patients decided to take part in the study with their carers, they were advised to be seen separately to ensure complete accuracy and honesty in their answers; however, the decision to be assessed separately or not was ultimately left up to the patients and their carers.

The research student scheduled, interviewed, and assessed the participants⁸.

3.4.10.4 *Interview strategy and techniques*

Individual interviews were the primary method of collecting and generating data for the study. The interviews ranged from two hours to nearly four hours in duration. Smith and Eatough (2006) pointed out that semi-structured interviewing and qualitative analysis seem to fit seamlessly together as the interview allows for a rich, in-depth exploration of the research issue⁽⁹⁵⁾, necessary for adequate qualitative analysis. This is due to the 'open' nature of semi-structured interviews⁽⁹⁵⁾.

Developing the interview schedule and conducting the interviews required planning and preparation. The interview schedule for the study was developed, discussed, and modified with the supervisors who included one neurologist and two psychologists with extensive experience in 'interviewing' patients. The questions were carefully selected. Since the discussion of hypersexuality is highly sensitive, it was important for the researcher to use

⁸ The research student has a degree in Psychology, has experience in dealing with sensitive issues, and became familiar with the issue of hypersexuality during the course of her MSc Clinical Neuroscience project.

terms that would not be offensive to the participants (e.g. the word ‘masturbation’ was changed to ‘pleasing oneself’).

Furthermore, during the actual interview, it was imperative for the researcher to establish rapport and trust with the participants as it provided them with a safe and comfortable enough environment to share their personal experiences⁽⁹⁶⁾. This was established both verbally (e.g. by explaining the research and its importance and implications, as well as informing the participants that the researcher is a psychologist, which made them feel like she could possibly understand their pain and experiences) and non-verbally (e.g. smiling when appropriate). The researcher thus aimed to come across as approachable, non-judgmental, and professional and tried, to the best of her abilities, to make the participants feel as if they were in control of the conversation and that she was just there to guide the discussion. It is important to note that attention was given to participants’ non-verbal cues (e.g. body language), which also helped the researcher guide the interviews. Due to the sensitive nature of the issue discussed, the researcher did not want to cause participants any discomfort or cause them to feel ‘unsafe’. The researcher also expressed gratitude before and after the interview for their consent to participate, as this typically makes participants feel valued and may thus motivate them to share.

It is important to note that due to the sensitive nature of the issue being explored, the interviewer was responsible for modifying the interview question as was deemed fit during the interview process to alleviate any possible discomfort or uneasiness of participants. This will be discussed in more detail in section 3.4.10.8 (under *Reflexivity*).

3.4.10.5 Confidentiality

Ethical and legal practice was followed and all information about patients and carers was handled in confidence. If the participant consented to taking part in the study, the records obtained while in the study, as well as any other related health records, remained strictly confidential at all times. The information is held securely on paper and electronically at the Department of Uroneurology at the NHNN under the provision of the 1998 Data Protection Act. Storage of the data was done using encrypted USBs. There were two USBs in case one was lost. All collected information is securely stored in a locked filing cabinet in the Department of Uroneurology at the NHNN to which only the research team has access. To ensure confidentiality, all data collected was labelled with a unique identification number rather than participant name or any other identifiable data. All personal data was only made available to the direct clinical team as part of routine clinical practice. No identifiable data could be accessed outside the research team without prior consent at any stage of the study. Only authorised members of the research team were able to link the identification numbers with the participants’ personal details. Participants were informed, however, that this may need to be made available to other neuropsychologists, UCLH and UCL research and development monitors, and the Independent Ethics Committee members, if necessary. Names were not included on any forms, reports, and publications and will not be included in any future disclosures. The participants were informed that they have the right to check the accuracy of the data held about them and consequently correct any errors, if any.

Furthermore, the Dictaphone, an audio-recording device, was used to record the participant interviews. The research student carried out the transcription. In the case that the data had to be transferred, it was done using an encrypted USB. The recorded material was only used in writing up the transcripts, which was done almost immediately after the interview and

assessment, and was not passed on. The recorded material was deleted at the end of transcription.

In line with the regulations, data will be securely archived for a minimum of twenty years. Arrangements for confidential destruction will then be made.

3.4.10.6 *Risk governance*

Because of the sensitive nature of the topic of sexuality, the Social Research Association (SRA)'s Code of Practice⁹ was consulted to ensure researcher safety. According to the SRA, the topics for discussion in many social research interviews may provoke strong feelings in participants and prompt angry reactions⁽⁹⁷⁾. Researchers are thus advised to take precautions to minimise risk in the interview situation and ensure that help is at hand if needed. The following guidelines were followed throughout the course of this study: (1) Avoided dressing provocatively⁽⁹⁷⁾; (2) Let the participant know that others know where they are by informing them that other investigators were close-by and might, at any moment, drop in to say hello⁽⁹⁷⁾; (3) Informed the other investigators about the details of the schedule and appointment times⁽⁹⁷⁾; (4) Established the right social distance by neither appearing "over-familiar nor too detached"⁽⁹⁷⁾; (5) Was prepared to deal with the effects of the interview on the participant⁽⁹⁷⁾; (6) Was ready to recognise the participants potentially becoming upset or angry⁽⁹⁷⁾; (7) Understood that there may be occasions where it is more sensible to end the meeting⁽⁹⁷⁾.

Furthermore, although it was only the research student who was assessing the participants, the meetings with the patients and carers were scheduled during a time when at least one of the other members of the research team was available to assist in the case of any unexpected occurrences. Support was available for both the research student and the participants in the case any party became unexpectedly uncomfortable, anxious, angry, or distressed during the interview or testing. In that case, participants were informed that they could take a break or could choose to stop their participation entirely. The participants were provided with contact details for a highly specialist clinical neuropsychologist, and a chartered health psychologist, both of whom were part of the research team for the study.

3.4.10.7 *Data analysis*

Thematic analysis is an inadequately delineated and seldom-recognised, yet widely-used qualitative analysis method⁽⁹⁸⁾. It is not associated with any specific pre-existing epistemological and theoretical paradigms, and can therefore be used within different ones⁽⁹⁸⁾. Virginia Braun and Victoria Clarke's (2006) thematic analysis approach was used to analyse the qualitative data for this study.

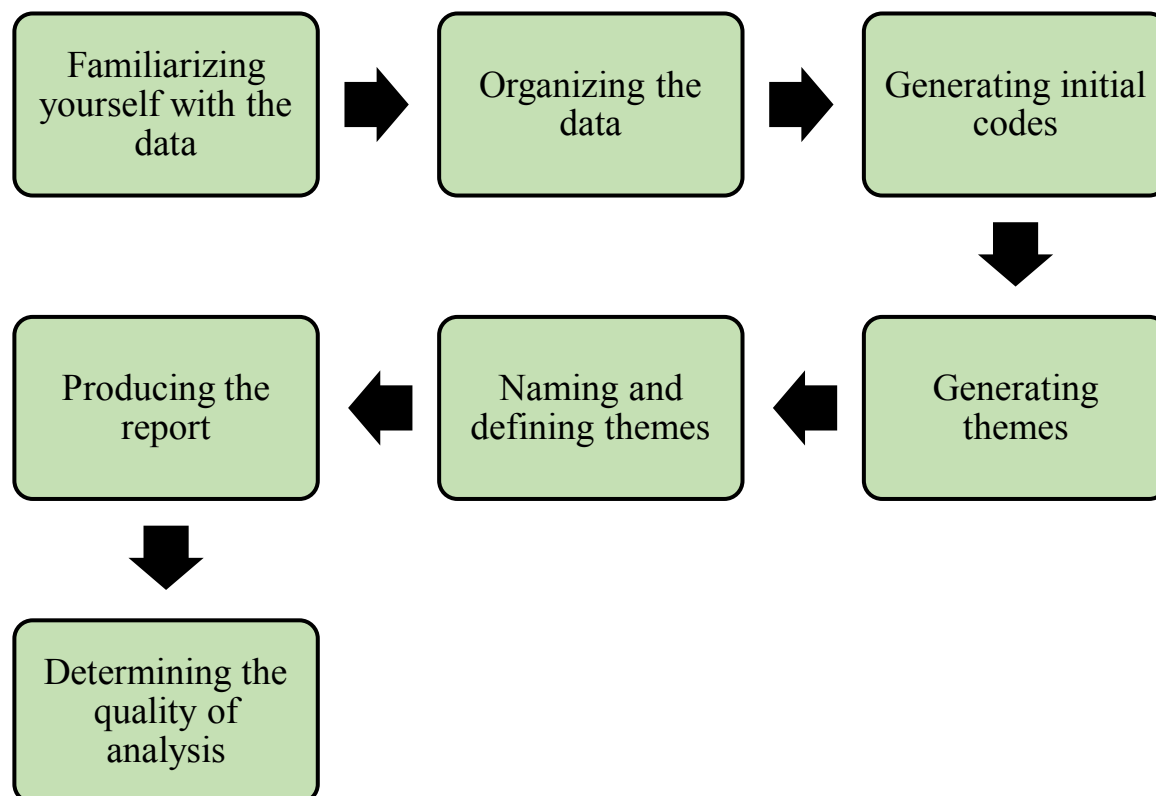
Thematic analysis constitutes a bottom-up (inductive), 'a posteriori' approach with themes being identified, analysed, and described from the interview data set⁽⁹⁸⁾. This process is thus "data-driven"⁽⁹⁸⁾, rather than relying on researcher's "analytic preconceptions"⁽⁹⁸⁾. A theme can be defined as a "recurrent and distinctive features of participants' accounts, characterizing particular perception, and/or experiences which the researcher sees as relevant to the research question"⁽⁹⁹⁾.

Two sets of thematic analysis, one for the patients and one for the carers, were performed on the qualitative data obtained during the patient and carer interviews.

⁹ Code of conduct for social researchers, which is widely adopted as a standard of research ethics by funding agencies in the social sciences.

The steps for thematic analysis as expressed in the literature^(98, 100) are represented in Figure 14.

Figure 14 – Steps for thematic analysis of the qualitative data



1. Familiarizing yourself with the data

Initially, the interviews were transcribed by the research student. The process of transcribing the interviews required the researcher to playback the audio recordings of the interviews and transform them into verbatim written form to include words as well as other non-verbal communications¹⁰ (e.g. their pauses and/or laughter). Though time consuming, transcription is crucial as it “informs the early stages of analysis, and will [help the researcher] develop a far more thorough understanding of the data”⁽⁹⁸⁾. The audio recordings were played back twice to ensure transcription accuracy.

Transcription was unavailable in some cases because some participants declined having the Dictaphone record their interviews. The data collected, therefore, was based on thorough note-taking during the interviews for each question, which included some verbatim quotations.

After all the participants’ data were written up, several readings of the data were carried out by the research student and two independent researchers. This allowed the researchers to develop familiarity with the data.

2. Organizing the data

After the interviews were transcribed and re-read, the participants’ various answers to each interview question were entered in Excel in chart form. This method of organization made the data more easily accessible, more visually pleasing⁽¹⁰⁰⁾, and

¹⁰ This could provide another source of meaning and interpretation of experiences than words alone.

made it easier not to overlook any details, allowing the researchers to go through every participant's responses to each of the questions without having to go back and forth between and through every transcript.

3. **Generating initial codes**

After having become familiarised with and having organised the data, the researchers began identifying extracts, either through annotation or highlighting, from the participants' responses that could be combined to reflect specific ideas, words, and patterns⁽⁹⁸⁾. These combinations of data extracts are called codes^(98, 100). "Codes identify a feature of the data (semantic content or latent) that appears interesting to the analyst, and refer to the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way regarding the phenomenon"⁽⁹⁸⁾.

4. **Generating themes**

After the data was collated and coded, the researchers compared and discussed codes, established coherent connections between them, and consequently categorised them within appropriate themes⁽⁹⁸⁾. Braun and Clarke (2006) state that "there should be clear and identifiable distinctions between themes"⁽⁹⁸⁾. It is important to note that frequency of a theme is not necessarily reflective of the "keyness"⁽⁹⁸⁾ of a theme, as some themes worth reporting might appear "in relatively little of the data set"⁽⁹⁸⁾. The inclusion and importance of themes in the analysis relies primarily on researcher judgment.

5. **Naming and defining themes**

After initial themes were generated, they were reviewed and kept, modified, or removed according to their "coherence, consistency, and distinctiveness"⁽⁹⁸⁾. Consequently, the themes were labelled and defined appropriately according to the codes within each. In some cases, subthemes emerged, which are single, significant elements within the main "overarching"⁽¹⁰⁰⁾ themes.

6. **Producing the report**

After the themes were generated, reviewed between the independent researchers, named, and defined, the research student was required to write a "coherent, logical, non-repetitive and interesting account of the story the data tell"⁽⁹⁸⁾. The research student ensured that enough data extracts were used to "demonstrate the prevalence of [each] theme... [and] capture the essence of the point [the researcher] is demonstrating"⁽⁹⁸⁾.

7. **Determining the quality of analysis**

Finally, the thematic analysis was checked against a 15-point checklist⁽⁹⁸⁾ of criteria for good thematic analysis which was produced by Braun and Clarke (2006; p. 96). This checklist has been reproduced below:

- 1) Transcription: The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for "accuracy".
- 2) Coding: Each data item has been given equal attention in the coding process.
- 3) Coding: Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive and comprehensive.
- 4) Coding: All relevant extracts for all each theme have been collated.
- 5) Coding: Themes have been checked against each other and back to the original data set.
- 6) Coding: Themes are internally coherent, consistent, and distinctive.

- 7) Analysis: Data have been analysed – interpreted, made sense of – rather than just paraphrased or described.
- 8) Analysis: Analysis and data match each other – the extracts illustrate the analytic claims.
- 9) Analysis: Analysis tells a convincing and well-organised story about the data and topic.
- 10) Analysis: A good balance between analytic narrative and illustrative extracts is provided.
- 11) Overall: Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly.
- 12) Written report: The assumptions about, and specific approach to, thematic analysis are clearly explicated.
- 13) Written report: There is a good fit between what you claim you do, and what you show you have done – i.e., described method and reported analysis are consistent.
- 14) Written report: The language and concepts used in the report are consistent with the epistemological position of the analysis.
- 15) Written report: The researcher is positioned as *active* in the research process; themes do not just ‘emerge’.

The qualitative analysis of the interviews was followed by the quantitative analysis of the data collected from the questionnaires and tests. Initially, descriptive statistics was completed for all the questionnaires using SPSS (v. 24) for Macintosh. Frequency analysis was then completed for all the questionnaires that had cut off scores and categorical measures. For the questionnaires that did not provide cut off scores and categorical measures, a single sample t-test using SPSS was completed to determine if a statistically significant difference existed between the mean score of the study sample for each questionnaire and the mean scores reported in the literature⁽¹⁰¹⁾. Despite the presence of standard deviations of the data samples in the literature, a single sample z-test was not used because the sample size is less than 30.

The four assumptions that were met before completing the single sample t-test were:

1. The dependent variables should be continuous⁽¹⁰¹⁾.
2. The data being compared must be independent⁽¹⁰¹⁾.
3. There should be no significant outliers⁽¹⁰¹⁾. This was determined using SPSS.
4. The dependent variables should be approximately normally distributed. This was determined by normality analysis of the data for each questionnaire using the Shapiro-Wilk test because the sample size < 2000 ⁽¹⁰²⁾.

Correlational analysis was then completed for the questionnaires of interest. Pearson Correlation test, which is used to “measure the strength and direction of an association that exists between two variables”⁽¹⁰³⁾, was used. The three assumptions that were met before completing the Pearson Correlation test were:

1. The dependent variables should be continuous⁽¹⁰³⁾.
2. There should be no significant outliers⁽¹⁰³⁾. This was determined using SPSS.
3. The dependent variables should be normally distributed⁽¹⁰³⁾. This was determined by normality analysis of the data for each questionnaire using the Shapiro-Wilk test.

Spearman’s Rho test, a “nonparametric measure of the strength and direction of association that exists between two variables”⁽¹⁰⁴⁾, was used for the non-normally distributed variables.

3.4.10.8 Rigour/quality of the qualitative component

There is plenty of debate regarding the scientific rigour associated with qualitative research and data analysis. Generally, quantitative research is considered more reliable and less biased than qualitative research, which is believed to lack generalizability^(3, 105).

1. Objectivity and subjectivity

Typically, research is deemed rigorous when it displays objectivity, which is linked to “truth and validity”⁽¹⁰⁶⁾. Objectivity suggests that research should be free of bias and researcher values, and this is achieved by maintaining distance between the researcher and the researched⁽¹⁰⁶⁾. This distance in qualitative research specifically may hinder the research process and consequently its quality⁽¹⁰⁶⁾. Building rapport and trust “based on a sense of shared understanding and empathy”⁽¹⁰⁶⁾ with the participants by engaging in conversation is essential. As discussed, making the participants feel safe and welcome in expressing their thoughts, feelings, and experiences is necessary as part of the qualitative research process. Expressing empathy for participants’ negative experiences was important in order to make them feel comfortable although one might argue that the limitations of “overidentifying” with the participants⁽¹⁰⁶⁾.

It is challenging to try and eliminate subjectivity in qualitative research as subjectivity allows the generation of rich, in-depth information, necessary for adequate qualitative analysis. For this reason, maintaining objectivity and eliminating subjectivity was not possible for this research. The only way the subjectivity was counteracted was by using a reflexive approach, which is discussed in more detail on page 125.

Furthermore, considering the philosophical and methodological perspectives assumed in this research, subjectivity is key to what is “real”, for purposes of this study.

2. Ensuring reliability of analysis

Ensuring the reliability of analysis consists of preserving thorough records of interviews and observations, and by writing the procedure of analysis in detail to guarantee retest reliability⁽¹⁰⁵⁾. As detailed in 3.3.10.7, transcripts were generated for the participants and the steps of the thematic analysis were outlined.

Moreover, multiple coding was used. Multiple coding, similar to “inter-rater reliability” in quantitative analysis, refers to having more than one independent researcher and cross checking the coding strategies and interpretation of the data between them⁽¹⁰⁷⁾. Mr. Fahed Hassan, a psychologist with experience in qualitative research and analysis, and Ms. Lynda Joeman, a sociologist with experience in qualitative research and analysis, both looked over the transcripts and followed the steps of thematic analysis. Any discrepancies were resolved between the reviewers.

3. Safeguarding validity

Safeguarding validity strategies involve triangulation and respondent validation^(105, 107). Triangulation refers to the use of more than one method of data collection to answer a research question^(105, 107). “Because no single research method can tap all dimensions of a complex research problem, it is often valuable to combine two or more methods, drawing conclusions from a synthesis of results”⁽³⁾. In this research, the use of triangulation is limited since the findings are mainly drawn from interviews. Nonetheless, some of the findings from the qualitative analysis were triangulated with

the appropriate quantitative results. This could increase the credibility of the findings, although some research suggests that that is not always the case⁽¹⁰⁸⁾. The results from triangulation could nevertheless provide directions for future research.

Respondent validation refers to reiterating the findings to participants to see if they agree that the accounts are accurate^(105, 107). One may argue that participants should have a voice in how they are being portrayed so that they are empowered to be involved in research. However, this research did not employ this strategy as using participants to agree or disagree with coding/analysis is not preferred as they could reject the accuracy of the analysis because it is socially undesirable or accepting the coding/analysis, though faulty, because it flatters them⁽⁹⁹⁾. This is very important to consider when discussing sensitive issues involving sexuality. These issues, however, are fairly diminished in this study by the anonymization of transcripts and analyses.

4. Reflexivity

The reflexive process in research practice is essential, whereby the researcher critically reflects on her own role during the development of the research questions, data collection, and data analysis^(96, 109). During these stages, the researcher's "values, beliefs, and life experiences need to be brought into conscious awareness if they are to facilitate rather than impede critical analysis"⁽¹⁰⁹⁾. Personal biases that might affect the research need also to be acknowledged⁽¹¹⁰⁾.

The researcher has had direct clinical experience, both while acquiring her psychology degree and during postgraduate training. The researcher had also familiarised herself with the issue of hypersexuality during her MSc in 2013. Even though during the MSc the researcher did not assess or interview the patients and carers herself, she learned the necessary approach to addressing the participants about this sensitive issue. The researcher has also undergone good clinical practice, research governance, emotional intelligence, and conflict resolution courses as part of the skills training associated with the research degree. This experience equipped the researcher to better the grasp the issue of hypersexuality and the appropriate, ethical way of interacting with these participants. This experience also allowed the researcher to play a visible, active, and interested role rather than the role of a disconnected observer⁽¹¹¹⁾, which is emphasized by psychology researchers.

It is important now for the reflexive process to acknowledge the power differentials between the researcher and participants at the different stages of the research process^(96, 112).

At the stage of data collection, the participants were more in power than the researcher. This is because the participants actually held the information required for the study, as well as the decision to share information or not and consent to taking part in the study or not^(112, 113). On the other hand, however, some participants may regard the researcher as the one possessing the control⁽¹¹⁴⁾, as she is the one deciding the questions, doing the questioning, and determining the course of the interview⁽¹¹²⁾. Furthermore, due to her psychology background, the researcher believed that some participants expected her to provide solutions to their negative experiences and feelings about hypersexuality; however, the researcher tried, to the best of her abilities, not to give them this impression⁽¹¹²⁾.

At the stage of data collection, the researcher had not previously met any of the

participants. However, the participants did learn as part of their familiarization with the research that the study was connected with the Urology Department where some of the patients were seen for their neurological disorders (as part of their routine clinical practice). The researcher tried to assure the participants of the independence of the study from the hospital department; however, it may be possible that some participants were influenced by this affiliation. For this reason, the researcher tried to establish rapport and trust with the participants, as well as provide a welcome environment in order to get them to better open up about their experiences and feel secure and comfortable in doing so. The researcher's background in psychology helped achieve this; the reflexive approach at this stage was adopted by taking a non-judgmental stance, respecting, paying close attention to, and giving importance to the participants' opinions, feelings, and experiences. The researcher also ensured the creation of an "informal and non-hierarchical environment" to provide the participants "a sense of intimacy and balance of power"⁽¹¹²⁾. This balance of power was also established when the researcher did not judge the participants on views separate from her own and when the researcher provided the participants with comprehensive information about the study⁽¹¹²⁾. The latter helped counteract the inequalities of knowledge; "the realities of the participants' lives coupled with their requests for help was addressed through a reciprocal process: the investigator obtained information from the participants and at the same time provided them with information"⁽⁹⁶⁾. The participants were also informed that the research depended on them and their contributions to it, which may have given them control and consequently a motivation to share necessary information.

Because of the researcher's background in psychology and her training in emotional intelligence, she knows how to read non-verbal cues and understands shifts in body language. In this regard, the researcher was able during data collection to internally acknowledge such changes and consequently alter the course of the interviews as deemed necessary in that moment. This may have resulted in variable interview quality across the dataset, although this was anticipated considering the nature of the research and the types of questions asked (e.g. frequency of masturbation). This variable quality of data was more evident in the patient group rather than carer group. A possible reason for this could be that the patients are the ones actually experiencing the hypersexuality, so the potential feelings of shame, guilt, and embarrassment may have caused them discomfort enough during the interview for the researcher to decide to modify questions, cut the questions short or move on to different ones. This, however, is solely based on researcher judgment and may thus have generated some research bias, although it was necessary in order to keep the research process running smoothly, without causing any upset.

Furthermore, the researcher is of different age, culture, and background than the participants. The researcher is decades younger than the participants in the study. Considering the presence of possible stigma surrounding sex in older age⁽¹¹⁵⁾, the participants may have felt more comfortable sharing their opinions, thoughts, feelings, and experiences with someone younger who might better understand than someone within their same age range. Contrary to this however, the different in age may have made some participants feel like the researcher is not 'mature' enough to understand their experience with hypersexuality and its impact. This was counteracted by telling the participants of years of experience with hypersexuality in patients with neurological disorders.

Moreover, the researcher was not from the same culture or background as the

participants. This could have enabled interaction with them since the researcher does not ‘run in their same circles’, which could have increased trustworthiness of the data and minimised bias. The difference in culture, however, may have made the participants feel like the researcher could not understand their sexual practices and that she would possibly make judgments based on her own culture and beliefs⁽¹¹²⁾, which was not the case. The researcher is an open-minded individual with an organic desire to bring the research on hypersexuality in neurological disorders to the forefront.

The researcher is a female, which may have made the male participants feel uncomfortable. This may have influenced their openness in answering the interview questions. The only way the researcher counteracted this was by informing all participants of her support for them and their experiences, no matter what they consisted of.

During the data analysis stage, the participants would have already provided the required information and, in doing so, would have transferred the power back to the researcher, who is then responsible for interpreting and disseminating the data as appropriate and as required by the process of thematic analysis⁽¹¹²⁾. Multiple coders of the data were used to try and minimise bias and increase credibility; however, data analysis may not have been completely free of bias because it relied in large part on the interpretation and judgment of the researcher. It definitely helped the research process that the researcher is fluent in English and, for the most part, was able to communicate easily with the participants¹¹.

Conclusively, the reflexive process undertaken by the researcher required acknowledgment of power and knowledge differentials, acknowledgement of the identity of the researcher without which the entire process would not be⁽¹⁰⁹⁾, and practicing accountability by “laying open for examination, or making visible, the research process in all its disorder”⁽¹⁰⁶⁾.

3.3.10.9 Data saturation

One of the most debated issues in qualitative interviewing and analysis is whether it is possible, or even desirable, to estimate the number of interviews to conduct prior to undertaking them and the number of interviews required to reach “saturation”. Saturation can be defined as the point researchers reach whereby more data would no longer be of benefit in answering the research questions^(3, 116). A study by Lee et al. (2002) suggests that studies using more than one method requires fewer participants⁽¹¹⁷⁾. Further, a paper by Baker and Edwards (2012) published by the National Centre for Research Methods reports a study that included 14 renowned social scientists and 5 early career researchers who were all asked the question “How many qualitative interviews is enough?”⁽¹¹⁸⁾. The consensus was generally that “it depends on the purpose of the research”⁽¹¹⁸⁾. Table 21 reports some of the answers.

Table 21 – “How many qualitative interviews is enough”: responses from paper by Baker and Edwards (2012)⁽¹¹⁸⁾

¹¹ This is where the importance of language comes in as assumed by the interpretivist-constructivist epistemological approach.

Expert	Response
Adler and Adler (p. 8)	12-60 interviews (mean = 30) Conducting too many interviews may not only be unnecessary and time consuming, but may also reduce the time given to the analysis of data consequently reducing the quality of the analysis
Becker (p. 15)	One interview may be enough to give a rich account of a unique event A few may be enough if the purpose is to highlight that an issue is more complex than previously thought
Bryman (p. 18)	>20 interviews for purely interview-based studies
Charmaz (p. 21) and Doucet (p. 25)	Depends on career stage of researcher, their analytical ambitions, and the community reviewing the study
Jenson (p. 39)	Depth and complexity of analysis matter more than sample size
Mason (p. 29)	Cautions against “knee-jerk reaction” that more interviews are always better

3.5 Findings

Part A

3.5.1 Prevalence

Of a total of 251 QUIP questionnaires circulated at ECH, only thirty-three were completed and returned within the planned six-month period. Ten of the thirty-three were returned to the researcher at the NHNN by mail, while the remainder ($n = 23$) of the questionnaires were collected from the hospital. In descending order, results showed that, of the thirty-three patients who completed the questionnaires, 12.22% expressed compulsive sexual behaviour, 12.22% expressed hobbyism, 6.06% expressed punding, 3.03% expressed compulsive gambling, 3.03% expressed compulsive buying, 3.03% expressed compulsive eating, 3.03% expressed medication use, and 0.00% expressed walkabout behaviour. These results are presented in Table 22.

Table 22 – Prevalence figures of impulse control disorders from Edgware Community Hospital

Behaviour		<i>n</i>	%
Compulsive gambling	Yes	1	3.03
	No	32	96.97
<i>Compulsive sexual behaviour</i>	Yes	4	12.12
	No	29	87.88
Compulsive buying	Yes	1	3.03
	No	32	96.97
Compulsive eating	Yes	1	3.03
	No	32	96.97
Hobbyism	Yes	4	12.12
	No	29	87.88
Punding	Yes	2	6.06
	No	31	93.94
Walkabout	Yes	0	0.00
	No	33	100.00
Medication use*	Yes	1	3.03
	No	32	96.97

*. Medication use can also be referred to as dopamine dysregulation syndrome.

The Parkinson's Lead at ECH informed the research team that a reason for the low number of QUIPs filled is that the patients were hesitant in completing the questionnaires, possibly because it required them to disclose private and sensitive information despite ensured anonymity.

Part B

3.5.2 Recruitment

3.5.2.1 Patients

From April 2015 to August 2017, a total of thirty-three patients with PD indicated hypersexuality as having been or still being an issue, twenty-eight of them from the NHNN, four from ECH, and one from Parkinson's UK.

After indicating hypersexuality during their clinical appointments, twenty-eight patients from the NHNN were initially informed about the study by their consultant neurologists or neuropsychologists. Twenty-seven of them initially agreed to participate and one refused because he believed it would be too embarrassing for him to take part. Of the twenty-seven patients who expressed interest, only eight were successfully recruited for the study. The remaining nineteen either did not attend on the scheduled assessment date, did not provide an exact date to partake, later declined participation after initially agreeing, or were deemed unsuitable due to having hyposexuality rather than hypersexuality. Several attempts were made by the research student and primary supervisor to contact these patients to no avail.

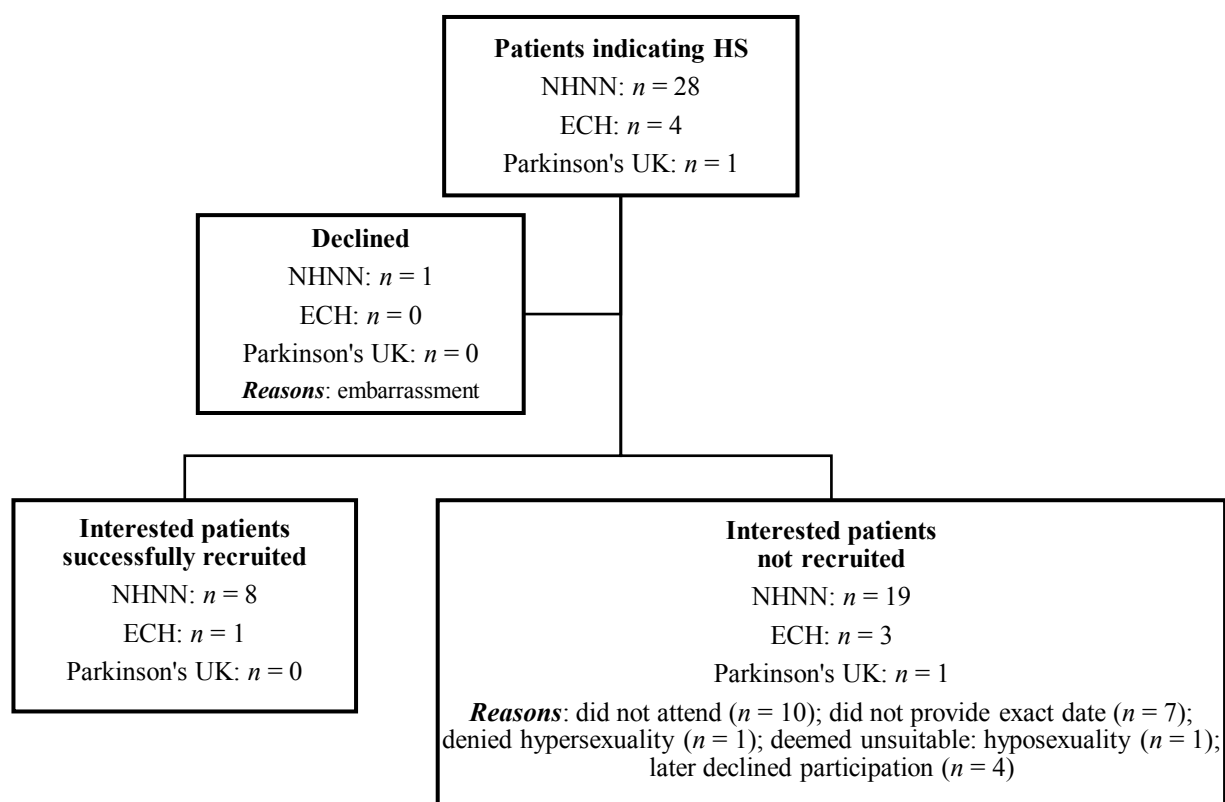
After leaving their contact details on the QUIP, as was requested if they were interested to take part in the study, four patients from ECH were contacted by the research student and informed about the study. Of the four patients who expressed interest, only one was successfully recruited for the study. The remaining three patients either later declined participation or later denied having hypersexuality. One of the patients refused because his wife was unhappy for him to take part. Several attempts were made to contact these patients to no avail.

After being contacted and provided verbal consent, the one patient from Parkinson's UK did not attend on the scheduled assessment date.

In total, nine PD patients took part in the study.

These results are summarised in Figure 15.

Figure 15 – Summary of recruitment results for Parkinson’s disease patients
 ECH: Edgware Community Hospital; HS: hypersexuality; NHNN: National Hospital for Neurology and Neurosurgery



3.5.2.2 Carers

From April 2015 to August 2017, a total of twelve carers indicated hypersexuality as having been or still being an issue, eight of whom were carers of patients with PD, four of whom were carers of patients with FTD, and none of whom were carers of patients with AD.

PD

After indicating hypersexuality during their spouses' clinical appointments, eight carers from the NHNN were initially informed about the study by their spouses' consultant neurologists or their neuropsychologists. Six of them initially agreed to participate and two declined because they believed it would be too embarrassing for them to take part. Of the six carers who expressed interest, only five were successfully recruited. The remaining carer later declined participation due to her worry that her spouse's reputation would be tarnished if people learned of his hypersexuality. Several attempts were made to contact this carer by the research student and assure her of the confidentiality of the study to no avail.

AD/FTD

After reading about the study in the periodical newsletter, three carers of patients with FTD and one carer of a patient with AD emailed the research student indicating their partners' hypersexuality. After being further informed about the study by the research student, all three carers of FTD patients were successfully recruited for the study while the only AD carer was

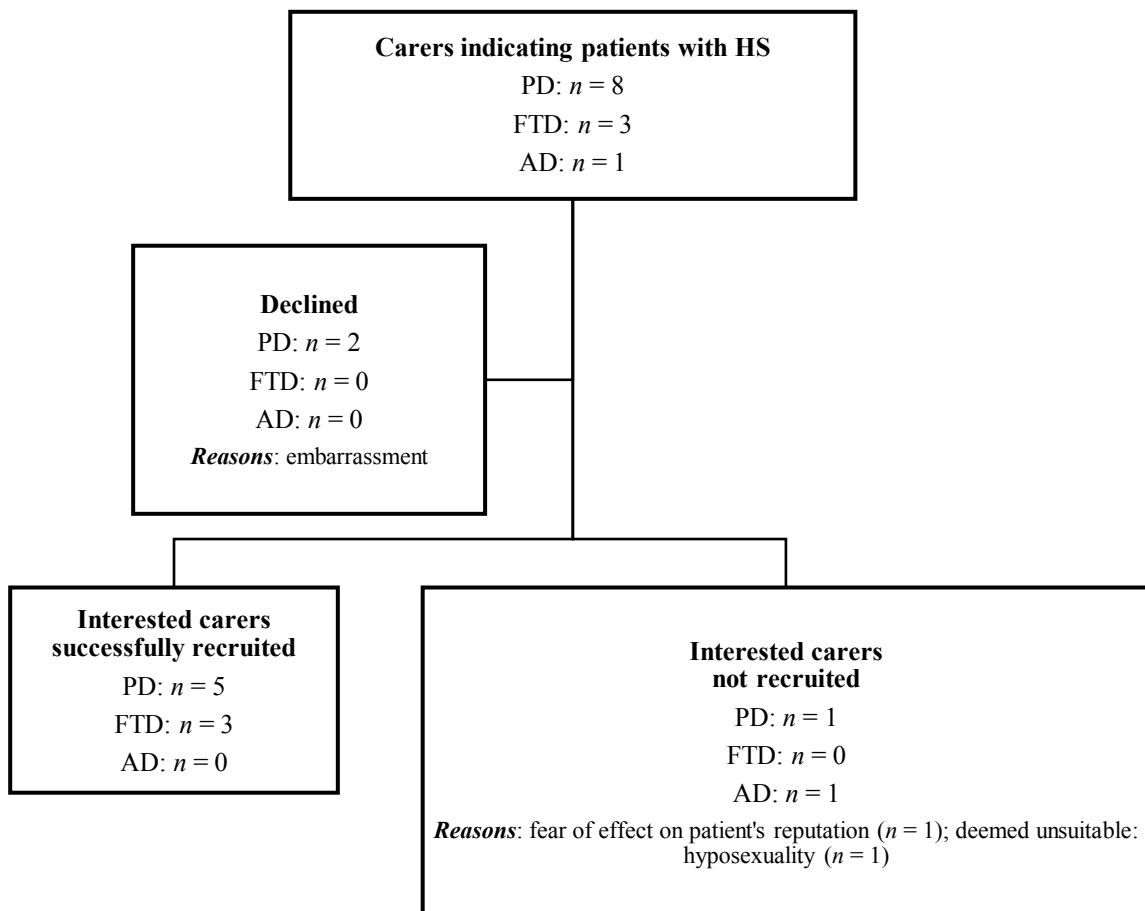
not because she was deemed unsuitable due to her spouse having hyposexuality rather than hypersexuality.

No carers were recruited from the FTDSG seminar.

In total, eight carers took part in the study.

These results are summarised in Figure 16.

Figure 16 – Summary of recruitment results for Parkinson’s disease and dementia carers
AD: Alzheimer’s disease; FTD: Frontotemporal dementia; HS: hypersexuality; PD: Parkinson’s disease



3.5.3 Sample descriptives

3.5.3.1 Patients ($n = 9$)

Patient sample descriptives are summarised in Table 23 (p. 135).

Gender and age

A total of nine patients with PD, six males and three females, participated in the study.

The patients' ages ranged from 44 to 78 years ($M = 62.56$; $SD = 10.96$).

The age of onset of PD ranged from 31 to 68 years ($M = 51.44$; $SD = 12.47$).

The age of onset of hypersexuality ranged from 35 to 68 years ($M = 54.11$; $SD = 11.47$).

Relationship status

Eight of the nine patients are in monogamous relationships and one is single.

Sexual orientation

Eight patients identified as being heterosexual and one patient identified as homosexual, which was altered by the hypersexuality.

Past sexual abuse

Three of the nine patients indicated having been sexually abused at an early age.

Past addictions/cognitive behavioural disorders

Eight patients indicated having no past addictions¹², while one indicated a past addiction of alcohol during her twenties which has since resolved.

No patients indicated past cognitive or behavioural disorders.

Pharmacology

Information was obtained from the patients' clinical notes about the medications they were on when the hypersexuality was first indicated in clinic.

Six patients indicated ropinirole as the medication most likely contributing to the hypersexuality, one indicated rotigotine, one indicated rasagiline, and the remaining two were unsure which medication but the first suspected Sinemet or selegiline and the second suspected Madopar.

Four patients had their implicated medication discontinued, with only one of them having the hypersexuality resolved since assessment. Two patients had their implicating medication reduced to no avail.

The remaining three patients did not have their implicating medication altered because they did not inform their clinicians of their hypersexuality and were thus still hypersexual.

DBS

Only two of the nine patients had STN DBS with one indicating that it exacerbated the hypersexuality symptoms and the other indicating that it reduced the hypersexuality symptoms.

¹² Prior to PD.

Symptoms of hypersexuality

The symptoms associated with hypersexuality were many, some of which were increased desire for sex, preoccupation with sex, change in sexual orientation, increased masturbation, and exhibitionism. These symptoms will be discussed in further detail in the thematic analysis section.

Impulse control disorders and other compulsive behaviours

Six of the nine patients indicated developing other impulse control disorders including compulsive gambling ($n = 1$), compulsive buying ($n = 4$), and compulsive eating ($n = 5$).

Six of the nine patients also indicated developing other compulsive behaviours which included constructing, exercising, constantly rearranging lounge, running, jumping, decluttering and tidying, and cleaning.

Consent to use of Dictaphone

Only two patients did not consent to having the Dictaphone audio record their interviews, while the remaining seven did consent.

Partner taking part in study

The partners of four of the eight patients who indicated having partners took part in the study. Of these four patients, three were assessed separately to their partners while one was not as per his request of wanting his spouse to be present during his assessment.

Completed full set of assessments

Seven patients completed all assessments required for the study while two did not, the first due to falling ill and the other due to extreme embarrassment.

Table 23 – Patient sample descriptives

Variable	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5	Patient 6	Patient 7	Patient 8	Patient 9
Gender	Male	Male	Male	Female	Female	Male	Female	Male	Male
Age (year)									
Onset of PD	31	37	68	52	58	42	54	56	65
Onset of hypersexuality	35	42	68	55	63	44	54	61	65
At assessment	44	47	78	58	69	66	66	68	67
In a relationship	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Sexual orientation	Homosexual	Heterosexual	Heterosexual	Heterosexual	Heterosexual	Heterosexual	Heterosexual	Heterosexual	Heterosexual
Past sexual abuse	Molested by uncle; aged 3	No	No	No	Inappropriately touched by tennis coach; aged 8-9	Inappropriately touched by stranger in local forest; aged 8	No	No	No
Past addictions	None	None	None	None	Alcohol	None	None	None	None
Past cognitive or behavioural disorders	None	None	None	None	None	None	None	None	None
Medications when hypersexuality first indicated in clinic*	Ropinirole Amantadine Fesoterodine Pregabalin	Ropinirole Amantadine Selegiline Madopar Stalevo	NA**	Stalevo Rotigotine patch Azilect Clonazepam	Ropinirole Rasagiline Entacapone Amantadine	Ropinirole Madopar Rasagiline Amantadine	Ropinirole Madopar Citalopram	Ropinirole Madopar Stalevo	Ropinirole Sinemet Escitalopram
Medications at the time of assessment	Stalevo Trihexyphenidyl Amantadine Clonazepam Detrusitol Fluoxetine	Stalevo Madopar Amantadine Selegiline Movicol	NA**	Stalevo Rotigotine patch Rasagiline	Ropinirole Stalevo Amantadine	Ropinirole Madopar Rasagiline Amantadine	Madopar Duloxetine	Ropinirole Madopar Stalevo	Ropinirole Sinemet
Patient perception of implicating medication	Ropinirole	Ropinirole	Unsure (Sinamet or Selegiline)	Rotigotine	Rasagiline	Ropinirole	Unsure (Ropinirole)	Ropinirole	Ropinirole
Implicating medication reduced/discontinued*	Yes discontinued	Yes discontinued	No	Yes reduced	Yes discontinued	No	Yes discontinued	No	Yes reduced

Hypersexual at assessment	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Currently hypersexual*	Yes (not as severe)	Yes	NA**	Yes	No	Yes	Yes	Yes	Yes
DBS*	No	Yes	No	No	No	Yes	No	No	No
Type	-	Bilateral STN	-	-	-	Bilateral STN	-	-	-
Consented to Dictaphone	Yes	No	Yes	Yes	Yes	Yes	No	Yes	Yes
Partner took part in study	No partner	Yes (Carer 2)	No	No	Yes (Carer 4)	No	Yes (Carer 3)	Yes (Carer 5)	No
Completed full set of assessments	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	No
Associated symptoms									
Sexual behaviour	Preoccupation with sex	Increased desire for sex with wife	Preoccupation with sex	Preoccupation with sex	Preoccupation with sex	Preoccupation with sex	Pornography	Increased masturbation	Increased desire for sex
	Increased desire for sex	Having sex more frequently	Increased desire for sex with girlfriend	Increased desire for sex	Increased desire for sex with husband	Increased desire for the female body	Insatiable desire for masturbation	Increased desire for sex with wife	Preoccupation with sex
	Change in sexual orientation	Increased masturbation	Having sex more frequently	Having sex more frequently	Having sex more frequently	Increased masturbation			Pornography
	Pornography	Pornography		Increased masturbation	Lust for therapist	Increasingly flirtatious with other women			Exhibitionism
	Having sex more frequently			Extramarital affair	Increased masturbation	Pornography			Massage parlors
	Prostitutes								Naturist clubs
	Promiscuity						Massage parlors		
	Bath houses						Extramarital affair		
	Saunas								
	Prostitutes								

Other impulse control disorders	Compulsive gambling	None	None	Compulsive buying	Compulsive eating	Compulsive eating	Compulsive eating	None	Compulsive eating
	Compulsive eating					Compulsive buying	Compulsive buying		
	Compulsive buying								
Other compulsive behaviours	Constructing	Listening to music	Cleaning the house	Running	Trying to put things right around the house	Playing music	None	None	None
	Exercising	Constantly rearranging lounge		Jumping	Working on anything that needed fixing	Painting			
		Redoing jobs that do not need doing		Decluttering and tidying the house					
				Planning unrealistic things					

DBS: deep brain stimulation; STN: subthalamic nucleus

*. Information obtained from patient's clinical notes.

** Information could not be obtained due to inability to access clinical notes at ECH.

3.5.3.2 *Carers (n = 8)*

Carer sample descriptives are summarised in Table 24 (p. 141).

PD (n = 5)*About carers***Gender and marital status**

A total of five carers of patients with PD, three females and two males, participated in the study.

They were all married spouses of the patients with hypersexuality.

Dictaphone

Three carers consented and two declined to having the Dictaphone audio record their interviews.

Partner taking part in study

The partners of four of the carers took part in the study while the remaining one did not because he is deceased. Although one of the carers was present during her partner's interview, as mentioned above, she requested her interview to take place privately.

Completed full set of assessments

All the carers completed all assessments required for the study.

*About patients***Age**

The age of onset of the patients' hypersexuality ranged from 42 to 73 years ($M = 59.40$; $SD = 11.84$).

Sexual orientation

All the patients were heterosexual with the sexual orientation of one changing because of hypersexuality.

Past sexual abuse

None of the patients were sexually abused.

Past addictions/cognitive behavioural disorders

Only one of the five patients had a past addiction of alcohol during her twenties which has since resolved.

None of the patients had any past cognitive or behavioural disorders.

Pharmacology

Three patients allegedly developed hypersexuality after using ropinirole, one developed hypersexuality after using entacapone, one developed hypersexuality after using rasagiline.

Four of the five patients had the implicated medication discontinued. Only one had the hypersexuality resolved, three remained hypersexual, and one has died.

The remaining patient did not have the implicated medication reduced or discontinued because the hypersexuality was never mentioned to the clinician.

DBS

Only one of the patients had DBS, which exacerbated his PD symptoms.

Symptoms hypersexuality

The symptoms associated with hypersexuality were many, some of which were increased desire for sex, preoccupation with sex, change in sexual orientation, increased masturbation, fetishism, visiting sex shops, and dating sites. These symptoms will be discussed in further detail in the thematic analysis section.

Impulse control disorders and other compulsive behaviours

Two of the five patients developed other impulse control disorders including compulsive eating ($n = 2$) and compulsive buying ($n = 1$).

Only one of the five patients, however, developed another compulsive behaviour, which was a desire to move.

FTD ($n = 3$)*About carers***Gender and marital status**

A total of three carers of patients with FTD, all of whom were females, participated in the study. They were all married spouses of the patients.

Dictaphone

All three carers consented to having the Dictaphone audio record their interviews.

Partner taking part in study

The partners of the carers did not take part in the study because dementia patients were not recruited.

Completed full set of assessments

All three carers completed all assessments required for the study.

*About patients***Age**

The age of onset of the patients' hypersexuality ranged from 56 to 69 years ($M = 62.67$; $SD = 6.51$).

Sexual orientation

All the patients were heterosexual.

Past sexual abuse

Only one of the three patients was sexually abused by his headmaster as a child in boarding school.

Past addictions/cognitive behavioural disorders

None of the patients had any past addictions or cognitive or behavioural disorders.

Status of hypersexuality

Two of the patients were still hypersexual while the remaining one was not because he is deceased.

Symptoms of hypersexuality

The symptoms associated with hypersexuality were many, some of which were increased desire for sex, preoccupation with sex, increased masturbation, dating sites, sex phone lines, engaging with prostitutes, developing deviant interests such as for cross-dressing children and transvestite sex. These symptoms will be discussed in further detail in the thematic analysis section.

Impulse control disorders and other compulsive behaviours

All three patients developed other impulse control disorders including compulsive eating ($n = 2$) and compulsive buying ($n = 2$).

Only one of the three patients, however, developed other compulsive behaviours including obsessively clock-watching and writing down the electricity and water meter readings.

Table 24 – Carer sample descriptives

Variable	Carer 1	Carer 2	Carer 3	Carer 4	Carer 5	Carer 6	Carer 7	Carer 8
Gender	Female	Female	Male	Male	Female	Female	Female	Female
Relationship to partner	Wife	Wife	Husband	Husband	Wife	Wife	Wife	Wife
Consented to Dictaphone	Yes	No	No	Yes	Yes	Yes	Yes	Yes
Partner took part in study*	Deceased	Yes (Patient 2)	Yes (Patient 7)	Yes (Patient 5)	Yes (Patient 8)	-	-	-
Completed all assessment	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Neurological disorder	PD	PD	PD	PD	PD	FTD	FTD	FTD
Age at onset of hypersexuality (year)	73	42	54	63	65	63	69	56
Sexual orientation	Heterosexual	Heterosexual	Heterosexual	Heterosexual	Heterosexual	Heterosexual	Heterosexual	Heterosexual
Past sexual abuse	No	No	No	No	No	Abused by headmaster	No	No
Past addictions	None	None	None	Alcohol	None	None	None	None
Past cognitive or behavioural disorders	None	None	None	None	None	None	None	None
Medications at the time of hypersexuality**	Stalevo Rasagiline Clonazepam Fludrocortisone Movicol Atropine	Ropinirole Amantadine Selegiline Madopar Stalevo	Ropinirole Madopar Citalopram	Ropinirole Rasagiline Entacapone Amantadine	Ropinirole Madopar Stalevo	-	-	-
Implicating medications**	Stalevo	Ropinirole	Unsure (Ropinirole)	Rasagiline	Ropinirole	-	-	-

Implicating medication reduced or discontinued**	Yes discontinued	Yes discontinued	Yes discontinued	Yes discontinued	No	-	-	-
Still hypersexual ⁺	Deceased	Yes	Yes	No	Yes	Deceased	Yes	Yes
DBS*	No	Yes	No	No	No	-	-	-
Type	-	Bilateral STN	-	-	-	-	-	-
Associated symptoms								
Sexual behaviour	Preoccupation with sex	Preoccupation with sex	Preoccupation with sex	Increased desire for sex with husband	Preoccupation with sex	Preoccupation with sex	Preoccupation with sex	Preoccupation with sex
	Increased desire for sex generally	Increased desire for sex with wife and generally	Increased desire for sex with husband and generally	Having sex more frequently	Increased desire for sex with wife and generally	Increased desire for sex generally	Increased desire for sex with wife and generally	Increased desire for sex generally
	Change in sexual orientation	Having sex more frequently	Having sex more frequently	Sexual attraction for therapist	Increased masturbation	Pornography	Having sex more frequently	Increased masturbation
	Uncontrollable masturbation	Increased masturbation	Insatiable desire for masturbation	Having sex on stairs	Pornography	Dating sites	Increased masturbation	Pornography
	Pornography	Pornography		Hint of S&M	Sex phone line	Massage parlors		Deviant interests
	Sex phone lines	Fetishism		Pornography	Dating sites	Prostitutes		Fantasies of dressing in women's underwear
	Sex channels							
	Visiting sex shops							

Other impulse control disorders	None	Compulsive eating	None	Compulsive eating	None	Compulsive buying	Compulsive eating	Compulsive eating
		Compulsive buying						Compulsive buying
Other compulsive behaviours	None	None	None	Desire to move	None	None	None	Clock-watching
								Writing down electricity and water readings

DBS: deep brain stimulation; FTD: frontotemporal dementia; PD: Parkinson's disease; STN: subthalamic nucleus

*. There is no data available for the respective variables for Carers 5, 6, and 7 criteria only applicable to PD patients.

+. Information obtained from patient's clinical notes.

3.5.4 Qualitative thematic analysis

Based upon the methods of qualitative data analysis outlined in the methodology section (p. 120-123), several themes emerged from the interview data for the patients and carers.

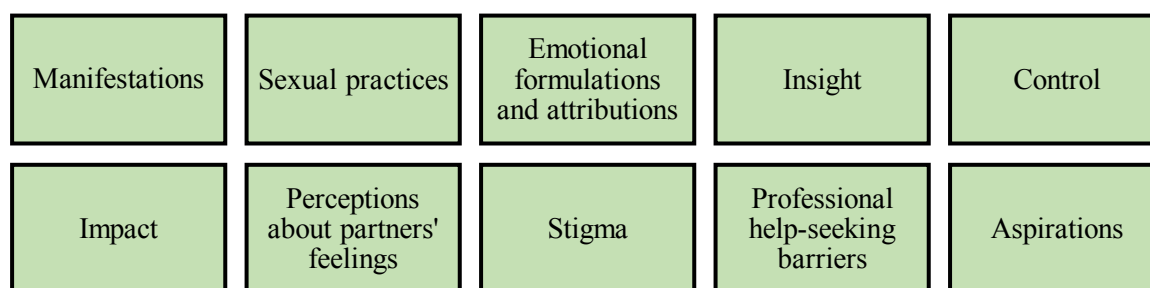
Two separate sets of detailed qualitative analysis were conducted, one for the patients and one for the carers.

It is important to note that the themes are not mutually exclusive and, although presented and analysed separately, are interconnected as they investigate the same phenomenon. Some notions may thus overlap between different themes.

3.5.4.1. Patients

The themes that were analysed for the patients are reported in Figure 17.

Figure 17 – Emergent themes analysed for Parkinson’s disease patients



Theme 1: Manifestations

The qualitative findings revealed that hypersexuality did not manifest in the same way among all patients, although there were also some commonalities between them. Several key sub-themes were identified from the data relating to the ways in which hypersexuality manifested among this sample of patients.

1.1 Cognitions

Cognitions pertaining to hypersexuality included patients’ thoughts about sex, image about the other, sexual desires, and self-image.

A common factor reported by almost all the patients was a marked increase in thinking about sex or doing so recurrently since developing the condition of hypersexuality. Seven of the research participants indicated that they had experienced this, with several reporting that thoughts about sex were constantly on their mind or felt obsessive to them. For example, Patient 1 explained that sex was on his mind “*all the time*”, while others also described recurrent or obsessive thoughts about sex:

“It’s a recurrent thing that you think about ... on the way to work this morning I was thinking ‘I could go to my naturist place tomorrow at three o’clock and should I tell my wife where I’m going?’ ...” (Patient 9)

“I wanted a lot of sex... I was thinking regularly about sex ... I mean every day I could’ve had sex...” (Patient 5)

Whether or not they reported thinking constantly about sex, all of the participants indicated that they had experienced an increased desire for frequency of sexual acts and increases in desire for other people

following the development of their hypersexuality. However, the specific ways in which this manifested varied considerably between the research participants. Four reported developing an increased desire towards their existing partners, with one noting a specific desire for his wife when she dressed up, for example, in sexy lingerie.

“I just had more of a desire for my wife and it continues... I quite like the idea of dressing up my wife... dressing in...” (Interviewer: “Lingerie?”) “Yeah... and whatever...” (Patient 8)

For one female patient her initial increased desire for her husband was accompanied, however, by the development of romantic feelings for her therapist which detracted somewhat from her intensified desire for her spouse.

“I was in love with my therapist... he was... you know... he was a focus of mine... not that we had an affair or anything... but I mean I was in love with him...” (Patient 5)

Others reported experiencing a more general increase in desire for other people of the opposite sex in general or, in the case Patient 1 who identified as homosexual, an increased desire for males and females alike. For three of the participants, new types of feelings about others were experienced following the onset of hypersexuality. Patient 2 explained that he increasingly noticed other women although never actively looked for anyone besides his wife, while Patient 5, who had developed an attraction to her therapist, claimed that this would never normally happen to her. Patient 6 developed a general adoration for the female form and felt like *“anybody was a [sexual] challenge”* for him.

The increase in sexual desired manifested in different ways for two of the participants: Patient 7 indicated that he had developed an increased desire for masturbation, while Patient 9 developed a desire for exhibitionism and visiting massage parlours. Both of these individuals along with Patient 5 reported that their sexual desires had become extremely strong and almost insatiable. Patient 9, for example, described having to *“fight”* himself at one point to resist the urge of going into the massage parlour.

“I find that I can’t get enough you know... there is no satisfaction...” (Patient 5)

“The more I did it the more I wanted it...” (Patient 7)

Just two of the patients (1 and 2) described an increased awareness of self-image and the sensation of being desired by others. While Patient 2, however, expressed his surprise at how many women find him more attractive than he thinks he is, Patient 1 appeared much more self-confident about his own sexual attractiveness:

“Us Arabs quite wanted... if you have certain look... certain thing... you know... rugged... manly... masculine... everybody all over you... when we go out... I mean I dress up nice... I dress smart... when we go out with a group of friends seems I’m the only one... mostly I’m the only one that gets the attention of all...” (Patient 1)

1.2 Behaviours

Noticeably, hypersexuality either caused changes in pre-existing behaviour or the development of different, unusual, and risk-taking behaviour. Almost all the patients indicated an increase or intensification of pre-existing behaviour after the onset of their hypersexuality, whether this consisted of sexual activity with others or, in the case of Patient 7, a greatly increased frequency of masturbation which she viewed as unusual. Five of the patients just reported that they were having sex more frequently. Three

explained that while they had always had a high sex drive or enjoyed being adventurous in their sexual activities, their previous affinity to sex had intensified following the development of hypersexuality.

“I think I’ve always been highly sexual and I’ve always had girlfriends... apart from when I was married... I’ve always had a high sex drive...” (Patient 3)

“Always been highly sexed... but more intense now...” (Patient 8)

Hypersexuality also caused unusual, different, and risky behaviours to develop for some of the participants. When asked if there has been anything unusual about their sexual behaviour since getting PD, about half of the patients agreed that this was the case. In one of the most extreme forms of new risky behaviours, Patient 1, who had identified as a homosexual his entire life and had formerly been in an eight-year monogamous relationship with a man, recalled being in a “hyper” state with a newly-developed unusual sexual interest in women and call girls, as well as an unusual increased desire for sex with men. He recounted spending six hours a day in gay bath houses and saunas, sleeping with up to fourteen to fifteen strange men a day. This patient also admitted having been careless and indiscriminate about his sexual pursuits and having had multiple sexual partners at once without asking about the status of HIV and other sexually transmitted diseases. Like Patient 6 who also reported visiting massage parlours, Patient 1 admitted to paying a lot of money for sex, something he did not do before the onset of his hypersexuality.

Patient 9 also spent considerable time on “happy endings” in massage parlours, as well as developing other new unusual behaviours. He was the only patient who developed paraphilic behaviours after developing hypersexuality:

“I’m interested in things that I was never interested in before... exhibitionism... one day I took all my clothes off and lay down in the garden... and since then... I have been to a few nude beaches... and then... I started thinking ‘I wonder what these massage parlours are like’... so I had to fight with myself... I went in... you get a proper massage if you choose somebody carefully... and then they have this formula... they say ‘Would you like any extras?’ and one day I said yes... I also go sometimes to this naturist club...” (Patient 9)

Two of the married patients (4 and 6) reported having had extramarital affairs since the onset of their hypersexuality. Apart from being newly-developed and different forms of behaviour, these may also be considered risky due to potential repercussions on existing marriages. For one, this was in the context of becoming unusually and increasingly flirtatious with women other than his wife, a behaviour that was not present prior to the hypersexuality. For Patient 5, although her behaviour never culminated in an affair, she did admit feeling like she was in love with her therapist, which she eventually realised was probably more “lust” than love.

1.3 Preoccupation¹³

Preoccupation can be defined as excessively thinking about something to the extent where it affects daily living⁽¹¹⁹⁾. Most of the patients indicated being preoccupied with sex, which was evident in their lack of adherence to other commitments, obsessive thoughts about sex, and the mental effort that they placed into planning for upcoming sexual endeavours. In total, six of the nine patients reported specific ways in which their preoccupation with sex was affecting their daily lives.

¹³ It can be argued that Preoccupation can be placed within the “Cognitions” subtheme; however, it was purposefully listed and analysed separately to highlight its saliency.

For example, Patient 6's preoccupation with sex caused him to spend up to three hours a day thinking about sex, stay up late thinking about it, as well as planning next trips to the massage parlour. He explained that his hypersexuality is a constant cycle with many highs and lows; when he was at the peak of the cycle, his hypersexuality was at its highest and greatly affected his daily life.

Others also reported ways in which their preoccupation with sex affected their ability to carry out their everyday tasks or led them to neglect aspects of their life such as friends or even their marital relationship, as in the case of Patient 5 whose therapist became the focus of her attention rather than her husband. Patient 1's preoccupation with sex negatively affected his concentration and efficiency at work, while Patient 3's excessive thoughts about sex and his girlfriend impeded his ability to finish jobs around the house and caused him to stay home and neglect his social life, because he preferred staying home and thinking about sex.

"I was never late but the thing is the quality of my work..." (Patient 1)

It affects my social life because I'm always thinking about it... I choose to stay at home..."
(Patient 3)

1.4 Compulsivity¹⁴

Compulsive behaviour can be defined as behaviour that is done repetitively and persistently⁽¹²⁰⁾. Preoccupation with sex evidently translated into actual compulsive behaviour as was the case for Patients 1, 6, 7, and 9, who all identified compulsivity.

For three patients, this took form in frequent visits to establishments such as massage parlours, bath houses, saunas, or naturist clubs. While two frequented these for the purpose of sexual massages (Patients 6 and 9), one homosexual participant (Patient 1) explained that his visits could take up to six hours of his day and often involved having sex with multiple men at once:

"I sleep five o'clock in the afternoon... that's when I come back from... sex... I sleep five in the evening... I wake up twelve in the midnight and put on my jacket and go back..." (Patient 1)

Another form of compulsive sexual behaviour reported by one participant was very frequent masturbation (Patient 7).

In the case of the remaining participants, some did not associate compulsivity with themselves yet some of the behaviours they discussed do suggest that this may be present. For example, Patient 3 explained that he had sex with his girlfriend every time he saw her, and Patient 5 described that after developing hypersexuality she was driven to have sex with her husband every day, though she stressed that she wasn't *"doing it all day long"*. These patients' lack of awareness of their compulsive tendencies may reflect a lack of personal insight into their own condition.

1.5 Emotional triggers

Most of the patients believed there were no specific feelings triggering their hypersexuality. However, three of the participants (1, 6, and 7) did indicate that various types of negative emotions did seem to act as triggers. These included, for example, sadness, depression, loneliness, anger, frustration and "OFF" states in PD.

¹⁴ It can be argued that Compulsivity can be placed within the "Behaviours" subtheme; however, it was purposefully listed and analysed separately to highlight its saliency.

“I’m not sure what it is... it’s probably frustration... anger...” (Patient 6)

“I would say when I’m depressed... when I’m sad... when I have no one to talk to...” (Patient 1)

Theme 2: Sexual practices

The patients’ hypersexuality manifested in increased urges which, for the most part, translated into different types of sexual practices. The various sexual practices that emerged from the interview data included patients’ practices with their partners, with themselves, with others, and deviant sexual practices.

2.1 Practices with the partner

The data revealed that an increased desire for sex due to hypersexuality did not necessarily mean an increased frequency of sex with the patient’s partner. On the contrary, most of the patients indicated either a decreased or similar frequency of sex with their partner as compared to the frequency prior to developing hypersexuality, while just three reported an increased frequency of sex with their partner.

In the case of the three patients (2, 3 and 5) who reported increased frequency of sex with partner, one of these had only experienced this with an ex-partner who had since passed away. This participant (Patient 3) had a new partner at the time of their interview and claimed there was no difference with his current partner. However, this level of sexual activity was already very high; he explained that they have sex every time they see each other, which could add up to two to four times a week, so there was little scope for increased frequency.

Of the remaining two patients who reported increased frequency of sex with their partner, one (Patient 2) explained that this had eventually tapered off due to tension in his relationship with his wife, while in contrast the other indicated that a high level of sexual activity had continued with her willing participant husband, including watching pornography together (Patient 5).

For two female patients, frequency of sexual activity with their partner had stayed much the same as before the development of their condition. For patient 4, this was relatively infrequent at about once a month. She claimed that she did not approach her husband for sex because she *“cannot be bothered”*. This is possibly due to their admitted lack of communication. The other participant (Patient 7) who indicated that the level of sexual activity had remained similar to before the onset of her hypersexuality, at around 2 or 3 times a week, indicated that she and her husband had deliberately *“tried not to let there be a difference”* in their sexual relationship.

Four participants (2, 6, 8, and 9) reported that the frequency of sexual practices with their partner had actually decreased since the onset of their condition. For some this appeared to be due to tensions or unhappiness in the relationship which arose at least in part as a result of this condition.

For example, although they were having more sex initially, the built-up tension in Patient 2’s relationship with his wife eventually caused a significant decrease in their frequency of sex, from three times a week to once every seven to ten days at time of assessment, a decline shared by another of the patients. Two others (6 and 9) reported having almost no sex with their partner; one reported that it had started its decline since he was diagnosed with PD and also as a result of having children, both of which he believed had *“changed”* his wife and her attitude towards sex (Patient 6).

2.1 Practices with themselves

Sexual practices with oneself include the act of masturbation and use of pornographic materials. There was a wide variation among the research participants in the extent to which masturbation was reportedly being

used as a sexual activity. The two patients who reported that they rarely or never masturbated were those who were indulging in quite promiscuous and risky sexual behaviours and therefore expressed the view that they had no need to pleasure themselves.

“I’ve stopped that... I find it a bit boring now... but as I say it’s all of ordinary people doing ordinary things... so after a while you think... it’s not very exciting...” (Patient 9)

In contrast, Patient 7’s hypersexuality seemed to have manifested solely in an increase in masturbation, which she was indulging in up to ten times a day. She claimed that *“the more [she] did it, the more [she] wanted it... [and] had to stop to get work done...”*. Although this patient claimed that the *“sense of release excites [her]”*, she also reported that she did not feel satisfied from masturbating because it made her want it more.

Patient 5, who chose to masturbate several times a week, similarly said that this did not leave her feeling fully satisfied. In the case of this patient, however, she may not have felt satisfied when masturbating because she was also engaging in regular sex with her husband. Patient 8, who reported that they had tried masturbating occasionally, perhaps because of a lack of intimacy or relationship difficulties with his wife, also indicated that this activity provided him with little satisfaction.

In contrast, three of the research participants (2, 4, and 6), who both reported that they chose to masturbate regularly did express a sense of satisfaction from this activity. In each case, this may have been associated with the reported decrease in sexual activity with their partner, and the use of masturbation as a substitute. For example, Patient 6 reported being impotent but achieving satisfaction from masturbation.

Five patients (1, 2, 6, 7, and 9) indicated using pornographic material as part of their sexual practices, with most having developed or increased the use of this activity following the onset of their hypersexuality. Patient 1 specified that, after developing hypersexuality, he was unusually preferring to watch heterosexual rather than homosexual porn.

2.3 Practices with others

This sub-theme is defined as sexual practices with people other than one’s regular partner, such as general promiscuity, anonymous sexual encounters, paying for sex, and extramarital affairs.

These were not found to be commonly used forms of sexual activity among this sample of patients with hypersexuality. At least seven of the participants did not report engaging in any form of promiscuous sexual behaviour. Only one of the participants reported regularly engaging in promiscuous behaviour; Patient 1’s hypersexuality caused him to be promiscuous and consequently have multiple anonymous sexual encounters, and also described paying for sex from call girls whose profile ads show up online. This patient, who claimed that sex was on his mind *“all the time”*, admitted also that he was constantly looking for it on online applications such as Grindr.

Although Patient 9 did not directly indicate promiscuity, he identified anonymous sexual encounters by frequenting massage parlours for *“happy endings”*:

“You have to understand... bath houses and sauna... in certain days you get like place full with at least two hundred and... us Arabs quite wanted... everybody all over you... I started to have sex with fourteen... fifteen person a day...” (Patient 1)

“There’s something terribly alluring about you walk into this little room with somebody you’ve never seen before and you take off all your clothes and you lie down flat and she rubs your body... I mean for God’s sake... that’s a pretty exciting sexual thing...” (Patient 9)

Another of the participants reported more occasional promiscuous behaviour, describing the way in which behaviour such as paying for sex at massage parlours (referring to it as *“buying stuff”*) was triggered by something in particular:

“Something will set it off like an image or something like that... it goes up and reaches a point where I might be buying stuff and then it crashes down...” (Patient 6)

Just two of the participants admitted to having extra-marital affairs. Patient 6 had an affair which was not sexual in nature, but an emotional relationship with another PD patient which had ended because he loved his wife, who guessed he was having an affair. One other patient, a woman, also admitted to an extra-marital affair, which she described as being purely sexual in nature and which she claimed had ended. However, participating in affairs was evidently not a widespread practice among the hypersexual patients in this sample who were married or with regular partners.

2.4 Deviant practices

Deviant sexual practices included paraphilic behaviours. Hypersexuality did not necessarily translate into paraphilic behaviour as one patient indicated exhibitionism, which can be defined as the act of showing one’s genitals in public:

“I suddenly... it wasn’t really a change in sexuality... it was in exhibitionism... so one day I took all my clothes off and lay down in the garden... my wife came out and said ‘What are you doing? The neighbours can see’...” (Patient 9)

Theme 3: Emotional formulations and attributions

Just as hypersexuality manifested differently in different patients, it also caused patients to develop different emotional formulations and attributions about it. Evidently, if the hypersexuality was internalised, patients tended to develop negative feelings about it. If the hypersexuality was externalised, patients appeared to develop neutral feelings about it. If the hypersexuality was neither internalised nor externalised, patients appeared to develop positive feelings about it.

3.1 Internalization of hypersexuality and negative feelings

Internalization can be defined as the integration of attitudes, values, standards, and opinions of others into one’s own identity and sense of self⁽¹²¹⁾. It refers to an internal locus of control where patients blame the development of their behaviours on themselves. Internalization does not insinuate that the patients have a lack of understanding about what has caused the hypersexuality, but rather the process by which the patients integrate the hypersexuality into their lives.

Among this sample of patients, it appeared that three of the participants (1, 6, and 7) had internalised their hypersexuality and also expressed negative feelings about the condition. The apparent reasons for internalizing their condition varied however. In the case of Patient 1, who claimed to feel depressed and “on the edge” all the time due to his hypersexuality, internalization of the issue had apparently first been instigated by his doctor’s initial unhelpful and negative reaction to it.

“The doctor’s reaction ... got me really depressed because I didn’t get an answer for any of my worries... about my body I felt like I ... haven’t been believed... and I started to reflect on my

personality. I used to say... I'm just [a] horrible person because I'm doing things no... nobody is doing and I always used to push it back on myself... (Patient 1)

In a contrasting situation, Patient 7 had clearly internalised the opinions of the strict Jewish household she grew up in. She was told she was “dirty” for masturbating and thus couldn’t help but feel “ashamed” after her masturbation intensified. Finally, Patient 6 felt “rough” and unhappy with his hypersexuality. He evidently internalised his wife’s unhappiness with his hypersexuality as he stressed that he loved her and did not like her being upset.

3.2 Externalization of hypersexuality and neutral feelings

Externalization can be defined as the projection of one’s characteristics onto the outside world and onto other people⁽¹²²⁾ and refers to an external locus of control. In this case, patients who externalise hypersexuality feel less responsible for it and regard it as a problem stemming from external determinants. Although they share similar attributes, externalization is not the same as knowing the causes of hypersexuality. Externalization refers to the patient’s process of understanding the hypersexuality and integrating it into their lives.

Three of the patients (2, 8, and 9), who seemed to have externalised their hypersexuality in this way, appeared to have more neutral findings about it. For example, Patient 2 claimed that his hypersexuality never felt unnatural to him. He attributed his hypersexuality to the sexual disparity he claims was always present with in his relationship with his wife, claiming that “*she is on one side of sex average and [he is] on the other*” and he just wanted to explore sexual options more than she did.

Patient 9, on the other hand, claimed his hypersexuality made him feel “surprised”. He seemingly attributed his hypersexuality to the “chemistry” of Ropinirole and his body’s need for it:

“I tried coming off the Ropinirole about three to four weeks ago... and it was unbearable... the Parkinson’s just suddenly kicked in and I wasn’t used to it... but I want it back to where it was... I’d rather be hypersexual than slightly weird... it’s better than the alternative ... if somebody can put me back on Ropinirole I’d take whatever comes... I’m addicted to Ropinirole it seems...”
(Patient 9)

Both Patients 2 and 9 attributed their hypersexuality to being “men”, viewing this as a normal male trait rather than something affecting them more specifically as individuals because of their health conditions or medications.

“When defined hypersexuality means outside the norm of the human race... so as a man I don’t see a problem...” (Patient 2)

“Men think about sex a lot... most men think about sex much of the time and hundreds of times more than women do... have you seen the statistics for the number of men who watch pornography on a regular basis?... it’s something like sixty-eight percent...” (Patient 9)

Patient 8 also regarded his hypersexuality as normal. He attributed it to his wife going through menopause, which he believed decreased her desire for sex and consequently made him seem hypersexual.

3.3 No internalization or externalization of hypersexuality and positive feelings

As mentioned above, patients who neither internalised nor externalised their hypersexuality appeared to develop positive feelings about it. In the case of this sample, three patients (3, 4 and 5) fell into this category, and reported feelings of happiness associated with their hypersexuality. For example, Patient 3

reported feeling “happy”, “satisfied” and “comfortable with it”, while Patient 4 described feeling a “kind of high” as a result of her condition.

Theme 4: Insight

Insight can be defined as an individual’s ability to understand a phenomenon accurately and thoroughly⁽¹²³⁾. In the case of hypersexuality, patients who have insight must first acknowledge the presence of the problem, understand that their hypersexuality is unnatural, have some awareness with regards to what has caused it, and have a true desire to overcome the problem⁽¹²³⁾. Data emerged from the interviews relating to each of these issues, which were therefore identified as the subthemes relevant to patient insights about hypersexuality.

4.1 Acknowledging the presence of the problem

When asked if they had experienced an increase in sexual behaviour or thoughts since developing PD, all the patients indicated that they had. This signified awareness of the change in their sexual demeanour; however, it did not mean that all the patients regarded their hypersexuality as a *problem*. As discussed in Theme 3, some patients developed either neutral or positive formulations around their hypersexuality, suggesting that they did not regard it as a *problem* but rather a normal or newly-acquired aspect in their lives. The patients who developed negative formulations, however, typically regarded hypersexuality as a problem because it caused them negative feelings.

4.2 Recognizing hypersexuality as natural or unnatural

More than half of the sample of patients ($n = 6$) expressed the belief that their hypersexuality was a natural condition. Some (2, 3, 4, and 8) indicated that this matched their personal values and beliefs and therefore felt normal and not unusual to them. Patients 5 and 9 also expressed views which demonstrated that they were generally comfortable with their hypersexuality and even regretted not being more sexually active before the onset of their condition:

“I think it’s fine in a way having that much... I mean I... it makes me in a way... discontented... like I should have had more sex in my life...” (Patient 5)

“One day I took all my clothes off and lay down in the garden... my wife came out and said ‘What are you doing? The neighbours can see’... and since then my wife and I have been to a few nude beaches... this is all harmless stuff but it’s... especially... you know my wife and I up to this point have been boringly straight... normal... straight... and not interested in anything unusual...”
(Patient 9)

The remaining three patients (1, 6, and 7), however, expressed views indicating a belief that hypersexuality was unnatural, mainly because it apparently conflicted with their personal values and beliefs. Patient 7, in particular, indicated that she believed her hypersexuality was unnatural and did not match her personal beliefs and values, even though her masturbation behaviour had been part of her life since she was four years old. She claimed her behaviour had become excessive and uncontrollable since developing PD and taking dopaminergic medication. Likewise, Patient 1 believed that his hypersexuality was “*too much*” for him, while Patient 6 indicated that the condition was not aligned with his personal beliefs and values, as it was causing his wife unhappiness.

4.3 Beliefs about causes of the problem

Whether or not they regarded their own hypersexuality as a natural or unnatural condition, all of the patients expressed the belief that the condition had been primarily influenced by the dopaminergic

medication used to manage their PD. The main form of medication believed to have caused hypersexuality was Ropinirole, cited as such by more than half the sample (Patients 1, 2, 6, 8, and 9).

“I take it like every hour... every two hours because I can see it numbing my... [PD symptoms] ... but while it’s numbing my... it’s getting me so hyper...” (Patient 1)

“I was on Ropinirole ... gave me a buzz... good stuff... used to take it and it would give me an erection...” (Patient 6)

Patient 2 believed the DBS further exacerbated his perceived Ropinirole-induced hypersexuality, while Patient 6 believed his DBS helped in reducing it.

Two of the patients (4 and 5) attributed their hypersexuality to other forms of medication used to manage their PD, such as Rasagiline or Rotigotine patches. The remaining two patients (3 and 7) were less certain as to which medication contributed to their hypersexuality, but expressed the suspicion that this might be the Sinemet or Selegiline (Patient 3), or Madopar (Patient 5).

It is important to note that the patients were only asked directly about these specific forms of medication and not about any other factors which might have contributed to the development of hypersexuality. The in-depth interviews did, however, provide ample opportunities for the participants to volunteer other information about factors believed to have contributed to their hypersexuality, but none emerged.

4.4 Desire to overcome the problem

The participants can also be categorised roughly into three main groups in terms of their desire to overcome their hypersexuality problem. Only three patients (1, 6, and 7) indicated what appeared to be a clear-cut and genuine (true) desire to overcome their hypersexuality. One explained this in intense terms of dissatisfaction with his hypersexuality:

“Horrible... my sex life... I’m dissatisfied... always I have the idea that I wish always that I been a boring straight man... has wife and kids... that’s all I’m dreaming of... I wish I was just like any guy... beggar... street cleaner... I just want to be straight... have no... I’m tired of it...” (Patient 1)

A further three patients (2, 8, and 9), although also indicating a desire to overcome hypersexuality, appeared not fully convinced or convincing and therefore were not considered as having a true desire to overcome it. For example, Patient 2 believed he had already overcome the problem, although this was not evident in his interview nor after interviewing his wife. The incongruity suggests that he may not fully grasp what overcoming the problem entails. He may also have claimed that he has overcome it because his interview took place in front of his wife, as per his request, possibly skewing his answers.

In a similar vein, Patient 8 explained, *“I’d like to be a position where I can overcome that and therefore I’m not too pushy and therefore we can go back to where we were”*. The reasons he provided for wanting to overcome the hypersexuality were not related to his own acknowledgement of the problem, but rather to the effect the hypersexuality had on his wife, which suggests a lack of true desire to overcome the condition. Finally, Patient 9 also indicated a desire to overcome his hypersexuality, *“only in the sense... it would be quite nice if it all just went away... but I don’t work fantastically hard to help it...”*. This suggests that he has not made a full commitment to overcoming it as he admittedly does not do much to change it.

Finally, the remaining patients (3, 4, and 5) did not indicate any obvious desire to overcome hypersexuality.

Theme 5: Control

The research findings indicated that these patients had little control over the development of hypersexuality after taking dopaminergic medication to manage their PD. However, having developed this condition, some patients indicated that they were able to control their behaviour and reported making conscious attempts to reduce or stop the hypersexuality. Loss of control and attempts to reduce/stop it were therefore identified as the main subthemes relating to control of hypersexuality.

5.1 Loss of control

Only three of the patients (1, 6, and 7) expressed the feeling that they had no control over their hypersexuality, for example as explained by Patient 1:

“I always think ‘Is it like a habit that I’m living?’ ... it’s in my life... I keep going back for it... like eating... Because I have it since I was three... it’s something part of my personality... I can’t... I tried ... it would be good to know if I can control it more... what’s the methods... is there any particular way out... I’ll do anything just to have that...” (Patient 1)

In contrast, the rest of the patients all indicated that they felt they could control their condition¹⁵.

5.2 Attempt to reduce/stop

Most patients ($n = 6$) indicated that they had made attempts to reduce/stop their hypersexuality. These patients were categorised into two groups: patients who truly attempted to reduce/stop their hypersexuality due to what might be conceptualised as “internal” factors and patients who attempted to reduce it due to “external” factors. For example, internal factors included the patients’ own feelings about their condition, while external factors included the views or feelings of other people, such as their partner’s unhappiness with their hypersexuality.

Three of the patients (1, 6, and 7) reported trying to reduce/stop their hypersexuality as a result of internal factors such as the way it made them feel. Patient 1 explained, for example *“All the time I just wondered... wondering and asking myself why am I doing it”*. He claimed that his inability made him feel *“desperate... I just wanted to... I just wanted help... I was... screaming... crying for help...”*. Patient 6, who also attempted to reduce/stop their hypersexuality to no avail, claimed that these failed attempts made him feel *“rough”*.

The three other patients (2, 8, and 9) who reported attempts to control their hypersexuality appeared to have been motivated to do so mainly by external rather than internal factors. For example, Patient 2 reported that he had attempted to abstain from sex only for the sake of his wife’s happiness; he expressed the view that his condition made him sad because sex should really be *“part of a healthy relationship between husband and wife”*. Patient 8 had similarly attempted to reduce or stop his hypersexual behaviours because of his wife’s rejection of his sexual advances and claimed that although he had been successful to an extent, he had *“spurts where I try again”*, while Patient 9 similarly reported temporary success in stopping or reducing his hypersexuality because of his wife’s discontent.

The three remaining patients (3, 4, and 5) all indicated that they did not attempt to reduce/stop their hypersexuality, with Patient 5 claiming she was happy with it *“even though it is a bit weird”*.

¹⁵ The information for this subtheme is limited as it was based upon one “Yes/No” question in the interview.

Theme 6: Impact

The positive or negative impacts of hypersexuality on the patients may span different areas of daily living including marital life, family life, social life, work and daily activities, finances, health, mood, sleep, self-confidence, and quality of life. These make up the subthemes for impact of hypersexuality.

6.1 Marital life

Four of the eight patients who had a spouse or partner (2, 5, 6, and 9) explicitly indicated that the hypersexuality impacted their marital life either positively or negatively. The remainder indicated that their behaviours had no particular impact on their marital life, or that their partners would only be upset if their behaviours became public. Patient 1 did not have a partner or spouse and thus was not considered as being part of the patients whose marital life was not affected by hypersexuality.

All but one of the patients reporting an impact of hypersexuality on their marital life indicated that this was a negative impact, particularly in relation to the closeness or sense of intimacy in their marriage. This appeared to arise for two different reasons. In the case of some patients, increased demands for sex which took a more impersonal or mechanical form than in the past had caused resentment or disgust on the part of their spouse (increased tension in the relationship causing breakdown in communication or in sexual relations) or had resulted from infidelity or not being focused on partner.

The first was that there was a breakdown in communications or in sexual relations between the patient and their partner, since the partner was upset about their condition and was unresponsive either to sex or to discussion of the hypersexuality and how the patient was feeling. This type of situation was reported by three of the patients. Patient 2 described being unhappy with where he and his wife were sexually and said that he no longer spoke to his wife about his sexual desires because it upset her. He explained that he wanted a normal sexual relationship with his wife, which he defined as a “*compromise between the needs of two people*”. Patient 9 claimed his wife did her “*very best to understand*” the hypersexuality but did not ask about his sexual practices. He explained that although he was very honest with her about his hypersexuality, “*she’s very withdrawn... she doesn’t like talking about [it]*”. Additionally, Patient 3 indicated that, although he perceived no direct impact of his hypersexuality on their relationship and said that they rarely argued, his wife was often annoyed by his sexual advances towards her, especially at inappropriate times or places:

“I might touch her... and that might annoy her because I’ve done it in the kitchen while she’s doing something... I want to touch her... but... she doesn’t like me touching her in the kitchen... for her the bedroom is the place...” (Patient 3)

The other main issue which appeared to have an impact on marital relationships was when the patient was not focused on their spouse or had been unfaithful to them. In this case, the patients had either increasingly sought sexual gratification elsewhere and the lack of intimacy had created more distance between them and their spouse, or their conditions such as dementia had resulted in a reduction in sexual activity or closeness within the marriage in general.

“My husband was a bit neglected... I mean I was... I was preoccupied... I mean I was in love with my therapist... he was... you know... he was a focus of mine... not that we had an affair or anything... but I mean I was in love with him... it was lust...” (Patient 5)

Patient 6, on the other hand, admitted that he had had an affair with another woman in the past and that although he had never confirmed this to his wife she suspected it, and that tension was still in their relationship as a result. The same patient reported that his wife had discovered on her own that he was

hypersexual through finding his pornography materials, rather than him telling her, which had “*really upset*” her, and that this had also damaged their relationship.

Some of the patients expressed awareness of the specific ways in which their behaviours made their spouses feel. The main types of negative emotions identified from the interviews, which appeared to have an impact on marital life, included anger, embarrassment, disapproval, betrayal and sadness. One of the patients who was keenly aware of how uncomfortable his wife was about his hypersexual behaviours described an incident intended to help her understand, but which only exacerbated her discomfort and lack of trust:

“We went to Brighton where there was a similar club and I dragged her into it... well this was a disaster because ... everybody was gay and all kinds of unspeakable things were going... it was a disaster... she ran out... I felt terrible because I subjected her to it... so now I think a little bit of her thinks the place I go to is like that... so there’s definitely this dimension of ‘What’s he getting up to sexually?’ that didn’t happen before...” (Patient 9).

“One day my wife and I were together talking about this and I think it was [the neuropsychologist] who said “Well you do understand this is just chemistry” and it’s obviously true... and it was very reassuring... she does her best to understand...” (Patient 9)

However, this patient also described the very understanding approach of his wife to his hypersexuality and indicated that this is important in helping them to sustain a good marriage.

In a similar vein, another of the patients explained that her hypersexuality had an indirectly positive impact on her marital life by acting as a catalyst for her and her husband to seek counselling. It was not entirely clear to what extent the reported communications difficulties between them had initially been caused by her hypersexuality, but the example does highlight a way in which one couple are dealing with the problem of hypersexuality in ways that may ultimately benefit their relationship more generally.

“I think what it’s done is that it’s highlighted the lack of communication between [us]... so in a way not negative... in a way it’s positive... in fact to the extent that I’ve arranged to have counselling to sort it out...” (Patient 4)

6.2 Family, social life and daily activities

Only two patients indicated that the hypersexuality negatively affected their family life. Patient 1 claimed that, due to his hypersexuality, he started to neglect his family. He explained that he paid less attention to his family and thus spent much less time with them. He also claimed to have been more absent and irritable towards them. Patient 2 claimed that his children’s happiness had been affected by hearing the arguments that happened between him and his wife about the hypersexuality. However, none of the other participants indicated that their hypersexuality had a negative or positive impact on their family life, with the exception of the impact on marital relationships discussed above.

Likewise, just two patients indicated that hypersexuality had negatively affected their social life. Patient 1 claimed that he had neglected his social life because of the focus on his hypersexuality and as a result there had been a reduction in his number of friends over time: *“I started to ignore best friends and I start to ignore people in general...”*. Patient 3 claimed that because of his preoccupation with sex, he chose to stay at home and think about this rather than socialise. The same two patients reported a negative impact of hypersexuality on their work or daily activities. Patient 1 explained that he had experienced a decrease in efficiency and a lack of concentration at work, due to thinking too much about sex, and stressed that hypersexuality had been his main focus for around three to four years. Patient 1 was also one of two

patients who indicated that hypersexuality had negatively affected their finances, which in his case was due to spending £400-500 an hour on call girls. None of the other patients reported a negative impact of hypersexuality on their finances, although Patient 6 did acknowledge that there might be financial implications if he did not change his behaviour, as he was spending almost £220 per trip to the massage parlour.

Patient 3 reported a negative impact on daily activities of hypersexuality, which had caused him to focus more on his girlfriend than on the things he was required to do around the house. Only one participant, Patient 5, indicated that hypersexuality had positively impacted her work life as it inspired her to write a novel about her experience with PD and her consequent obsession with sex. This suggests that hypersexuality helped influence her personal growth in a positive way.

In summary, only one of the research participants, Patient 1, reported that hypersexuality was having multiple impacts on his family and social relationships and daily activities. Overall, very few participants reported negative impacts of hypersexuality on these areas of their lives.

6.3 Health and well-being

Again, Patient 1 was the only participant who indicated that hypersexuality had negatively affected his health. He explained: “*I caught lots of... stuff like flu... bad flu... and I had horrible sore throat...*”. He had also caught sexually transmitted diseases and had an HIV scare. “*I think I had the... not herpes the other one... chlamydia or gonorrhoea...*”. Further, he claimed he felt anorexic as a result of only drinking milk and hot chocolate due to his preoccupation with sex.

In contrast with physical health impacts, most of the patients indicated that hypersexuality affected their mood in negative ways, with the main impacts being described in terms of depression, stress, unhappiness or anxiety. For example, Patient 1 explained that his hypersexuality caused him to feel depressed and very stressed. Patient 2, who reported being stressed, worried, and “*on the verge of depression*” indicated that this was mainly due to his wife’s unhappiness with his hypersexuality, which had a negative impact on his own feelings, while Patient 8 similarly explained that his wife’s rejection of his sexual advances made him “*moody*” and unhappy. The interviews also suggested that as a result of their hypersexuality – or perhaps the medications which were also causing this – the emotions of many of the patients were heightened or unstable and fluctuating. As Patient 4 explained “*Everything is more heightened so if I’m upset then I’m really upset...*”, while Patients 5, 6, and 7 also reported fluctuating emotions.

About half of the patients admitted that the hypersexuality affected their self-confidence. In the case of two of the participants (Patients 1 and 6), a positive impact on self-confidence was reported. For Patient 1, however, hypersexuality had increased his self confidence in some respects but diminished it in others. He explained that his confidence was boosted when other men were attracted sexually to him in the clubs that he frequented, but that after sex was done and he had time to reflect on his behaviour, he felt low in confidence as it made him feel “*evil*” and “*horrible*”. Patients 2 and 8 reported a negative impact on their self-confidence due to the attitudes of their wives towards their hypersexual behaviours.

About half of the patients indicated that their hypersexuality was negatively affecting their sleep, though the ways in which this happened differed between them. For Patients 1 and 6 respectively, hypersexuality resulted in a lack of sleep because of the amount of time each day spent in massage parlours indulging in sexual activity, or in staying up late planning visits to these types of places. Patient 5 also reported that her preoccupation with sex kept her up at night. Patients 3 and 9 also reported that they did not sleep well, but it was not so clear in their cases whether their sleep difficulties were directly caused by the hypersexuality or other symptoms of their neurological disorder.

The majority of the patients indicated that the hypersexuality had some impact on their quality of life in general, although several indicated that this impact was fairly minimal, or that they tried to reduce the impact and live their lives as normal.

“Somewhat... I wouldn’t exaggerate it though... it has an effect but... I live my life much the same as usual...” (Patient 5)

“Not really... it’s just sort of you feel a bit down after rejection... that’s all...” (Patient 8)

The accounts of Patients 1, 2 and 3 suggested a greater impact of hypersexuality on their quality of life. Patient 1, for example, said that it had an impact *“big time”* on his quality of life, while Patient 3 explained, *“my quality of life is better if I’m having sex”*. Patient 7 claimed that her quality of life was negatively affected as *“anything that makes you feel badly about yourself must make you feel negatively”*.

When directly asked if hypersexuality negatively affected their lives in general, Patients 3 and 9 were the only ones who indicated that it did not. Further probing into the impact on areas of daily living discussed above, suggests that it indeed had, as each of the patients indicated at least one of the different areas of living as being negatively affected by the hypersexuality.

The areas of living that were impacted by the hypersexuality, in descending order of frequency of patients indicating an impact, were quality of life, mood, marital life, sleep, self-confidence, work and daily activities, family life, social life, finances, and health.

Theme 7: Perceptions about partners’ feelings regarding hypersexuality

Around half of the patients indicated that their partners had negative feelings about the hypersexuality; most of these reported that their wives were unwilling to discuss the condition with them or that they themselves did not feel comfortable raising the subject with their wives because of these negative feelings. In general, these patients appeared to be sad or upset by their partners’ attitudes towards their condition.

“It makes me feel rejected... I find it more difficult as time goes by to go back into the situation and having a conversation about the problem... I’m a coward like that I suppose...” (Patient 8)

“I initiate conversation about it... she puts it in a little box and locks the key and never thinks about it I’m sure... and when I raise it she says ‘Oh for God’s sake do we have to talk about it?’” (Patient 9)

Patient 4 similarly indicated that her husband never talked about her hypersexuality with her, and in her case she claimed she did not know how her husband felt about it, or if he even noticed it. This made her realise how little communication they had in their marriage.

In contrast, two of the patients indicated that their partners responded to their condition in a more light-hearted way, perhaps indicating a greater degree of understanding of their behaviours, even if these were sometimes regarded as unwelcome or excessive.

“I mean essentially he is amused by it you know... he wanted to see what it was... it is artificial in a way... I think he is a bit bemused...” (Patient 5)

“She ribs me... she jokes about it...” (Patient 3)

These were in the minority, however, and most of the patients acknowledged a negative effect of the hypersexuality on their partners, indicating the importance of obtaining carer accounts of the hypersexuality to provide holistic, extensive assessments of impact and caregiver burden.

Theme 8: Stigma

A stigma is a negative stereotype that individuals have about certain phenomena. Generally, there is huge stigma associated with sexual behaviour as it has long been regarded as a taboo subject. There appeared to be three forms of stigma associated with hypersexuality: personal stigma, social stigma, and help-seeking stigma.

8.1 Personal stigma

Personal stigma refers to the patients' internalization of stereotyped ideas and regarding them as facts⁽¹²⁴⁾. Personal stigma took form in feelings of shame, references to being male, and references to being older.

Two of the research participants (Patients 1 and 7) expressed guilt and shame about their behaviours, which possibly resulted from the sensitivity and taboo associated with sex in general, not just hypersexuality. Because it made the patients act in an unusual and intensified manner, hypersexuality appeared to exacerbate feelings about sex that already existed for these individuals. For example, Patient 1 appeared to be guilt-stricken as he described feeling like a *"horrible person because I'm doing things... nobody is doing"*. Patient 7, on the other hand, felt *"ashamed"* because she was raised in a Victorian household with Jewish upbringing that believed that the act of masturbation, which she enjoyed doing, was *"dirty"*.

Patients 2 and 9, both males, made references to being "men" and its relation to sex, as discussed in sub-theme 3.2. Both patients possibly used their gender to try and normalise their hypersexuality and overcome any feelings of personal stigma associated with it. Patients 8 and 9 also referred to age and how this was perceived to affect perceptions of sexual behaviour or the ability to discuss this. These comments appeared to be made with the purpose of justifying the embarrassment associated with discussing their hypersexuality. For example, Patient 9 expressed surprise at discovering his condition and commented that, at his age, nothing should be a surprise any more, while Patient 8 made the more general point that it is difficult for people, and particularly those in older generations, to discuss sex.

"You know I'm sixty-seven for God's sakes... isn't it time I knew... I should've known and done everything there is to do by the time I'm sixty-seven..." (Patient 9)

"It's not easy for people to discuss... I don't find it easy... not really... I think if you are in the older range it would be worse..." (Patient 8)

8.2 Social stigma

Social stigma refers to the stereotyped views that others have about the patients' behaviour. With regards to hypersexuality, the stigmatisation that the patients felt was evident, as they were influenced to try to hide the hypersexuality and worried that others would find out about it. Most of the patients indicated that they did try to hide their hypersexuality from anyone other than their partner or people very close to them.

"I always do... I don't talk about it... to anyone..." (Patient 1)

"Nobody knows about it... except my oldest friend... he knows something's wrong and I'm going to talk to him on Friday..." (Patient 9)

About half of the patients indicated worry about others finding out about their hypersexuality. In the case of Patients 1 and 6, the main concern was that their family members would find out about their condition, while the others worried about other people finding out. For example, even though her husband was aware of her hypersexuality, Patient 7 worried that other people would find out because it would threaten their social status. Patient 9 also indicated concern about others finding out about his hypersexual behaviours, and their resulting perceptions of him.

“If I walked out of this naturist club straight into the arms of a friend I’d be so embarrassed... it would be terrible... I just worry that people will think I’m a weirdo...” (Patient 9)

Patients 2 and 8, on the other hand, were not worried about others finding out about their hypersexuality. Patient 8 indicated that he was not worried about others finding out because *“to me it’s almost completely normal... some people are like that”*. Patient 2 similarly recognised it was just *“society’s perception”* that is the potential problem. It is worth noting however that this patient was initially very hesitant about taking part in the study but was encouraged to do so by his wife. For this reason, his answers may not be fully accurate.

Furthermore, during their interviews, most of the patients tended to laugh inappropriately and nervously after being asked sexually-specific questions or if their answers prompted them to go into detail about their sexual experiences. This might also be due to the embarrassment associated with sex and talking about it.

“I’ll tell you something that you’re allowed to laugh at because it is funny... I suddenly... it wasn’t really a change in sexuality... it was in exhibitionism... so one day I took all my clothes off and lay down in the garden... my wife came out and said ‘What are you doing? The neighbours can see’... and since then my wife and I have been to a few nude beaches... this is all harmless stuff but it’s... especially... you know my wife and I up to this point have been boringly straight... normal... straight... and not interested in anything unusual... so that was the first thing and then... what happened next... oh then we had the massage [laughing]... God this is so embarrassing...” (Patient 9)

Patient 9 also asked if he could be completely honest before describing parts of his hypersexuality during the interview. This further highlighted the hesitation many patients felt when discussing this issue. It would be excessive, however, to list all these moments of laughter for each of the patients.

It is worthy of note that at the other extreme, however, Patient 5 had written a book about her hypersexuality, indicating that she felt little sense of social stigma and was keen to share her experiences with others.

“It’s sort of a biographical fiction... it’s about Parkinson’s... it’s about my journey through therapy and sex obsession...” (Patient 5)

8.3 Help-seeking stigma

Help-seeking stigma refers to the stereotyped views the patients have regarding professional help. Two of the male patients, in particular, highlighted their strong preferences for discussing their hypersexuality with a male doctor and feeling uncomfortable or embarrassed about doing so with a female doctor.

In explaining this, Patient 2 demonstrated a stereotypical perception of women who *“all think the same way”* and expressed the view that a male doctor would understand him better. Patient 6 reported that he had not told his GP about his hypersexuality because *“she’s a female doctor”*, also indicating a lack of confidence in the medical relationship because of gender. This finding further emphasized the boundaries

often associated with sex that have only made the issue of hypersexuality more difficult to discuss. Help-seeking barriers will be discussed in more detail in the upcoming section.

Theme 9: Professional help-seeking barriers

Evidently, the patients were not getting the adequate and necessary information and help for their newly-developed hypersexuality. There appeared to be a lack of communication, lack of understanding, lack of education, neglect by the health professionals, stigma associated with hypersexuality, and difficulties in discussing sex.

Around half of the patients reported a lack of support and understanding from healthcare professionals, which led to them feeling helpless and confused. Patient 2 explained that the PD nurses at the hospital “*did not know much about it*”, although he had brought it up to them, and “*didn't dig deeper*”, while the lack of helpful information from his GP exacerbated Patient 1's negative feelings about himself.

“The doctor's reaction ... got me really depressed because I didn't get an answer for any of my worries... my inquiry... for my worries about my body and I felt like I... either neglected or denied or... haven't been believed... I thought... and I started to reflect on my personality... I used to say I'm an evil... I'm anonymous... I'm just horrible person... I'm just horrible person because I'm doing things no... nobody is doing and I always used to push it back on myself...” (Patient 1)

Avoidance of the issue and a lack of knowledge or understanding about the condition on the part of healthcare professions were reported by several of the patients. For example, Patient 8 explained that he had been seeing the same neurologist for ten years and sexuality was never brought up, although other impulse control disorders such as gambling were. It was not until they met with the neuropsychologist, who is part of this study, that hypersexuality was brought up and confirmed as something that does sometimes result from taking Ropinirole.

“Did the psychiatrist know anything more than I knew? I don't think so... hypersexuality has not crossed the threshold where people can talk about it... it's really embarrassing to discuss... feels horrible being at consultation where everything is being discussed but this... the doctors don't know what to do...” (Patient 7)

Patient 2 also explained that he and his wife had been referred for marital counselling, which he reported as being unhelpful. He explained that he felt unable to discuss his hypersexuality in this setting and found that this created new problems in their relationship rather than breaking down the existing barriers.

“It's too generic... it facilitates discussion... but ... some things are kind of private... not because they need to be hidden... but because if you say it to your partner... you know nobody's perfect... if you sit with the counsellor and they make it okay to say those things... then the relationship... even though the theory of it is correct... the reality of the relationship takes a hit...” (Patient 2)

Although only half the patients reported difficulties in help seeking from professional groups, it cannot be assumed that the remaining patients had more positive experiences. These individuals may not have attempted to discuss their hypersexuality with health professionals or might have omitted to mention any experiences of doing so.

Theme 10: Aspirations

Although not directly asked, some patients expressed aspirations to help them move forward with hypersexuality. These aspirations were categorised under professional help-seeking, marital help, and control.

10.1 Professional help-seeking

The findings presented under the stigma and professional help-seeking themes have highlighted the patients' desperate need for information about hypersexuality from health professionals. Two patients in particular (7 and 8) expressed the hope that the issue of hypersexuality would cross the threshold where it could be more easily and openly discussed.

More generally, participants highlighted a need for the health professionals to warn their patients about hypersexuality, explain its phenomenology and how it manifests, and offer help to patients who are struggling through it. The majority of patients appeared to want to understand their hypersexuality better and be able to discuss it openly with their health professionals without fear or embarrassment. Patient 2 expressed needing "*people to be more decisive in their opinions*" rather than just having a platform to "*talk*".

10.2 Marital help

Three of the patients discussed aspirations to improve their marital relationships, which had in various ways been negatively affected by their hypersexuality. For example, Patient 4 hoped that counselling would help her overcome the issues in her marriage. She claimed that although she did "*not necessarily*" want to overcome her hypersexuality, she did want to "*feel comfortable talking about it with [her] husband*". She had therefore taken the initiative and booked a counselling session for her and her husband to talk through their lack of communication, but without informing her husband because she regarded it as a dire need for their relationship.

Others expressed the desire to be able to modify their sexual behaviours in order to make these more acceptable to their wives: Patient 2 indicated that he would like help with finding a sexual "*middle ground*" for him and his wife, while Patient 8 wanted to stop being "*too pushy*" in his sexual advances towards his wife so that they could return to the type of marital relationship they had before the onset of his hypersexuality.

10.3 Gaining control

Although several patients indicated in various ways that they would like to gain greater control over their hypersexuality, this was expressed most directly by Patient 1, who claimed he had no control over his hypersexuality:

"I need to know... it would be good to know if I can control it more... what's the methods... is there any particular way out... I'll do anything just to have that..." (Patient 1)

It is interesting that this patient used the term "way out", which suggests he feels stuck and wishes to climb out of the place he is in.

Table 25 below outlines the labels of each theme and a summary for each.

Table 25 – Labels and summaries of themes for patients

Label of theme	Summary
<i>Manifestations</i>	<p>Outlines the different ways the hypersexuality manifested among all patients and highlights some of the commonalities between them. With regards to the patients' cognitions, a marked increase or recurrence in thinking about sex was evident. There was also an increased desire for frequency of sexual acts and desire for other people. Furthermore, hypersexuality either caused changes in pre-existing behaviours or the development of different, unusual, risk-taking behaviours, as well as preoccupation with sex, which was evident in their lack of adherence to other commitments, obsessive thoughts about sex, and the mental effort put into planning for sexual endeavours. The preoccupation with sex also evidently translated into actual compulsive sexual behaviour, although not all patients indicated this (though it was suggested). Finally, findings suggested that negative emotions did seem to trigger patients' hypersexual episodes.</p>
<i>Sexual practices</i>	<p>Outlines how hypersexuality affected the patients' sexual practices. The participants' increased sexual urges translated to different types of sexual practices. The various sexual practices that emerged from the interview data included patients' practices with their partners, with themselves, with others, and deviant sexual practices. The data revealed that an increased desire for sex due to hypersexuality did not necessarily mean an increased frequency of sex with the patients' partners. On the contrary, most of the patients indicated either a decreased or similar frequency of sex with their partner as compared to the frequency prior to developing hypersexuality, while only a few reported an increased frequency of sex with their partners. Moreover, most of the patients indicated sexual practices with themselves, including masturbation and use of pornographic materials. There appeared to be a wide variation among the patients in the extent to which masturbation was reportedly being used a sexual activity. On the other hand, use of pornographic material seemingly developed or increased following the onset of hypersexuality. Patients also indicated practices with others including promiscuity, anonymous sexual encounters, paying for sex, and extramarital affairs. Lastly, hypersexuality did not necessarily translate into paraphilic behaviour.</p>
<i>Emotional formulations and attributions</i>	<p>Highlights the emotional formulations and attributions that the patients developed about the hypersexuality. Evidently, if the hypersexuality was internalised (blaming development of the behaviour on themselves), patients tended to develop negative feelings about it. If the hypersexuality was externalised (regarding behaviour as stemming from external determinants), patients appeared to develop neutral feelings about it. If the hypersexuality was neither internalised nor externalised, patients appeared to develop positive feelings towards it.</p>
<i>Insight</i>	<p>Highlights findings about patients having insight into their hypersexuality problem or not. In the case of hypersexuality, patients who have insight must first acknowledge the presence of the problem, understand that their hypersexuality is unnatural, have some awareness with regards to what caused it, and have a true desire to overcome it. When asked if they have experienced an increase in sexual behaviour or thoughts since developing PD, all the patients indicated that they had. This signified awareness of the change in their sexual demeanour; however, it did not mean that all the patients regarded their hypersexuality as a <i>problem</i>. Furthermore, more than half of the patients expressed their belief that their</p>

hypersexuality was a natural condition, as it matched their personal values and beliefs and thus felt normal and not unusual to them. The remainder of these patients, however, expressed views indicating belief that their hypersexuality was unnatural, mainly because it apparently conflicted with their personal values and beliefs. Whether or not they regarded their own hypersexuality as a natural or unnatural condition, all of the patients expressed the belief that the condition was primarily influenced by the dopaminergic medication used to manage their PD. Finally, the findings categorised the patients into three main groups in terms of their desire to overcome hypersexuality: a true desire to overcome problem, an unconvinced/convincing desire to overcome the problem, or no obvious desire to overcome hypersexuality.

Control

Highlights that although the patients had little control over the development of hypersexuality after taking dopaminergic medication to manage their PD, some indicated that they were able to control their behaviour, while others expressed loss of control. Further, most patients indicated that they had made attempts to reduce/stop their hypersexuality. These patients were categorised into two groups: patients who truly attempted to reduce/stop their hypersexuality due to what might be conceptualised as “internal” (i.e. patients’ own feelings about condition) factors and patients who attempted to reduce it due to “external” (i.e. views or feelings of other people such as partners’ unhappiness about their hypersexuality) factors.

Impact

Outlines the positive and negative impacts that hypersexuality had on patients’ marital lives, family lives, social lives, work and daily activities, finances, health, mood, sleep, self-confidence, and quality of life. Findings indicated that hypersexuality negatively impacted at least one of the different areas of living for each of the patients. The majority of the patients reported a negative impact on their marital lives, particularly in relation to the closeness or sense of intimacy in their marriage. This appeared to arise for two different reasons. In the case of some patients, increased demands for sex which took a more impersonal or mechanical form that in the past had caused resentment or disgust on the part of their partner (increased tension in the relationship causing a breakdown in communication or in sexual relations) or resulted from infidelity or not being focused on partner. Further, some of the patients expressed awareness of the specific ways in which their behaviours made their spouses feel. The main types of negative impacts identified from the interviews, which appeared to have an impact on marital life, included anger, embarrassment, disapproval, betrayal, and sadness. Interestingly, only one patient indicated that hypersexuality had an indirectly positive impact on her marital life by acting as a catalyst for her and her husband to seek counselling. Negative impact on family life included neglect of family members, more absence, and more irritability. Negative impact on social life included neglect and avoidance of socializing due to preoccupation with sex. Negative impact on work and daily activities included decrease in efficiency and a lack of concentration on work due to preoccupation with sex. Negative impact on finances included spending large sums of money on call girls and in massage parlours. Negative impacts on physical health included sexually transmitted diseases, as well as loss of appetite due to preoccupation with sex. Negative impact on mood included feelings of depression, stress, unhappiness, and anxiety. The findings also suggested that as a result of their hypersexuality – or perhaps the medications which were also causing the hypersexuality – the emotions of many of the patients were heightened or unstable and fluctuating. Negative impact on sleep included staying awake due to preoccupation with sex and planning next sexual endeavours.

Self-confidence, on the other hand, was equally positively and negatively impacted with some patients feeling more sexually attractive and others reported lower self-confidence due to attitudes of their wives towards their hypersexual behaviour. In general, most of the patients indicated the hypersexuality as having a negative effect on their lives.

Perceptions about partners' feelings regarding hypersexuality

Highlights the patients' perceptions of their partners' feelings about hypersexuality. Around half of the patients indicated that their partners had negative feelings about the hypersexuality. Most of these reported that their wives were unwilling to discuss the condition with them or that they themselves did not feel comfortable raising the subject with their wives due to these negative feelings. Generally, the patients appeared to be sad or upset by their partners' attitudes towards their condition. In contrast, some patients indicated a more light-hearted response from their participants about the condition. This could be indicative of a greater degree of understanding of their behaviours, even if these were sometimes regarded as unwelcome or excessive. These patients were in the minority, however, and most of the patients acknowledged a negative effect of the hypersexuality on their partners.

Stigma

Highlights some of the stereotypes that patients had about hypersexuality. Findings showed three forms of stigma associated with hypersexuality: personal stigma, social stigma, and help-seeking stigma. Personal stigma took form in feelings of shame and guilt about behaviour possibly resulting from the sensitivity and taboo associated with sex in general, in references to being male and possibly using this gender to try and normalise their hypersexual tendencies, and in reference to being older and it being more embarrassing to discuss sex in older age. Social stigma was evident as patients tried to hide hypersexuality and worried that others would find out about it. This was also clear during the interview process when patients laughed inappropriately and nervously after being asked sexually-specific questions or if their answers prompted them to go into detail about their sexual experiences and practices. Help-seeking stigma was evident in some male participants highlighting their strong preferences for discussing their hypersexuality with male doctors and feeling uncomfortable or embarrassed about doing so with female doctors. This indicated an overall lack of confidence in the medical relationship. These findings further emphasized the boundaries often associated with sex that have only made the issue of hypersexuality more difficult to discuss.

Professional help-seeking barriers

Highlights the difficulties patients faced when seeking information about their hypersexuality from health professionals. Findings showed a lack of communication, lack of understanding, lack of education, neglect by health professionals, stigma associated with hypersexuality, and difficulties in discussing sex, all of which impeded patients' ability to seek advice and discouraged them from doing so.

Aspirations

Highlights some of the patients' expressed aspirations to help them move forward with hypersexuality, although this was not directly asked. The patients' desperate need for information and advice about hypersexuality from health professionals was evident. Generally, participants highlighted a need for health professionals to warn their patients about hypersexuality, explain its phenomenology and how it manifests, and offer help to patients who are struggling through it. The majority of patients appeared to want to understand their hypersexuality better and be able to discuss it openly with health professionals without fear or embarrassment. In regards to marital help, some patients discussed aspirations to improve their

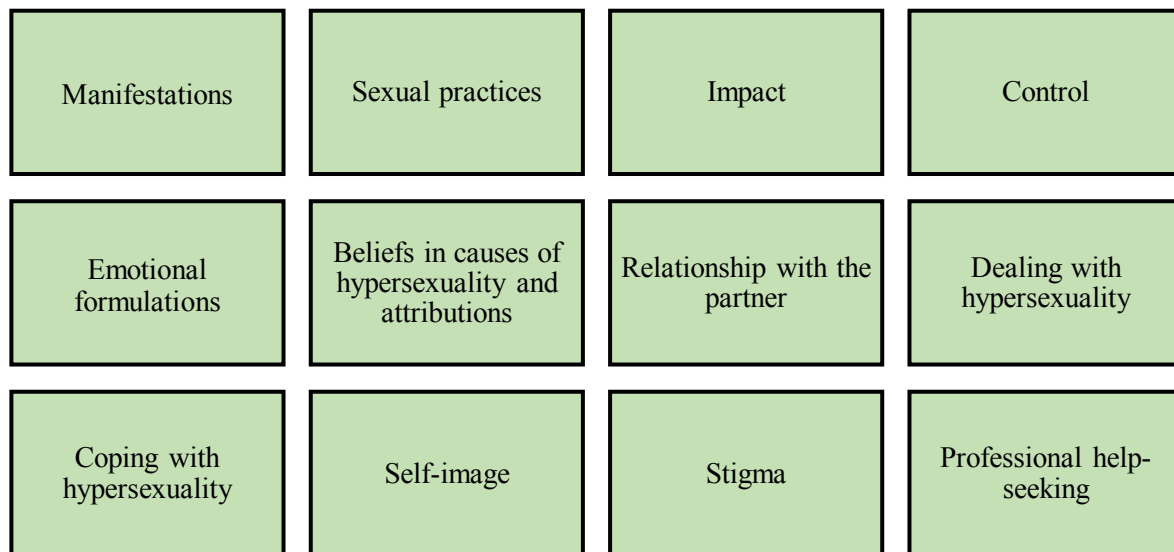
relationships with their partners. These aspirations took form in booking counselling sessions and in expressing desires to be able to modify sexual demeanour in order to make it more acceptable for partner. Furthermore, several patients indicated in various way that they would like to gain greater control over their hypersexuality.

PD: Parkinson's disease

3.5.4.2 Carers

The themes that were analysed for the carers are reported in Figure 19.

Figure 19 – Emergent themes analysed for Parkinson's disease/frontotemporal dementia carers



The following legend shows which carers correspond to which patients:

Carer 2 – Patient 2
Carer 3 – Patient 7
Carer 4 – Patient 5
Carer 5 – Patient 8

Theme 1: Manifestations

Just as in the patient cohort, it emerged from the perceptions of the carers that hypersexuality manifests differently across different patients. Differences were observed in the accounts of carers regarding the patients' sexual desires, their sexual behaviour after the development of hypersexuality, the indicators of their hypersexuality, their preoccupation with it, and the possible consequent compulsivity. These all make up the subthemes for the partner-perceived manifestations of hypersexuality.

1.1 Indicators

The carers were asked how they first noticed and became aware of the hypersexuality. These instances were termed 'indicators' of hypersexuality. Their responses fell broadly into three categories: their partners told them directly about their hypersexuality, they found out based on changes in their partner's sexual behaviours towards them, or they discovered their partner's clandestine behaviours.

Two of the male carers (3 and 4) had been told directly by their partners about their hypersexuality. In the case of Carer 4, when told by his wife of her condition, he reported that he did not see this as “*big news*” as he had noticed a gradual change over time in her behaviours. Similarly, Carer 3 expressed the view that he would have noticed his wife’s sexual behaviour changes even if she had not told him.

A further two of the carers, both female, found out about their husbands’ hypersexuality from their actions or behaviours towards them. Carer 2 became aware of the hypersexuality as her husband was always asking for more sex and never seemingly having enough. Carer 7’s husband constantly asked for more sex, mentioned that his wife’s sister’s skirt was very short, and made comments about being able to see the lining of some women’s underpants, which had raised her suspicions. Carer 7 also recounted an instance where her husband got out his penis to pee on the pavement. Although she recognised that this was not an entirely sexual act, it was enough to indicate to her that something strange was transpiring.

Finally, four of the carers found out about the hypersexuality when they discovered their partners’ clandestine actions or behaviours. For example, Carer 1 had found evidence that her husband had been buying gay magazines, which was out of character for him, while Carer 5 recalled them having been in a motel and waking up to finding her husband going through all the “*adult channels*” while he thought she was asleep. She also found regular phone calls on his monthly bill, messages from strange women, and a search history for pornographic websites. Carer 6 recounted multiple incidents which revealed her husband’s behaviours. These included being contacted by a prostitute who asked her for money owed to her by her husband, being asked by her husband to order more Cialis and Viagra for him, even though they had not been using these medications in their own sexual relationship, having him admit to having sex with another person who turned out to be the prostitute, and finding evidence of sex sites in the search history on his mobile phone. The discovery of a trail of evidence of pornographic transvestite websites on their home computer also alerted Carer 8 to her husband’s hypersexuality, along with the discovery of a pornographic magazine.

“I found a till receipt for a gay magazine... I sat on the knowledge for a couple of weeks but first of all I went straight up to WH Smith and bought a copy of the magazine thinking that either it wasn’t what I thought it was... it was Gay Times... or this had been bought by mistake... I got a copy... I sat there outside and read it and realised it was highly unlikely that it had been bought by mistake...” (Carer 1)

1.2 Desires

Increased desire following the development of hypersexuality was evident in the carer-perceived experiences of all the patients. The carers indicated an increase in patients’ desire for their partner, for others, or both.

Only Carer 4 directly indicated that his wife developed a heightened desire for sex with him but not for others. However, the accuracy of this perception is questionable as this patient reported developing feelings for her therapist, which she later told her husband about and which he interpreted as “*voracious lust [which] is of its nature impersonal*”.

Three of the female carers (1, 6, and 8) reported that their husbands did not develop heightened desires in them sexually but rather for others or in self-pleasure. Carer 1, whose husband had already passed away, noted that they “*always had a very fulfilling sexual relationship*” and that she therefore found it difficult to understand his new behaviours, which included buying gay pornographic magazines. Carer 6, whose husband had regularly been visiting a prostitute explained “*he desired somebody or something else... he didn’t want me...*”. Carer 8, on the other hand reported that despite the increased sexual desire for other

things, her husband also developed a heightened desire for “*sex with himself*”, because he always said he was in love with himself.

The most common type of carer response was that their spouses developed a heightened desire for sex with them as well as an increased sexual desire either people outside the relationship or for self-pleasure in the form of masturbation or the use of pornography. This was the experience of Carers 2, 3, 5 and 7.

“That’s the only thing he’s interested in ... to have sex...” (Carer 7)

Carer 5, in particular, reported finding these behaviours difficult as her husband’s increased desire for sex coincided with her own declining level of sexual desire:

“I don’t know where desire’s gone because it is practically... it is non-existent... they happened about the same time I think... I think it must be... it must be a good five or six years as far as he’s concerned... and I honestly think that things changed for me around sixty...” (Carer 5)

1.3 Behaviours

Hypersexuality apparently caused changes either in pre-existing behaviour or development of new behaviours, according to the accounts of the carers. The changes fell into two main categories: first, the adoption of pornographic materials or new sexual behaviours involving others, and second, an increase in levels or forms of sexual behaviour towards partners, or the intensification of old sexual behaviours.

Four of the carers described marked changes in their partner’s sexual orientation or behaviour after developing hypersexuality. One of the most extreme was reported by Carer 1, whose husband’s sexual orientation seemingly changed after developing hypersexuality. Despite having been presumably heterosexual his entire life and having been married to his wife for fifty years, he expressed homosexual tendencies, and adopted new behaviours such as taking taxis to bookstores and sex shops and returning home with pornographic materials, and masturbating while using pornographic DVDs or homosexual magazines in the sitting room. Carer 5’s husband also began to use porn, to make sexual advances to her at inappropriate times, and to request role-playing during sex. Carer 6 explained that her husband had started new sexual behaviours such as making advances to other women and visiting a prostitute. In the case of Carer 8, it transpired that her husband had transferred his attentions from her into “*pornography... transvestite sex... and looking online at little boys dressed up in women’s underwear and then going upstairs to masturbate to it...*”, with the police and social services even being involved “*because he had been looking at images of little boys dressed in women’s underwear...*”. She also reported that they had stopped going out for meals together because all he did was stare at the waitresses or women on other tables.

Three of the carers reported that the main change in their respective partner’s behaviour following the onset of hypersexuality was an intensification of sexual behaviour or advances towards them. For example, although Carer 7’s husband did not express new sexual interests or preferences, he just wanted more sex with her. Likewise, Carer 3’s wife did not develop new sexual behaviours but rather an intensification and increased frequency of masturbation, a longstanding behaviour. In the case of Carer 4, who explained that his wife’s sexual desire for him had increased, this was not entirely unwelcome. However, he did express some amusement at the changes, which were quite out of character for her:

“Normally she likes tenderness and sweetness and this was sort of a bit more lust... go for it... behaviour was extreme if you like because she’s a reserved person ... who has other high standards of good behaviour... so this was like nature in the raw really...” (Carer 4).

In contrast, many of the new or rekindled behaviours exhibited by Carer 2's husband were not welcomed by her. These included swallowing and anal sex, which were she had always been resistant to as she did not regard them as "*normal for procreation*". Her husband also wanted her to dress more suggestively and be more sexual and he made sexual advances to her or asked her to perform oral sex on him at inappropriate times, such as in his hospital shower right after DBS surgery.

1.4 Preoccupation

Six of the eight carers indicated that their partners were preoccupied with sex, with many using terms such as "*obsessive*" to describe their thought patterns. For example, Carer 3 claimed his wife was "*obsessed*" with masturbation. He claimed that "*her thoughts are uncontrollable and come so much of the time...*", while Carers 2 and 8 also expressed the belief that all their husbands thought about was sex. Two of the carers (5 and 6) reported less obsessive thought patterns but noted that their husbands thought more about sex than they did in the past, with Carer 5 specifying that it had become a "*bit consuming*". Only two did not believe their spouses were preoccupied with sex. Overall, these findings indicate that from the perspective of the carers one of the main manifestations of hypersexuality was a preoccupation with sexual thoughts.

1.5 Compulsivity

The translation of sexual thoughts into actual compulsive behaviour was perceived by many of the carers to be another of the main manifestations of the patients' hypersexuality: five of the eight carers who reported that their spouses are preoccupied with sex also indicated that they demonstrate compulsive behaviours.

The types of compulsive behaviours reported by carers varied however, including the regular or intensive use of pornographic materials (Carers 1 and 8), visiting and apparently becoming "*obsessed*" with a prostitute (Carer 6), and generally indulging in sexual behaviours throughout the day (Carer 3).

"Hypersexuality is present all throughout the day and during the night while I am asleep..."
(Carer 3)

Additionally, the two carers who had not reported a preoccupation with sex on the part of their partners did identify aspects of compulsivity, such as demanding very frequent intercourse. Carer 4 admitted that although he could not quantify how much time his wife spent on her hypersexual behaviours, he admitted this was probably "*more than I realised*".

Theme 2: Sexual practices

Just as in the patient cohort, it emerged from the perceptions of the carers that the patients' hypersexuality manifested in increased urges which translated into different types of sexual practices. These sexual practices included patients' practices with the carer, practices with themselves, practices with others, and deviant practices.

2.1 Practices with the partner

Sexual practices with the partner involved changes in both the frequency and nature of sexual acts. For example, Carers 3, 4, and 7, indicated that their partners were demanding a higher frequency of sex with their spouses since developing hypersexuality. Carer 7 reported, for example, that this had increased from four times a week to twice a day, seven days a week.

"And now [he was asking for sex] every morning... every evening... sometimes he's asking during the day..." (Carer 7)

Five of the eight carers reported that there had been changes in the nature of the patient's sexual demands or behaviours, which they typically described as being out of character with the person they were before developing this condition. These included, for example, more aggressive sexual advances, demands for role play, and more adventurous sexual practices than they had used in the past, such as oral or anal sex.

“She didn't ask for Fifty Shades of Grey no... but still ... a little hint of S&M which really wasn't part of our repertoire...” (Carer 4)

“Things like going outside the door and knocking on the door and coming in or something... you know... I'm somebody he's picked up outside or something and who knocks on his door and slips in with exotic underwear on or something... never had all this before... it's just weird... like he was sort of switched off... he's actually thinking he's with a prostitute or something I don't know...” (Carer 5)

However, five of the carers reported a decline in sexual activity with their partner – in some cases because they started to resist their frequent or inappropriate advances. Carer 2 claimed, for example, that after her husband developed hypersexuality he asked for sex every day and that, at one point, they were having sex three to four times a day. However, he still found this insufficient to fulfil his desires, and as a result of this and other problems the hypersexuality caused in their relationship, they began having sex far less often. Carer 5 also explained that although her husband desired more sex with her, they had no sex at all because she did not want to.

In other cases the decline in sexual activity within the marriage apparently occurred because the patient was instead seeking sexual gratification from other sources. Carer 1, whose husband had developed homosexual tendencies as part of his hypersexuality, reported that although he continued having sex with her, she felt that he was emotionally absent from the activity, using her physically while thinking about the male pornography he had started using. Carer 8 claimed that she and her husband did not have sex at all because he no longer desired her, while Carer 6 admitted that she had even bought a Kama Sutra book to try and excite her husband and rekindle his interest in the marriage, while not realizing at that point that he was going outside of the relationship.

2.2 Practices with themselves

Sexual practices with oneself may include the act of masturbation and use of pornographic materials. Both these types of practices were reported by most of the carers.

In the case of masturbation, six of the eight carers claimed that their spouses had increased their frequency of masturbation, which it appeared they could not control. Carers 1, 2, 4, 5, 6, and 8 indicated that their spouses had been using pornographic materials, with Carer 8 specifying that her husband was using sadomasochistic child pornography.

2.3 Practices with others

Sexual practices with others may include anonymous sexual encounters, paying for sex, and developing sexual attraction to people other than their spouse.

Only Carer 6 reported that her husband had actively sought sexual gratification outside of the marriage, in the form of a range of anonymous sexual encounters and one-night stands. According to this research participant, her husband had paid for prostitutes, used sex and dating sites and sex phone lines, and visited massage parlours. Carers 1 and 5 also reported that their husbands had used sex phone lines, though in their case they had no evidence that they had actually had sex in person with anyone else. The remaining

carers also claimed that their spouses had not actively had sex with anyone else since developing hypersexuality though Carer 2 reported that her husband had sometimes threatened to do so if she did not do what he asked of her sexually. Carer 4 was aware that his wife had developed a sexual attraction for her therapist, but again this was not translated into actual sexual activity.

2.4 Deviant sexual behaviour

Carer 8 was the only carer who indicated that their spouse developed deviant sexual behaviour. She expressed a belief that her husband's condition could not be described as heterosexual hypersexuality, but rather as deviant hypersexuality. According to her, since its onset, her husband developed an interest in dressing as a woman, viewing transvestite websites involving young boys dressed as women, and masturbating in front of these images while dressed in women's underwear.

“It needs to be more upfront that it's not just about a decrease in sex or an increase in sex... it could be a decrease in a normal sexual relationship and a... a subverted or a hidden cover increase in some kind of deviant sexual behaviour which had been what was going on for twenty years and I didn't know about...” (Carer 8)

Theme 3: Impact

The carer-perceived impacts of hypersexuality on the patients spanned different areas of daily living. These included marital life, family life, social life, work, finances, health, mood, sleep, self-confidence, and quality of life, which make up the subthemes for the impact of hypersexuality.

3.1 Marital life

Almost all carers indicated that the hypersexuality had negatively impacted their marital lives. They reported multiple impacts including reduced intimacy, increased distance between themselves and the patient, and a range of negative emotions on their own part, such as anger, embarrassment and despair. Overall, there was a sense from the interviews that the carers more than the patients perceived there to have been quite severe and extreme impacts on their marital life due to the ways in which the hypersexuality had changed their partners.

“It was dreadful... devastating ... I couldn't make head and the tail of it... it just didn't add up to the man I'd been living with for nearly fifty years...” (Carer 1)

“It's awful really because he's not the same person... apart from everything else that's going on... I feel like I'm sort of living a double life and I sort of have to live his life as well and double check everything ... life's so difficult so it's not surprising that I'm tired...” (Carer 5)

Most of the carers, like many of the patients, also identified that hypersexuality had had a negative impact on the closeness or sense of intimacy in their marriage. This appeared to arise for two different reasons. In some cases, increased demands for sex which took a more impersonal or mechanical form than in the past result had caused resentment or disgust on the part of their spouse or had changed the nature of their sexual relationship in ways that were not welcome to them.

“I've always thought of it very old fashioned as making love... sex for sex's sake for me is nothing... so the fact that he was then using these magazines to psych himself up to come and have sex with me was really meaning he was just using me to have sex...” (Carer 1)

“It’s kind of became more of ritual... more of a... I mean he would say things like ‘I need a fuck’... like every morning and every evening... I have felt really pursued... that’s the only thing he’s interested in... is to have sex...” (Carer 7)

Several of the carers, however, identified ways in which their intimacy and other aspects of their marital relationship had diminished due to the hypersexuality or related behaviours.

“It’s difficult to separate if it’s the dementia or more the sexual aspect of it... it’s kind of loss of companionship in all areas so it has affected the relationship...” (Carer 7)

“I’m competing with the women on television... sometimes I’m thinking... does he think that he’s making love to me or does he think he’s making love to somebody off the television...” (Carer 5)

The main types of negative emotions identified from the carer interviews, which appeared to have an impact on marital life, included anger, embarrassment, disapproval, betrayal and sadness. Among the carers, one of the most commonly mentioned negative emotions was anger about their spouse’s behaviour or the way they were treated by them after they developed the hypersexuality. Many of the carers also expressed a sense of disapproval or embarrassment about the patient’s hypersexuality, and several expressed feelings of betrayal, self-blame or reduced self-confidence as a result of their partner’s hypersexual behaviours, which in some cases had turned to anger over time. The types of emotions experienced by the carers are examined further in later sections of the findings chapter.

Some of the responses suggested that a substantial shift had occurred in the nature of the marital relationship due to the hypersexual behaviours, with a growing lack of respect for the patient, for example, or a sense of taking control over them in order to preserve the marriage. This was particularly noticeable in the case of Carer 8, who had discovered her husband was indulging in deviant practices.

“I’ve lost respect for him... how can you respect someone that gets off of watching little boys being humiliated... I’ve said to him I won’t collude or condone with anything he’s done... and I won’t accept those things either... and that whilst he lives in the house with me he behaves in a way I would want him to behave legally...” (Carer 8)

It would be difficult for the carers to separate their own view of the impact the hypersexuality has had on the marital life from their perceptions of the impact on just the patient as their marital lives involve both of them. For this reason, the impact of hypersexuality on the carers’ relationships with the patients will be discussed in more detail in an upcoming section.

3.2 Family, social life and daily activities

Half of the carers indicated that the hypersexuality had negatively impacted their family life, identifying effects on their children which ranged from having fathers who were absent much of the time to being traumatised or stressed by their father’s hypersexuality. For example, Carer 2 claimed that the marital arguments caused by the hypersexuality were stressing out their eighteen-year-old daughter, who was diagnosed with chronic fatigue. She also mentioned that their sixteen-year-old son developed a face rash, which may be stress-related. Other comments included:

“My kids were shocked, so mentally and emotionally distanced themselves...” (Carer 1)

“The children just could not understand it... he never denied it... both the children were irritable... they couldn’t understand it you know because [of] the way he’d been brought up and how he’d brought them up...” (Carer 6)

Little information emerged from the carers interviews on the impacts of hypersexuality on the patients' social lives, but the available findings indicated that these could be either positive or negative. According to Carer 6, hypersexuality had both a negative and a positive impact on her husband's social life as some of his friendships strengthened with those who believed him but weakened with others as he chose to see the prostitute instead of trying to maintain a social life. The only other comments relating to the area of social life suggested that hypersexuality was having a negative influence: Carer 2 indicated that her husband was less outgoing than he used to be, at least in part because of his awareness that she spoke to some people about his hypersexuality. Carer 3 indicated that his wife's social life was not negatively impacted by the hypersexuality alone, but that this along with other features of the PD made her more reclusive as she did not feel inclined to go out or see people.

Likewise, the available carer interview findings suggested that hypersexuality could impact patients' work either positively or negatively. Carer 4 suggested that the hypersexuality positively affected his wife's work as *"it was grist to the mill with her writing you see... it gave her a subject matter..."*. Conversely, Carer 6 indicated that the hypersexuality negatively affected her husband's work as he went to see the prostitute instead of completing the work he was supposed to.

About half of the carers indicated that the hypersexuality negatively impacted the patients' finances; this was the case mainly for those patients whose hypersexual behaviours included visiting sex shops to make purchases (Carer 1) or spending time with prostitutes (Carer 6). Carer 1 recounted how she had tried to help control her husband's spending, but with little success:

"I decided that if he agreed... and he did agree... that I would take his credit and debit cards off him... hide any money I'd got in the house... I left him... I think we agreed on fifteen pounds which would be enough for taxi and whatever so he couldn't do that... I hid the cheque books and hid any money I'd got in the house do he didn't have any access to cash... and that worked well for a couple of months and then he remembered that he had an account that I'd forgotten about..." (Carer 1)

In another type of situation, Carer 8 explained that her husband started investing money unwisely because he was influenced by the *"very pretty"* financial advisor. She asserted that, as a result, he lost £40,000 of her savings.

3.3 Health and well-being

Only Carer 8 directly indicated that the hypersexuality negatively affected her husband's health. She believed his bladder infections¹⁶ were related to his frequency of masturbation because as long as he was not masturbating, there were no bladder infections. However, sleep disturbances were a fairly frequently reported effect of hypersexuality, with half of the carers reporting that patients experienced these. Carer 2 and Carer 6, for example, indicated that the hypersexuality dramatically affected their husband's sleep due to frustration or sadness about their condition and how it was affecting their marriage.

"He couldn't sleep because I was working so hard and he was messing around... he said he cried most nights..." (Carer 6)

Carer 1's husband lost sleep largely because of his use of middle-of-the-night sex channels on television, as well as a tendency to lie awake planning trips to sex shops.

¹⁶ Documented in clinical notes.

The reported impacts of hypersexuality on the psychological health of patients were more commonly reported than any physical health impacts. More than half of the carers indicated that the hypersexuality negatively impacted the patients' mood, for example. Some reported anxiety, worry and stress as the main results.

"He was anxious and depressed... worried about everything..." (Carer 1)

"He was more stressed because he just couldn't understand what he was doing..." (Carer 6)

Carer 8 reported a more extreme impact on her husband's mood and state of mind involving psychological withdrawal and apathy which clearly was a big concern to her:

"He seemed very withdrawn... he was completely locked into this mad behaviour... there was no happiness... there was no joy... he never smiled... he was apathetic... he was almost irritable... he was quite angry... he doesn't get irritable... he doesn't show it... if he is and this is what frightens me about him... I feel it's like watching a pressure cooker and there's going to be a time when it pops..." (Carer 8)

With regard to the impact of hypersexuality on the patients' self-confidence, the findings from the carer interviews were not clear-cut, with some participants noting a positive and some a negative impact, while others were unsure whether their partner's self-confidence had been affected by their condition. Positive impacts were reported by three carers but for different reasons: Carer 4 noted that his wife became more confident, largely because she was writing about her condition, which reinforced her positive self-identity, while Carer 8 reported that her husband developed a new sense of self-love and importance.

"Probably more confident... I mean she was writing at the time... that's her identity... she's a writer..." (Carer 4)

"When I asked him when he stopped loving me ... he said he didn't know and he eventually said 'I think I'm narcissistic and I'm in love with myself..." (Carer 8)

Carer 3, however, indicated that the hypersexuality negatively impacted his wife's self-confidence as she felt she could not go to places when she was having sexual thoughts as she felt as if people knew about them. Others were unclear whether hypersexuality was having any impact on the patient's self-confidence, although some noted possible signs of this such as having more pride in his appearance (Carer 2) and generally being quite "cocky" at times (Carer 6).

When asked about their perceptions of the impact of hypersexuality on the patient's quality of life more generally, the findings from the carer interviews were similarly mixed. Four of the carers indicated that hypersexuality was having a negative impact on quality of life but only one explained their answer, specifying that this was because her husband now felt he had a wife who did not love him as much as before, causing him to feel deflated in general. In contrast, two of the carers noted positive impacts of hypersexuality on quality of life.

"I think that as with the madness of love or something... it raises you up but it also is a madness so it is a sickness... it is a sickness we all enjoy..." (Carer 4)

"I knew he was dating again... he'd go out looking really quite handsome in something that I'd suggested to upgrade his wardrobe... go out looking attractive..." (Carer 6)

When directly asked if the hypersexuality negatively affected the patients' lives in general, Carers 4, 5, and 7 were the only ones who indicated that it did not; however, further probing into the impact that the hypersexuality had on the areas of daily living discussed above suggested that it indeed did, as each of the carers indicated at least one of the areas of living as being negatively affected by it.

In conclusion, the areas of living impacted by hypersexuality, in descending order of frequency of carers indicating an impact, were marital life, quality of life, mood, sleep, self-confidence, family life, finances, social life, work, and health.

Theme 4: Control

As seen in the patient data, carers also indicated that the patients expressed a loss of control over their sexuality after developing hypersexuality. A number of the patients had indicated a desire to overcome their hypersexuality and indicated that they had made attempts to reduce or stop it, though not always successfully. Carers were thus asked about their perceptions of the patients' ability to control their hypersexuality. Loss of control, attempt to reduce/stop, and desire to overcome make up the theme of control of hypersexuality within the carer data.

4.1 Loss of control

All the carers believed that their spouses did not have control over their sexual behaviour, but their descriptions indicated that this loss of control was much more extreme for some than for other patients. At one extreme, Carers 1 and 7 reported that their husbands had almost completely lost control of their behaviours, in the case of Carer 7 due to her husband's dementia as well as the hypersexuality.

"He couldn't resist it... it was hopeless... he couldn't stop it..." (Carer 1)

"It's become like a bit of a habit... like something he asks for... it's a bit like asking for a bit more wine..." (Carer 7)

However, Carer 8 who reported that her husband had become almost completely uninhibited also expressed the view that his deviant sexual behaviours were not so much a lack of control but rather a deliberate choice.

"There is a difference... the impulse to do something and the ability to know right from wrong... he knows what's right and what's wrong but he chose to take a risk and his risk-taking has increased... he is the one with his hand on his penis..." (Carer 8)

Others (5 and 6) commented that their husbands were in denial of their behaviours or the damage these were causing, which was also seen to reflect a loss of control, particularly when the patients acknowledged that they had done wrong but claimed that they were unable to help themselves.

Carer 4 admitted that his wife had probably lost some control over her behaviours but indicated that this was not regarded by either of them as a problem.

"I think she probably hadn't got [control]... I think she probably felt a bit out of control... but she didn't seem distressed..." (Carer 4).

4.2 Attempt to reduce/stop

Half of the carers indicated that the patients attempted to reduce/stop their hypersexuality, with varying degrees of success reported between them.

Carers 1 and 6, for example reported that their husbands had tried on occasion to stop their hypersexual behaviours but had been unable to do so. Carer 1's husband had reportedly tried on at least two occasions to get rid of the pornographic material he had bought but would just end up going out and buying more material. Carer 3's wife had also tried to reduce/stop her hypersexuality to no avail. Her husband claimed, however, that since the hypersexuality only manifested in masturbation, "*does it matter? It could be worse...*". Only Carer 2 reported that her husband had been successful in at least reducing his behaviours; although he still wanted sex whenever he could have it he was no longer putting pressure on her. She asserted: "*I think he's doing a good job in trying to keep a lid on it... it's still there but more controlled...*".

Of the two carers (4 and 8) who were unsure whether their partners had attempted to stop or reduce their hypersexuality, Carer 4 indicated that this was in any case not a concern for the couple as they were "*happy in lust ... we like being [sexual]*". The remaining carers (5 and 7) indicated that the patients did not attempt to stop or reduce their hypersexuality or that they were unsure whether they did so.

4.3 Desire to overcome

More than half of the carers indicated that the respective patients had a desire to overcome their hypersexuality. Their responses were based either on the direct verbalization of this desire to them or to others by the patient (Carers 1, 6, 8), or through observing the ways in which they were trying to control their behaviours, such as not asking them for sex as much as before (Carer 2).

"[He] desperately wanted to stop it... he just couldn't work out what had hit him..." (Carer 1)

"[It] absolutely drives her mad and does not make her happy... if clitoris removal existed she would have gone for it..." (Carer 3)

Carer 8 believed her husband wanted to overcome his hypersexuality as he wrote a letter to the psychologist and consultant neurologist explaining that his hypersexuality made him feel ashamed and that he was determined to give it up but it was difficult because he was "*addicted*". She also recognised, however, that he might have said that to the health professionals just to get by and not be held accountable for his sexual changes.

The remaining three carers indicated either that the patients did not have a desire to overcome their hypersexuality, or that they were not sure whether this was the case. Carers 5 and 7 expressed the view that their husbands were in denial about their hypersexuality and for this reason had expressed no desire to overcome it:

"I don't think that he admits that he's hypersexual... because whenever it's come up like now or even when the neuropsychologist was there... it's not something that he'd actually readily say 'Yes I have got a problem' ... I don't think he thinks he's got a problem..." (Carer 5)

"I don't think he understands actually..." (Carer 7)

Theme 5: Emotional formulations

The interview findings suggested that hypersexuality was affecting the carers just as much as the patients, if not more. The carers clearly developed emotional formulations around their partners and/or around the hypersexuality itself. In the interviews, they were asked about their feelings and reactions towards their partners and about the hypersexuality separately.

5.1 Around hypersexuality

At least half of the carers regarded the hypersexuality as a strange phenomenon that they found difficult to understand, and therefore they developed a negative emotional formulation around the condition. These research participants described their emotions towards the hypersexuality largely in terms of shock, confusion, and horror, reflecting the way in which their long-term partner underwent such a significant change in their feelings and behaviours with the onset of the condition.

“I just didn’t know what had happened ... it’s like waking up on the other side of the mirror like Alice in... Through the Looking Glass... it was just so abnormal... he was cold towards me...”
(Carer 8)

“I was shocked... I couldn’t make head and the tail of it... it just didn’t add up to the man I’d been living with for nearly fifty years...” (Carer 1)

In contrast, however, three of the carers expressed emotional formulations around the hypersexuality that were more positive in nature. This was the case in particular for Carer 4, who expressed emotions such as amusement and interest in relation to his wife’s newly developed lustful approach.

“Normally she likes tenderness and sweetness and this was sort of a bit more lust... go for it... [laughing]... and in a way that was fresh and amusing... again one took that as a positive thing... for a while anyway...” (Carer 4)

The other two carers who expressed relatively positive emotions about their partners’ hypersexuality appeared to be more accepting of the condition and reasons for it. Carer 7 expressed understanding that the hypersexuality was part of her husband’s disease and was less anxious about this than about his worsening dementia. She also asserted that she was happy that she was able to meet his newly developed sexual needs. Although Carer 3 was not happy in general about his wife having *“something that is not good for her”*, which affected both their lives, he also claimed to feel relaxed about the hypersexuality because he recognised that *“it could have been worse”*.

5.2 Around partner

All the carers, except one, developed negative emotional formulations around their partners due to the hypersexuality. The interviews revealed that carers often experienced a wide range of negative emotions towards their partners, which often evolved and changed over time along with their changing behaviours. The types of emotions expressed included irritation and annoyance, embarrassment, repulsion, hurt, despair, betrayal, and pity.

For example, although Carer 1 was initially *“very sympathetic”* after discovering that her terminally ill husband had been a repressed gay all his life, as the hypersexuality progressed, she reported feeling *“embarrassed”*, *“hurt”*, *“angry”* and *“totally betrayed”* because he told her that he had been buying homosexual magazines for longer than she was aware. She also reported that she had found him *“repulsive”*, due to what she saw as his *“appalling”* behaviours. Carer 2 described feeling *“cheapened”* and *“uncomfortable”* by the sexual acts her husband was asking her to perform, as well as *“stupid”*, and *“hurt”* by his comments after her rejection of his sexual advances. Similarly, Carer 6 described her feelings

towards her husband in terms such as “*embarrassed*”, “*hurt*”, “*betrayed*”, “*abandoned*”, “and “*repulsed*” by her husband.

Losing respect for the patient and feeling a sense of pity for them was another type of emotional formulation expressed by several of the carers. For example, Carer 6 recalled feeling “*pity*” for her husband because he did not seem to be able to control his sexual behaviour and though it was hard for her to say that she lost respect for him after his death, at the time he was alive and hypersexual, she reported that “*I had no respect... none at all*”. The pity that Carer 7 felt for her husband apparently made it easier for her to accept his condition and cooperate with his sexual demands:

“I just felt really sorry for him... the only pleasure he has in life is to have sex so I didn’t find it difficult for me to... you know... have sex with him... because I felt sorry for him... it was fine for me as well...” (Carer 7)

Several of the carers reported feeling irritated and annoyed by their hypersexual partners, or a sense of hopelessness about their condition. For example, Carer 3 claimed that even though he initially felt turned on by his wife’s hypersexuality, as time went on he started feeling irritated and turned off by her. Carer 5 also claimed that her husband made her “*cross*” and in “*despair*”.

A sense of anger mixed with sadness and betrayal was particularly strong in the case of Carer 8, the only carer whose husband had engaged in deviant sexual practices.

“I was so angry... it wasn’t just emotion... there was anger... I felt very angry about what he’d done ... I wouldn’t want him to touch me because I don’t know who he is... he was doing things that are completely unacceptable... sad... I was very sad... I felt rejected... I felt confused... I feel such a fool... let down...” (Carer 8)

Carer 4, on the other hand, was the only carer who did not develop a negative emotional formulation towards his partner. He reported feeling happy since his wife became more interested in sex with him:

“I was a bit unquestioned maybe looking back... it wasn’t that extreme you know... it was extreme if you like because she’s a reserved person who you know... who has other high standards of good behaviour you know... so this was like nature in the raw really... which didn’t in the least turn me off...” (Carer 4)

With the exception of Carer 4, therefore, the carers all expressed negative emotional formulations which suggested the struggles that are associated with the development of hypersexuality fall not just on the patients but on their carers as well.

It is noteworthy that the carers had a difficult time separating their emotional formulations around their partners from those around the hypersexuality in itself. This may be indicative that the effects of the hypersexuality are overwhelming enough to cause the carers to regard them as being one and the same.

Theme 6: Beliefs in the causes of hypersexuality and attributions

Carers expressed different opinions about the perceived reasons for the onset and progression of the hypersexuality. Some carers attributed it to themselves, some attributed it to the neurological disease and/or its management, and others attributed it to their partners and their past experiences.

6.1 Self-blame

Only Carer 5 placed some blame on herself for the progression of her husband's hypersexuality. She claimed that her menopause, which occurred simultaneously with her husband's hypersexuality, caused her to lose her libido and sex drive. She explained: "*The longer he's not having sex the worse it's making him... so basically that might be my fault...*". The rest of the carers, on the other hand, indicated no self-blame for the development and/or progression of their partners' hypersexuality.

6.2 Blame on neurological disease and/or its management

This was the main reason given by carers for the development of the patients' hypersexuality, with all of the carers attributing the onset of hypersexuality to the neurological disease or to the medications taken for it.

All five carers of the PD patients attributed the hypersexuality to the PD and its' management (pharmacological and surgical). In particular, specific medications of Entacapone (Carer 1), Ropinirole (Carers 2, 3, 5), Madopar (Carer 3) and Rasagiline (Carer 4) were cited as being causes or possible causes of the hypersexuality, as well as the surgical procedure of DBS which was cited by Carer 2.

"I suppose now I can point to Ropinirole and say it's Ropinirole's fault..." (Carer 5)

"He was already on this medication then so you know... and we tried to work out which it was... I thought it was when the entacapone had been added..." (Carer 4)

"Part of the pain in the neck of the disease... awfulness of package that's changed our lives..." (Carer 3)

The three carers of the dementia patients, on the other hand, attributed the hypersexuality to the FTD as there had been no sign of it before the onset of dementia.

"I think it just came with the disease... right before he passed I said to him 'You couldn't help it... it wasn't you... it wasn't what you were like... it was a disease and you've got two of them and they're both serious'..." (Carer 6)

"I recognised that it isn't his fault... it doesn't make it any easier to bare..." (Carer 8)

6.3 Blame on partners and their past experiences

Half of the carers attributed at least some aspects of the hypersexuality to their partner's past experiences. For example, Carer 1 linked its development with his underlying homosexuality:

"[Husband's] parents were away... he was allowed... for a night... and he was allowed to ask his friend from his school to stay overnight which he did... and then some sort of homosexual activity occurred... I mean the implication has always been that he was a repressed homosexual and the hypersexuality had overridden his control of that and was forcing him... allowing him... whatever... stimulating him to pursue the homosexuality as he never had done as far as I know..." (Carer 1)

Carer 6 also claimed that her husband's hypersexuality may be due to two past experiences. First, he had been sexually abused as a seven-year-old child by the headmaster of his school. Second, he had an ex-girlfriend of Indian descent during his twenties who died in a car accident. She indicated that both prostitutes her husband had been involved with were dark-skinned and considered that there might be a link between this and the evolution of his hypersexuality.

Carer 8 claimed that, during her husband's teenage years, he did put on women's makeup and clothes and he did masturbate while wearing his mother's underwear when he was eleven years old. She explained that he told her that those behaviours had gone by the time he met and married her but that they have since "come back". She expressed that he her husband "reverted to factory settings... I will never know how much is the illness and how much isn't...".

Theme 7: Relationship with the partner

As mentioned earlier, relationships with partners were impacted more than other areas of life by the patients' hypersexuality. This negative impact was coupled with changes in the image of their partners as well as aggressive response to the hypersexuality.

7.1 Impact on marriage

All the carers, except Carer 4, indicated that the hypersexuality had negatively impacted their marital life. Three main ways in which this occurred could be identified: changes in the nature of sexual activity, a reduction in affection between the marital partners, and a shift in the balance of the relationship.

Three of the carers in particular noted that sex with their partners had become much more mechanical and less loving than before. For example, Carer 2 no longer believed that her husband loved her as a person and instead saw her as a sex object, while Carer 7 reported that since his dementia had developed, he asked for sex multiple times a day and that this became the only thing he was interested in. This individual as well as Carers 2, 5, and 7 described how they felt about the change in their sexual relationships.

"It's not like an intimate loving relationship... it's more mechanical and ritual-like..." (Carer 7)

"Hypersexuality is his way of being masculine... not for sexual gratification but rather for me to enjoy it as well... but he doesn't understand that I don't..." (Carer 2)

"It's not making love to me or me making love to him in the way that I used to know... it's not that anymore..." (Carer 5)

Many of the carers also stressed that their partners had become much less affectionate and loving towards them in general since developing hypersexuality. This was particularly the case for Carer 6, whose husband chose to visit prostitutes and developed a close relationship with one. Carer 6 recalled how he would tell her how he did not love her enough and that she was "second best" to the prostitute. She explained that as a result they divorced afterwards after forty-one years of marriage, although they did remarry four days before her husband passed away. Carer 2 explained that her husband became less affectionate in non-sexual ways, though he apparently accused *her* of being less affectionate and having abandoned him, a point that she did not agree with. Overall, nearly all of the carers reported ways in which their spouses were less affectionate towards them since developing hypersexuality.

"Before he died we were civil to each other... we have always had a loving marriage... but my marriage was wrecked... and he died among the wreckage..." (Carer 1)

Closely related to this, several of the carers reported ways in which the ways in which they perceived their own role in the relationship had changed as a result of the patient's hypersexual behaviours and attitudes towards them.

"I stopped being a wife and became a housekeeper and a carer..." (Carer 1)

“I’m just there to put food on the table... to clean the house... and he’s polite to me because that’s how he’s been brought up... to be polite... but it’s not a marriage...” (Carer 8)

“I actually feel now that I’m... it’s a role reversal... I don’t think he’s looking after me... I think I’m looking after him...” (Carer 5)

Carer 4, on the other hand, claimed that the hypersexuality did not cause problems in their relationship. Despite his wife’s lusting after her therapist, he did not feel insecure about their relationship:

“I half felt amused in a way because I don’t really feel insecure ... you know... it’s a good relationship...” (Carer 4)

7.2 Image of partner

Some of the carers stressed that their image of their partners had changed as a result of their hypersexual behaviours. It appeared that these carers no longer viewed their partners as being the same individuals they were before developing hypersexuality, further suggesting their inability to separate between their partners as individuals and the hypersexuality itself.

“It just didn’t add up to the man I’d been living with for nearly fifty years...” (Carer 1)

“I’m losing the husband that I had... he’s just not the same anymore...” (Carer 5)

“The man I married was intelligent... vibrant... really really fun to be with... very very loving... I’m now living with not just the fact that I lost my husband but that my husband was never who I thought he was... I don’t know who this person is and in fact I got him to move out of our bedroom the night I found out about the pornography... and I lay in bed that night on my own... he was in the other room... and I had the duvet and my arms underneath and I thought ‘Put your arms on top’ and then I thought ‘Why did I think that?’ and I thought ‘Because he might come in... I’m frightened’ then I got up and I locked my bedroom door... because I was so frightened of who this person was because he was not the man I married and I now had proof he was not the man I married... this is a man who was having to imagine he was wearing women’s clothes before he could get an erection with me... who is this man and did I ever know? It made me question everything...” (Carer 8)

7.3 Aggression

Evidently, some carers, due to their stress and frustration from dealing with their partners and the hypersexuality, expressed either a desire or an actual instance where they had an aggressive response to their partners’ hypersexuality. Carer 6, for instance recalled once hitting her husband “hard” because of her frustration with him.

“I think the worst thing was that on one occasion I actually momentarily considered violence towards him... he’d had one of his trips to the sex shop... he got stuff... I’d been out in the garden... and I’d seen him through the window of his office... obviously he was busy looking at some stuff... and it was lunch time and I came in to give him his lunch... and I stood behind him and I really can’t believe it now but I’ve got to tell you... it’s the truth... I stood behind him with this big hammer in my hand... and I thought quite clearly ‘A couple of blows to your skull with this and this would all be over’... and then I put the hammer away and served his lunch...” (Carer 2)

“Even after I’d found out, I couldn’t get him to talk to me about it and I remember going to his workshop one day like this and I asked him and asked him and he just stood there like a defiant little boy... and I picked him up... I’m only five feet... he’s five foot six... he’s much bigger... I picked him up by his boiler suit and I walked him backwards to the wall... just lifted him off the floor... banged him against the wall and I said ‘Talk to me’ and he just stood there till I let go of him... nothing moves him... nothing moves him... my GP said ‘Make sure you’re not near the knife block when you do hit him... get out of the kitchen’... she said ‘Don’t put yourself in danger’ and what she meant was danger of being arrested I think...” (Carer 8)

These aggressive responses/contemplations indicate the level of burden that is inflicted on the carers as a result of their partners’ hypersexuality.

Theme 8: Dealing with hypersexuality

Evidently, there were various ways in which carers dealt with their partners’ hypersexuality. The carers either attempted to limit the hypersexuality, attempted to uncover facts about the hypersexuality, or gave in to the hypersexuality.

It is important to note that all the carers tried at least one method of dealing mentioned above.

8.1 Attempt to limit hypersexuality

Three carers indicated that they actively attempted to limit their partners’ hypersexuality. For example, Carer 8 claimed that when she found the websites her husband was accessing, she called a technician to put a “block” on the computer so that he could no longer access any pornography. Furthermore, she noted that she would not be prepared to lie about any illegal activities in which he was indulging.

“If he did continue to do something and the police came... I would step aside... I would explain that he had a degenerative brain disease but I’m not going to protect him if he’s doing something illegal which he was... I think there’s a limit to how much protection I can afford someone who has done nothing to deserve protection...” (Carer 8)

“I would switch the television off and take the [pornographic] DVD out... I think I became very controlling... and I’m not sure if that was the right thing or the wrong thing to do but I did... for a start because I found it offensive... very offensive...” (Carer 1)

Carer 5 did not like to go to bed before her husband because she worried about what he was doing; by staying up, she felt she could perhaps limit his pornography viewing activity:

“I don’t like going to bed first because I lay in bed trying to listen whether he’s changing channels... whether it’s really Match of the Day or something else... and he started going to the second living room a bit too... the guest accommodation next door... he goes in there occasionally and says it’s because he wants to watch something different to what I’m watching and then he starts putting the DVD player on... and again it’s probably all okay but I think maybe... has he got some funny DVD or something...” (Carer 5)

8.2 Attempt to uncover facts about hypersexuality

Half of the carers reported that they had actively tried to find out about their partner’s hypersexual behaviours, for example by looking for their pornographic magazines or videos which were hidden in the house, checking their computers or phones for evidence that they had been visiting sex sites, or checking their phones for messages from other people that they might be involved with sexually.

“I certainly looked for materials he’d obtained and was using... when I realised that he had bought a gay magazine... because I found the receipt by chance... after it when I thought about it he just said he was just curious... when he was out I went and unlocked the case and found more magazines... so yes I did go looking for them... yes I did go and look in his case and see what he’d got...” (Carer 1)

“Partly I snooped... when I saw two thousand pounds being taken out of... you don’t just take that out... but partly I did a ring back... a 1471 and got connected to the sex line on our phone... I mean he didn’t bother to disguise it because I don’t think he could...” (Carer 6)

“He goes into day care two days a week... I search the room... I look under the mattress... I look under the carpet... I look inside the pillowcases... it’s turned me on to being hyper vigilant...” (Carer 8)

Only Carer 2 reported specifically that she did not try to uncover facts about her husband’s hypersexuality because *“I do trust him”*.

8.3 Giving in to hypersexuality

Around half of the carers indicated that they accepted their partner’s hypersexual behaviours although they were not happy with them. For a small number this tolerance extended to a greater degree of understanding and even support in helping their partner to indulge their hypersexual desires outside of the marital relationship.

Carer 1 in particular described the ways in which before her husband’s death she had come to terms with and supported his behaviours, and also demonstrated remorse upon learning later that it was likely to have been his medication that had caused these:

“I thought ‘God this poor man has been a repressed gay all his life... he’s never indulged in it... I know he’s ill... he hasn’t got that many more years to live... if he wants to indulge in this why shouldn’t he?’ and so I said to him ‘Look you can’t drive now... if you want to go to gay bars and clubs I will take you there’... after you’d phoned me and said that there is some evidence that it does alter sexual orientation... I just sat and cried... I thought ‘Poor man’... he must’ve been so confused with what’s happening to him... utterly... and he couldn’t resist it...” (Carer 1)

Carer 7 also demonstrated a very selfless attitude which resulted in her complying with her husband’s sexual demands to keep him happy:

“Not like I feel it’s a great suffering to me... it’s... to me... about his needs... maybe more than mine...” (Carer 7)

To a lesser extent, Carers 2, 3, and 4 were also accepting of and gave in to the demands of their hypersexual partners, though in the case of Carer 4 this was less of a challenge since he was more welcoming of his wife’s new levels of sexual interest.

Theme 9: Coping with hypersexuality

The primary difference between dealing and coping is that dealing refers to the behavioural responses the carers have towards the hypersexuality itself whereas coping refers to the strategies used to endure the effects of hypersexuality. The ways in which the carers coped with their partner’s hypersexuality fell into three main categories: taking on no personal responsibility for or guilt relating to the patient’s behaviours,

gaining an understanding of the reasons for hypersexuality, and forgiving their partners. All the carers expressed at least one of these aspects of coping. A final sub-theme consists of difficulties with coping.

9.1 Responsibility/guilt

All of the carers, except Carer 5, indicated that they had no feelings of responsibility over their partners' hypersexuality. The interview findings suggested that this may allow them to achieve the extent of psychological or emotional distance from the patient and their condition which is necessary to enable them to cope with the stress and pressure involved.

Carer 1, for example, had no feelings of responsibility over her husband's hypersexuality because they *"always had a fulfilling sexual relationship... I think the term was he'd 'never gone short'... and we both enjoyed it..."*. Carer 2 on the other hand acknowledged that there was a sexual mismatch between herself and her husband but for this very reason she did not feel any responsibility because this had always been the case. Although Carer 8 had initially thought her husband's rejection of her was her fault, she no longer felt responsible when she discovered that he had had an interest in transvestite sex for many years:

"I thought I had done something and I tried for twenty years to find out what it was and when I found out it had all been him I didn't feel responsible..." (Carer 8)

Carer 5, on the other hand, felt a sense of responsibility and guilt over her husband's behaviour, since the onset of his hypersexuality had coincided with her own declining sex drive at the time of her menopause:

"I sort of think well [laughing] maybe it is my fault... maybe it is my fault that you know I'm not... wanting to have sex every night or whatever... I don't know where desire's gone because it is practically... it is non-existent..." (Carer 5)

Apart from Carer 5 who felt guilty about rejecting her husband's advances, two other carers expressed feelings of guilt relating to aspects of their partners' hypersexuality. Carer 1 developed feelings of guilt since finding out it might have been the drug that caused her husband's homosexuality and not that he had been hiding his homosexuality from her throughout their 50-year marriage. Carer 3 developed feelings of guilt because he saw his wife was unhappy but knew that he was unable to help her in any way. The remaining carers did not indicate any feelings of guilt over their partners' hypersexuality.

9.2 Understanding the hypersexuality

As mentioned in a previous theme, all carers appeared to understand that the onset of hypersexuality was ultimately caused by the neurological disorder; however, this understanding did not necessarily imply that they have coped well with it. Some also demonstrated a more astute understanding of the nature of the condition and its manifestations.

Carer 7, in particular, whose husband is one of the dementia patients, reported having learned a lot about the issue of hypersexuality through her membership of an Alzheimer's society as well as some support groups. She also explained that she is a trained counsellor, and had learned a lot about sexuality as part of her training. This had enabled her to understand and cope with her husband's hypersexuality:

"Kind of owning the fact that... that sex is not just with the other... it's your relationship with yourself as well as the other person so I'm able to separate how to be who I am and who he is so I don't actually feel exploited... like I'm able just to see that he has a greater need for sex than me and for our relationship to work I help him to meet that need and I'm having lots of other needs met in our relationship... it balances quite nicely..." (Carer 7)

As mentioned in earlier sections, Carer 4 also conveyed an understanding of the psychological reasons for his wife's lustful attraction to her therapist, which meant that he did not feel threatened by this:

"I think I put it down to her transference and the peculiar relationship that is actually truly expected within... within a serious therapeutic relationship... I mean it is a relationship of huge power... and... I think in a way she was supposed to have this transference... I think that was part of the deal... he was meant to become her father and she felt a sort of way towards her father..."
(Carer 4)

Three carers reported that "talking" about the hypersexuality had been "therapeutic", and their explanations indicated that this may also have given them a greater understanding of the condition. For example, Carer 1, whose husband had already passed away, explained her reaction to learning from the researcher that he may not have been able to help his behaviour.

"After you'd phoned me and said that there is some evidence that it does alter sexual orientation... I just sat and cried... I thought 'Poor man'... he must've been so confused with what's happening to him... utterly... and he couldn't resist it..." (Carer 1)

Carers 5 and 8, on the other hand, both reported discussing their partner's hypersexuality with medical professionals, and indicated that these conversations had been very helpful in enabling them to cope even if, as in the case of Carer 8, the therapy mainly consisted of having someone listen to her and let her cry about the situation.

"She [GP] just let me cry and she said to me 'You know... you're always going to feel sad about this'... she didn't try and pretend it would go away... I said to her 'That's the most genuine response I've had so far'..." (Carer 8)

Carer 8 also indicated that she is a Buddhist and had used meditation as an attempt to mitigate her stress and negative feelings. She reported that it helped her realise that "it's not me that's let him down... it's been the other way round".

9.3 Forgiveness

Only three carers (1, 5, and 6) expressed an ability to forgive their partners for their hypersexuality, though three others (3, 4, and 7) indicated that there was nothing to forgive.

For those who felt that forgiveness was necessary and indicated that they could offer this, their responses however, indicated that this was quite difficult and could only be achieved sometime in the future. Carer 1, for example, reported that she was "on the road to forgiveness", and Carer 6 specified that she would forgive her husband only because she now knew that the hypersexuality was a by-product of the dementia.

Carers 2 and 8, however, both indicated that it will be difficult or impossible to forgive their husbands. Carer 8 claimed that she could never forgive her husband and that she had told him so, having discovering his longstanding deviant sexual behaviours and feeling that their whole marriage had been a "sham". Carer 8 also indicated that she could not forgive her husband because of the ways he had hurt her with his words and behaviours: "some things can't be unsaid".

9.4 Difficulties with coping

Coping is not an easy process and requires resilience. Around half of the carers indicated that they had often experienced difficulties in coping with their partner's hypersexuality, which for a minority extended to a desire to no longer exist.

Carer 2, for example, claimed she was “*further back than I have ever been because I don’t feel that safety and security that I feel I need to have*”. This individual reported using Citalopram and avoidance tactics to help her cope with her husband’s hypersexuality. The extent to which she found this difficulty was reflected in her comment that, although she was not exactly suicidal, if she were to get run over by a bus it would be fine: “*I just wished I didn’t exist*”. Carer 8 mirrored this sentiment and claimed that she “*didn’t want to commit suicide but I would like not to exist and there’s a difference between not wanting to exist and wanting to be dead...*”. Although Carer 6 did not have such extreme thoughts, she did indicate that coping was difficult and that it was easier during the daytime but “*awful*” during the night time, causing her lack of sleep.

Theme 10: Self-image

So far, it has been ascertained that the effects of the hypersexuality were mostly overwhelming and devastating for the carers. These effects were very easily translated into feeling unloved, feeling used, and changes in carers’ self-confidence.

10.1 Feeling unloved

Half of the carers (1, 2, 5, and 8) indicated feeling unloved by their husbands, especially those whose sexual relationship with their partners had become mechanical and non-affectionate as a result of the hypersexuality. Their comments indicated that this made them sad and nostalgic for the loving relationships they had before the onset of the condition, and reinforced findings about the shifts that tended to occur in roles within their relationships.

“I feel as if he is only interested in me sexually...” (Carer 2)

Carer 8 claimed that her husband told the memory nurse that he admired his wife, but she asserted that she did not want to be admired, she wanted to be loved.

Carer 5’s interview indicated that assurances from her husband that he loved her counted for little in the face of his hypersexual behaviours and overall decline in affection towards her, since she could no longer take these assurances seriously.

“All the time it will end up in ‘You don’t know how much I love you and I wouldn’t do anything to hurt you’ ... he used to always be telling me that he loved me and... I think that’s what I miss a bit really... he isn’t quite so affectionate... he used to say it on a daily basis how much he loved me and things and that was quite nice...” (Carer 5)

10.2 Feeling used

The same four carers indicated that they not only felt unloved but also “*used*” by their husbands for their sexual gratification. The types of concerns they expressed indicated that to them, this signalled a shift from a normal loving sexual relationship to one which was becoming primarily physical and for the purpose of satisfying their husbands’ hypersexual needs.

“I’ve always thought of it very old fashioned as making love... sex of sex’s sake for me is nothing... so the fact that he was then using these magazines to psych himself up to come and have sex with me was really meaning he was just using me to have sex... he was using me... like an animal really...” (Carer 1)

“I feel... I’m competing with the women on the television or in his mind... I feel like he wants me to be one of them rather than... being me...” (Carer 5)

“He has said he had had to imagine he was wearing women’s clothes before he could get an erection with me and that makes me feel really creepy because I was in bed with someone who was going to imagine he was wearing women’s clothes before he could touch me...” (Carer 8)

10.3 Self-confidence

Three of the same carers who indicated that they feel unloved and used by their partners (1, 2, and 8), along with Carer 6, also claimed that the hypersexuality and their husbands’ consequent demeanour had negatively impacted their self-confidence. Carer 1 explained that they had made her question herself even though she had always taken great care of her appearance.

“On one occasion I said to my husband ‘I don’t understand how you can do this to me’... I’ve always stayed slim... I was always reasonably dressed... I was his official wife... had to go to functions and things with him... he always said how well dressed I looked... I could talk to people and do the proper job as a wife... that he had never been short of sex... so what was it?” (Carer 1)

“At the time I felt completely worthless... completely and utterly worthless... I just felt so ugly and old...” (Carer 8)

Carers 5 and 7, on the other hand, indicated that the hypersexuality and their husbands’ consequent demeanour had no impact on their self-confidence. Both claimed to be confident individuals generally, a trait which apparently helped them to cope with their respective partners’ behaviours.

“[My] counselling training has helped me to be more confident in who I am so it doesn’t rattle me as much as it might other people...” (Carer 7)

Theme 11: Stigma

As mentioned in the previous thematic analysis section for the patients, there was huge stigma associated with sexual behaviour as it has long been regarded as a taboo subject. There appeared to be three forms of stigma associated with hypersexuality: personal stigma, social stigma, and help-seeking stigma. The carers, unlike the patients, expressed no help-seeking stigma in their interviews.

Only Carer 5 expressed personal stigma: *“We’re in our sixties so it’s quite obvious that we’re not going to feel how we did when we first met in our thirties... but he seems to be still back in that era and wants it in the same way...”*. Her reference to the older age group suggests that older people are not to be as sexual as younger people, which is not necessarily true. She may have said this to further solidify her view that the hypersexuality was unnatural.

Three of the carers made comments which indicated that they were concerned about the social stigma associated with hypersexuality. They expressed worry that others would find out about their partner’s condition and how that would reflect negatively on themselves and their families.

“I suppose the thing that bothered me most was the thought that other people would find out and laugh at me because I’d always... pride always comes before a fall... I’d always been proud of my happy marriage... we’d worked at it and the thought that my husband was gay and might be discovered to be gay are... yeah... that did worry me...” (Carer 1)

Carer 6, while expressing the view that people need more understanding and aware of the condition of hypersexuality, indicated that it would be too difficult for her to play a role in raising awareness in her local community because of the stigma involved.

“I can’t really spread the word because... I would... but because of the children and the embarrassment of you know having a father do that which is difficult Someone such as myself who has been through it... I’m actually quite free to talk about it away from home and I’m quite happy to talk about it away from home...” (Carer 6)

Furthermore, during the interviews, most carers tended to hesitate, laugh inappropriately and nervously, as well as apologise to the interviewer, after being asked sexually-specific questions or if their answers prompted them to go into detail about their partners’ sexual experience. This might be due to the embarrassment associated with sex and discussing it. For example, an instance of laughter was demonstrated by Carer 3: *“[laughing] she’d go straight to the... not too much foreplay... not too much... normally she likes tenderness and sweetness and this was sort of a bit more lust... go for it [laughing] ...”*.

An instance of apologising was demonstrated by Carer 3: “I mean the change was there in just the amount of sex we were having and the sort of... you know... on the stairs as it were you know... which wasn’t something we’d done for many years not since our young days... *sorry...*”. He may have apologised due to the possibility that he crossed a socially-constructed line.

An instance of hesitation was demonstrated by Carer 1 who, at one point after explicitly revealing her husband’s sexual experiences in detail, said: “I’m being horribly honest here... *is this alright?*”. Her hesitation may be due to fear of having been inappropriate. It would be excessive, however, to list all these moments for each of the carers.

Theme 12: Professional help-seeking

Professional help-seeking barriers may stem from the stigma associated with sex and the difficulties associated with discussing such a sensitive topic. It appeared that health professionals may not have wanted to cause the patients or their carers discomfort, do not know enough to broach the subject, and/or do not know what resources to provide if hypersexuality is presented as an issue. According to the carer interviews, problems in relation to professional help seeking included a lack of communication, lack of understanding, lack of education, neglect by the health professionals, stigma associated with hypersexuality, and difficulties in discussing sex. Because of these barriers, some of the carers expressed certain aspirations with regard to professional help for people with hypersexuality and their carers. Barriers and aspirations thus make up the subthemes for professional help-seeking based on the carer interviews.

12.1 Barriers

It was clear that the carers were not receiving adequate and necessary information and help for their partners’ newly-developed hypersexuality. All of the eight carers in the sample recounted experiences in which they had been unable to obtain the help and information they needed to effectively support their partner and described emotions such as frustration, sadness, and anger that this help was not available to them.

One of the main issues raised is that patients were not made properly aware of the likelihood of hypersexuality, and what this entailed, when taking drugs for PD. For example, Carer 1 claimed that after her husband developed hypersexuality, she went to her own GP who was not aware that there was a possible connection between PD and sex. She then went to her husband’s GP who she believed was

“useless” as he was very dismissive and laughed at her concerns. This carer queried the ethics of not warning PD patients of the risks of hypersexuality and what this entails.

“If somebody had said... well warning you that this might happen when he went on these drugs... I mean it says in the leaflets... it talks about hypersexuality... I looked at it and read the sheets through and I said ‘Oh hypersexual... he’ll be a bit frisky and that’ll be alright’... you know... the horrors of what were to come never occurred to me... if nobody speaks out then this will go on and other marriages will be ruined like mine was ruined... at least had we’ve been told it wouldn’t have been such a terrible shock...” (Carer 1)

Carer 4 also expressed surprise that health professionals had not brought up the issue of hypersexuality or spoken about it with his wife, and Carer 5 similarly noted her dismay with medical professionals’ avoidance of talking about hypersexuality:

“I have tried to broach this a few times with my husband’s neurologist... I do a bit more than hint at the problems now and again but he never sort of takes it and runs with it... we’ve been seeing him for ten years and not once has he asked about hypersexuality... or hinted... that it could be a problem... he would spend more time talking about gambling...” (Carer 5)

Several of the carers reported that one of the main problems seems to be that medical professionals themselves have little knowledge or understanding of the condition of hypersexuality, and an apparent unwillingness to investigate this further or take the concerns of patients and their carers seriously. For example, Carer 2 and her husband brought up the hypersexuality concern to the nurses who did not know much about it and who “*didn’t dig deeper*”. Carer 3 also expressed his frustration with nobody having an answer or an explanation about the hypersexuality, and claimed that there was thus no one to ask for help.

“No one cares enough ... you just don’t feel listened to ... the overwhelming feeling is of not being believed ... even neurologist, even psychoneurologists... don’t know enough about it” (Carer 6)

Carer 2 also identified a lack of respect as well as understanding on the part of her GP who commented: “*I know your husband is a nice man so just on with it. Do you want him to go elsewhere?*”.

Carer 8 reported a lack of support from counsellors and psychiatrists, who similarly had no experience of providing advice relating to the types of behaviours that her husband was exhibiting. For example, when seeing a psychiatrist because she was having a breakdown, she recalled “*sitting there crying trying to explain what had happened and he kept saying ‘FTD and transvestitism... oh my God! Oh, my God! How are you going to cope?’ and I said ‘I don’t know’ and I was crying... ‘That’s why I’m here’...*”. On another occasion a counselling suggested joining a transvestite support group, to which her response was “*No I don’t. I’m not going to share this with people who I don’t know... I might as well get into an open-top bus and shout it into the streets*”. Her GP was equally unhelpful in his advice, which at one point amounted to suggesting “*You’ll have to say to yourself... your little mantra has to be ‘He can’t help it... he can’t help it’...*” (Carer 8).

12.2 Aspirations

More than half (1, 2, 4, 6, and 8) of the carers expressed their desire for education of the health professionals about hypersexuality and its consequences to enable them to educate the patients and their carers about this condition. They viewed the ultimate objectives of this to include alleviation of the patient and carer burden of living with hypersexuality and the facilitation of more effective help-seeking behaviour.

Carer 1 expressed the concern that it is unethical not to warn people of the risks of hypersexuality, and therefore aspired to have better education and awareness raising for medical professionals. This view was shared by Carer 4 who expressed a belief in the “*necessity of full disclosure*” and argued that health professionals therefore need to speak up about hypersexuality.

Carer 6 claimed that hypersexuality “*has to become a specialty... I wish that they wouldn't say to go to marriage guidance and counselling because... they are not equipped to handle [it]*”. She expressed her hope that the problem of hypersexuality will be picked up quicker, which is the reason she consented to taking part in the study.

Carer 8 also claimed she needed help “*with managing the anger that I feel in a way that is useful... not in a way where somebody just sits there and tell me that my mantra should be that my husband can't help it... I want somebody who can help me understand why I'm angry and who can help me resolve these angry feelings before my husband dies*”.

Table 26 below outlines the labels of each theme and a summary for each.

Table 26 – Labels and summaries of themes for carers

Label of theme	Summary
<i>Manifestations</i>	Outlines the different ways the hypersexuality manifested among the carers' partners according to the carers' perceptions. Differences were observed in the accounts of carers regarding the patients' sexual desires, their sexual behaviour after the development of hypersexuality, the indicators of their hypersexuality, their preoccupation with it, and the possible consequent compulsivity. The carers reported on the ways they became aware of the hypersexuality. These instances, termed 'indicators', fell broadly into three categories: their partners told them directly about their hypersexuality, they found out based on changes in their partners' sexual behaviours towards them, or they discovered their partners' clandestine behaviours. Increased desire following the development of hypersexuality was evident in the carer-perceived experiences of all patients. The carers indicated an increase in patients' desire for their partners, for others, or for both. The most common type of carer response was that their spouses developed a heightened desire for sex with them as well as increased sexual desire whether with people outside the relationship or for self-pleasure in the form of masturbation or the use of pornography. Moreover, according to the carers' accounts, the hypersexuality apparently caused changes in pre-existing behaviour or development of new behaviours. These changes fell into two main categories: first, the adoption of pornographic materials or new sexual behaviours involving others, and second, an increase in levels or forms of sexual behaviours towards partners, or the intensification of old sexual behaviours. The findings indicated that from the perspective of the carers, one of the main manifestations of hypersexuality was preoccupation with sexual thoughts. The translation of sexual thoughts and preoccupation into compulsive behaviour was perceived by many of the carers to be another of the main manifestations of the patients' hypersexuality. The types of compulsive behaviours reported by carers varied, however, including the regular or intensive use of pornographic materials, visiting prostitutes, and generally indulging in sexual behaviours throughout the day.
<i>Sexual practices</i>	Outlines how hypersexuality affected the patients' sexual practices, according to the carers' perspectives. These sexual practices included patients' practices with

the carer, practices with themselves, practices with others, and deviant sexual practices. Sexual practices with the partner involved changes in both the frequency and nature of sexual acts. Some carers indicated that their partners were demanding a higher frequency of sex with their spouses since developing hypersexuality. Also, most of the carers reported that there had been changes in the nature of the patients' sexual demands or behaviours, which they typically described as being out of character with the person they were before developing this condition. These included, for instance, more aggressive sexual tendencies, demands for role play, and more adventurous sexual practices than they had used in the past, such as oral or anal sex. Furthermore, some carers reported a decline in sexual activity with their partner – in some cases because they started to resist their frequent or inappropriate advances. In other cases, the decline in sexual activity within the marriage apparently occurred because the partner was instead seeking gratification from other sources. A majority of the carers reported that the patients also indulged in masturbation and use of pornographic material. Sexual practices with others that were reported included anonymous sexual encounters, paying for sex, and developing sexual attention to people other than spouse. Lastly, desires did not appear to translate into paraphilic deviant practices as only one carer reported this.

Impact

Outlines the carer-perceived impacts of hypersexuality on different areas of patients' daily living. These included marital life, family life, social life, work, finances, health, mood, sleep, self-confidence, and quality of life. Almost all carers indicated that the hypersexuality negatively impacted their marital lives. They reported multiple impacts including reduced intimacy, increased distance between themselves and the patient, and a range of negative emotions on their own part, such as anger, embarrassment, and despair. Overall, there was a sense from the interviews that the carers more than the patients perceived there to have been quite severe and extreme impacts on their marital life due to the ways in which the hypersexuality had changed their partners. The loss of closeness or intimacy arose for two different reasons. In some cases, increased demands for sex which took a more impersonal or mechanical form than in the past had caused resentment or disgust on the part of their spouse or had changed the nature of their sexual relationship in ways that were not welcome to them. The main types of negative emotions identified from the carer interviews, which appeared to have an impact on marital life, included anger, embarrassment, disapproval, betrayal, and sadness. Among the carers, one of the most commonly mentioned negative emotions was anger about their spouses' behaviour or the way they were treated by them after they developed the hypersexuality. Most of the carers also expressed a sense of disapproval or embarrassment about the patients' hypersexuality, and several expressed feelings of betrayal, self-blame, or reduced self-confidence as a result of their partner's hypersexual behaviour, which in some cases had turned to anger over time. Some of the responses suggested that a substantial shift had occurred in the nature of the marital relationship due to the hypersexual behaviours, with a growing lack of respect for the patient, for example, or a sense of taking control over them in order to preserve the marriage. Many of the carers also stressed that their partners had become much less affectionate and loving towards them in general since developing hypersexuality. Half of the carers indicated that the hypersexuality negatively impacted their family lives, identifying effects on their children which ranged from having fathers who were absent much of the time to being traumatised or stressed by their father's hypersexuality. Little information

emerged from the carers interviews on the impacts of hypersexuality on the patients' social lives, but the available findings indicated that these could be either positive or negative. Likewise, the available carer interview findings suggested that hypersexuality could impact patients' work either positively or negatively. About half of the carers indicated that the hypersexuality negatively impacted the patients' finances; this was the case mainly for those patients whose hypersexual behaviours included visiting sex shops to make purchases or spending time with prostitutes. While only one carer directly indicated that the hypersexuality negatively affected her husband's health, half of the carers fairly frequently reported sleep disturbances as a result of hypersexuality. Reasons for this include feeling sadness and frustration about the condition and how it was consequently affecting the marriage, preoccupation of sex, and planning trips to sex shops. The reported impacts of hypersexuality on the psychological health of patients were more commonly reported than any physical health impacts. More than half of the carers indicated that the hypersexuality negatively impacted the patients' mood, for example. Some reported anxiety, worry and stress as the main results. With regard to the impact of hypersexuality on the patients' self-confidence, the findings from the carer interviews were not clear-cut, with some participants noting a positive and some a negative impact, while others were unsure whether their partner's self-confidence had been affected by their condition. When asked about their perceptions of the impact of hypersexuality on the patient's quality of life more generally, the findings from the carer interviews were similarly mixed. Four of the carers indicated that hypersexuality had a negative impact on quality of life but only one explained their answer, specifying that this was because her husband now felt he had a wife who did not love him as much as before, causing him to feel deflated in general. Generally, each of the carers indicated at least one of the areas of living as being negatively affected by hypersexuality.

Control

Highlights carer-perceptions regarding how much control they believed their partners had over their hypersexuality. A number of the patients had indicated a desire to overcome their hypersexuality and indicated that they had made attempts to reduce or stop it, though not always successfully. All the carers believed that their spouses did not have control over their sexual behaviour, but their descriptions indicated that this loss of control was much more extreme for some than for other patients. Half of the carers indicated that the patients attempted to reduce/stop their hypersexuality, with varying degrees of success reported between them. More than half of the carers indicated that the respective patients had a desire to overcome their hypersexuality. Their responses were based either on the direct verbalization of this desire to them or to others by the patient, or through observing the ways in which they were trying to control their behaviours, such as not asking them for sex as much as before.

Emotional formulations

Highlights the emotional formulations that the carers had around their partners and/or around the hypersexuality itself. In the interviews, the carers were asked about their feelings and reactions towards their partners and about the hypersexuality separately. At least half of the carers regarded the hypersexuality as a strange phenomenon that they found difficult to understand, and therefore they developed a negative emotional formulation around the condition. These research participants described their emotions towards the hypersexuality largely in terms of shock, confusion, and horror, reflecting the way in which their long-term partner underwent such a significant change in their feelings and behaviours with the onset of the condition. Other carers expressed emotional formulations around

the hypersexuality that were more positive in nature, such as in the case of one carer who expressed emotions such as amusement and interest in relation to his wife's newly developed lustful approach. All the carers, except one, developed negative emotional formulations around their partners due to the hypersexuality. The interviews revealed that carers often experienced a wide range of negative emotions towards their partners, which often evolved and changed over time along with their changing behaviours. The types of emotions expressed included irritation and annoyance, embarrassment, repulsion, hurt, despair, betrayal and pity. It is noteworthy that the carers had a difficult time separating their emotional formulations around their partners from those around the hypersexuality in itself. This may be indicative that the effects of the hypersexuality are overwhelming enough to cause the carers to regard them as being one and the same.

Beliefs in the causes of hypersexuality and attributions

Outlines the carers' opinions about the perceived reasons for the onset and progression of the hypersexuality. Some carers attributed it to themselves, some attributed it to the neurological disease and/or its management, and others attributed it to their partners and their past experiences. Attribution of the hypersexuality to the neurological disease and/or its management was the main reason given by carers for the development of the patients' hypersexuality. All five carers of the PD patients attributed the hypersexuality to the PD and its' management (pharmacological and surgical). The three carers of the dementia patients, on the other hand, attributed the hypersexuality to the FTD as there had been no sign of it before the onset of dementia. Half of the carers attributed at least some aspects of the hypersexuality to their partner's past experiences (e.g. homosexual experience during teen years).

Relationship with the partner

Highlights in more detail the impact of hypersexuality on the carers' relationships with their partners, which was coupled with changes in the image of their partners, as well as aggressive responses to the hypersexuality. The three main ways the hypersexuality impacted the relationships include changes in the nature of sexual activity, a reduction in affection between the marital partners, and a shift in the balance of the relationship. Some of the carers stressed that their image of their partners had changed as a result of their hypersexual behaviours. It appeared that these carers no longer viewed their partners as being the same individuals they were before developing hypersexuality, further suggesting their inability to separate between their partners as individuals and the hypersexuality itself. Furthermore, evidently, some carers, due to their stress and frustration from dealing with their partners and the hypersexuality, expressed either a desire or an actual instance where they had an aggressive response to their partners' hypersexuality.

Dealing with hypersexuality

Highlights the various ways in which the carers dealt with their partners' hypersexuality. The carers either attempted to limit the hypersexuality, attempted to uncover facts about the hypersexuality, or gave in to the hypersexuality. Carers attempted to limit the hypersexuality by placing blocks on the computer, for instance, so that their spouse could no longer access any pornography. Half of the carers reported that they had actively tried to find out about their partner's hypersexual behaviours, for example, by looking for their pornographic magazines or videos which were hidden in the house, checking their computers or phones for evidence that they had been visiting sex sites, or checking their phones for messages from other people that they might be involved with sexually. Around half of the carers indicated that they accepted their partner's hypersexual behaviours although they were not happy with them. For a small number this

tolerance extended to a greater degree of understanding and even support in helping their partner to indulge their hypersexual desires outside of the marital relationship.

Coping with hypersexuality

Highlights the ways in which the carers coped with their partners' hypersexuality. These fell into three main categories: taking on no personal responsibility for or guilt relating to the patients' behaviours, gaining an understanding of the reasons for hypersexuality, and forgiving partners. All the carers expressed at least one of these aspects of coping. All the carers, except one, indicated that they had no feelings of responsibility over their partners' hypersexuality. The interview findings suggested that this may allow them to achieve the extent of psychological or emotional distance from the patient and their condition which is necessary to enable them to cope with the stress and pressure involved. All carers appeared to understand that the onset of hypersexuality was ultimately caused by the neurological disorder; however, this understanding did not necessarily imply that they have coped well with it. Some also demonstrated a more astute understanding of the nature of the condition and its manifestations. Only some carers expressed an ability to forgive their partners for their hypersexuality, though others indicated that there was nothing to forgive. For those who felt that forgiveness was necessary and indicated that they could offer this, their responses however, indicated that this was quite difficult and could only be achieved sometime in the future. Coping is not an easy process and requires resilience. Around half of the carers indicated that they had often experienced difficulties in coping with their partner's hypersexuality which for a minority extended to a desire to no longer exist.

Self-image

Highlights the effects of the hypersexuality on the carers' self-image. These effects included feeling unloved, feeling used, and changes in self-confidence. Half of the carers indicated feeling unloved by their husbands, especially those whose sexual relationship with their partners had become mechanical and non-affectionate as a result of the hypersexuality. Their comments indicated that this made them sad and nostalgic for the loving relationships they had before the onset of the condition, and reinforced findings about the shifts that tended to occur in roles within their relationships. The same four carers indicated that they not only felt unloved but also "used" by their husbands for their sexual gratification. The types of concerns they expressed indicated that to them, this signalled a shift from a normal loving sexual relationship to one which was becoming primarily physical and for the purpose of satisfying their husbands' hypersexual needs.

Stigma

Highlights the two forms of stigma associated with hypersexuality as perceived by the carers: personal stigma and social stigma. One carer's reference to the older age group suggested that older people are not to be as sexual as younger people, which is not necessarily true. The carer may have said this to further solidify her view that the hypersexuality is unnatural. Three of the carers made comments which indicated that they were concerned about the social stigma associated with hypersexuality. They expressed worry that others would find out about their partner's condition and how that would reflect negatively on themselves and their families. Furthermore, during the interviews, most carers tended to hesitate, laugh inappropriately and nervously, as well as apologise to the interviewer, after being asked sexually-specific questions or if their answers prompted them to go into detail about their partners' sexual experience. This might be due to the embarrassment associated with sex and discussing it. Carers might have also

apologised and hesitated due to the possibility that they crossed a socially-constructed line and due to fear of having been inappropriate, respectively.

Professional help-seeking

Outlines the professional help-seeking barriers regarding hypersexuality, as well as certain aspirations with regards to professional help. According to the carer interviews, problems in relation to professional help seeking included a lack of communication, lack of understanding, lack of education, neglect by the health professionals, stigma associated with hypersexuality, and difficulties in discussing sex. Because of these barriers, some of the carers expressed certain aspirations with regard to professional help for people with hypersexuality and their carers. It was clear that the carers were not receiving adequate and necessary information and help for their partners' newly-developed hypersexuality. All of the eight carers in the sample recounted experiences in which they had been unable to obtain the help and information they needed to effectively support their partner and described emotions such as frustration, sadness and anger that this help was not available to them. One of the main issues raised is that patients are not made properly aware of the likelihood of hypersexuality, and what this entails, when taking drugs for PD. Several of the carers reported that one of the main problems seemed to be that medical professionals themselves have little knowledge or understanding of the condition of hypersexuality, and have an apparent unwillingness to investigate this further or take the concerns of patients and their carers seriously. More than half of the carers expressed their desire for education of the health professionals about hypersexuality and its consequences to enable them to educate the patients and their carers about this condition. They viewed the ultimate objectives of this to include alleviation of the patient and carer burden of living with hypersexuality and the facilitation of more effective help-seeking behaviour.

FTD: Frontotemporal dementia; PD: Parkinson's disease

3.5.5 Quantitative Analysis

The quantitative analysis of the patient and carer results are presented below.

3.5.5.1 Construct/scale descriptives

1. Patients

Patient questionnaire/test results are summarised in Appendix 40.

a. *Compulsivity*

Results from the QUIP indicated all ($n = 9$) patients as having compulsive sexual behaviour (a requirement for their inclusion in the study), one patient as having compulsive gambling, four patients as having compulsive buying, three patients as having compulsive eating, six as having hobbyism, four as having punning behaviour, none for walkabout behaviour and medication use and thus dopamine dysregulation syndrome.

Results from the QUIP showed that all ($n = 9$) of the PD patients screened positive for at least one ICD, with five of patients screening positive for more than just one. Only one patient screened positive for all four ICDs, one patient for three ICDs, and three patients for two ICDs.

b. *Sex addiction*

When compared to the published categorical measures and cut off scores, four of the eight PD patients who completed the SAST-R appeared to be sexually addicted, five appeared to be preoccupied with sex, three appeared to have loss of control over sex, two had disturbances in relationships due to sexual behaviour, and three had disturbances in their affect.

c. *Sexual function*

Erectile function (males)

When compared to the published categorical measures and cut off scores, two of the six PD males who completed the IIEF had erectile dysfunction, two had mild to moderate dysfunction, and two had severe dysfunction.

Function (females)

When compared to the published categorical measures and cut off scores, the two female PD patients who completed the FSFI had low sexual function.

d. *Impulsivity*

When compared to the published categorical measures and cut off scores, two of the eight PD patients who completed the BIS-11 were highly impulsive, while the remaining six were in the normal range for impulsivity.

Because the UPPS-P does not provide categorical measures or cut off scores for the impulsivity, a single sample t-test was conducted, after normality of the variable was met, to determine if a statistically significant difference existed between the mean score of the study sample ($M = 131.50$; $SD = 30.71$) and the means reported in a study by Banca et al. (2016) for samples of 25 individuals with compulsive sexual behaviour and 50 healthy controls ($M = 151.72$; $SD = 18.33$ and 129.27 ; $SD = 22.94$, respectively)⁽¹²⁵⁾. Results showed that there was no statistically significant difference in impulsivity between the

study sample and the samples of individuals with compulsive behaviour and healthy controls ($t(7) = -1.86, p = .11, ns$; $t(7) = 0.21, p = .84, ns$, respectively).

Normality assessment and results of the t-test for each of the scale with no categorical measures or cut off scores are presented in Appendix 41.

e. Risk-taking

Because the UPPS-P does not provide categorical measures or cut off scores for the Sensation-seeking scale (ssUPPS-P), a single sample t-test was conducted, after normality of the variable was met, to determine if a statistically significant difference existed between the mean score of the study sample ($M = 33.50; SD = 8.64$) and the mean reported in a study by Michalczuk et al. (2011) for samples of 30 pathological gamblers and 30 healthy controls ($M = 33.40; SD = 5.90$ and $M = 34.70; SD = 6.90$, respectively)⁽¹²⁶⁾. Results showed that there was no statistically significant difference in risk-taking between the study sample and the sample of pathological gamblers and healthy controls ($t(7) = 0.03, p = .98, ns$ and $t(7) = -0.39, p = .71, ns$).

f. Sensitivity to punishment and reward

Because the BIS/BAS does not provide categorical measures or cut off scores for sensitivity to punishment and reward, a single sample t-test was conducted, after normality of the variables were met, for each sensitivity to punishment from the BIS scale and sensitivity to reward from the BAS scale.

Sensitivity to punishment

The mean score of the study sample on the BIS scale ($M = 22.57; SD = 2.37$) was compared to the mean reported in a study by Aarts et al. (2012) in samples of 32 PD patients and 26 healthy controls ($M = 19.20; SD = 3.70$ and $M = 18.80; SD = 3.20$, respectively)⁽¹²⁷⁾. Results showed that there was a statistically significant difference in sensitivity to punishment between the study sample and the samples of PD patients and healthy controls ($t(6) = 3.76, p = .009$ and $t(6) = 4.21, p = .006$, respectively).

Sensitivity to reward

The mean score of the study sample on the BAS scale ($M = 42.86; SD = 8.49$) was compared to the mean reported in the same study as above in samples of PD patients and healthy controls ($M = 40.80; SD = 4.10$ and $M = 39.80; SD = 3.70$, respectively)⁽¹²⁷⁾. Results showed that there was no statistically significant difference in sensitivity to reward between the study sample and the samples of PD patients and healthy controls ($t(6) = 0.33, p = .75, ns$ and $t(6) = 0.64, p = .55, ns$, respectively).

g. Readiness for change

When compared to the published categorical measures and cut off scores, five of the eight PD patients who completed the URICA were in the precontemplation stage, while the remaining three were in the contemplation stage.

h. Mood

Anxiety

When compared to the published categorical measures and cut off scores, two of the seven PD patients who completed the Anxiety scale of the HADS were in the normal range for anxiety, four were in the borderline abnormal range, and one was in the abnormal range.

Depression

When compared to the published categorical measures and cut off scores, five of the seven PD patients who completed the Depression scale of the HADS were in the normal range for depression, one was in the borderline abnormal range, and one was in the abnormal range.

i. Quality of life

Because the PDQ-39 does not provide categorical measures or cut off scores for PDQ-39 SI, a single sample t-test was conducted, after normality of the variable was met, to determine if a statistically significant difference existed between the mean score of the study sample ($M = 34.11$; $SD = 18.61$) and the mean reported in a study by Peto et al. (2001) for a sample of 192 PD patients ($M = 44.00$; $SD = 15.85$)⁽¹²⁸⁾. Results showed that there was no statistically significant difference in quality of life between the study sample and the sample of PD patients ($t(6) = -1.60$, $p = .16$, *ns*).

j. Social cognition*Empathy*

1. Perspective-taking

Because the IRI does not provide categorical measures or cut off scores for the Perspective-taking scale, a single sample t-test was conducted, after normality of the variable was met, to determine if a statistically significant difference existed between the mean score of the study sample ($M = 18.29$; $SD = 2.14$) and the mean reported in a study by Fernandez et al. (2001) for a sample of 435 undergraduate students ($M = 16.94$; $SD = 4.95$)⁽¹²⁹⁾. Results showed that there was no statistically significant difference in perspective-taking between the study sample and the sample of undergraduate students ($t(6) = 1.67$, $p = .15$, *ns*).

2. Empathic concern

Because the IRI does not provide categorical measures or cut off scores for the Empathic concern scale, a single sample t-test was conducted, after normality of the variable was met, to determine if a statistically significant difference existed between the mean score of the study sample ($M = 20.43$; $SD = 7.00$) and the mean reported in the same study as above for the same of undergraduate students ($M = 18.40$; $SD = 4.71$)⁽¹²⁹⁾. Results showed that there was no statistically significant difference in empathic concern between the study sample and the sample of undergraduate students ($t(6) = 0.77$, $p = .47$, *ns*).

3. Personal distress

Because the IRI does not provide categorical measures or cut off scores for the Personal distress scale, a single sample t-test was conducted, after normality of the variable was met, to determine if a statistically significant difference existed between the mean score of the study sample ($M = 14.43$; $SD = 5.50$) and the mean reported in the same study as above for the same of undergraduate students ($M = 12.23$; $SD = 5.00$)⁽¹²⁹⁾. Results showed that there was no statistically significant difference in personal distress between the study sample and the sample of undergraduate students ($t(6) = 1.06$, $p = .33$, *ns*).

4. Fantasy

Because the IRI does not provide categorical measures or cut off scores for the Fantasy scale, a single sample t-test was conducted, after normality of the variable was met, to determine if a statistically significant difference existed between the

mean score of the study sample ($M = 18.43$; $SD = 3.91$) and the mean reported in the same study as above for the same of undergraduate students ($M = 15.41$; $SD = 5.62$)⁽¹²⁹⁾. Results showed that there was no statistically significant difference in ability to empathize with fictional characters between the study sample and the sample of undergraduate students ($t(6) = 2.04$, $p = .09$, *ns*).

Social sensitivity and emotional perception

Because the RMET does not provide categorical measures or cut off scores for social sensitivity and emotional perception, a single sample t-test was conducted, after normality of the variable was met, to determine if a statistically significant difference existed between the mean score of the study sample ($M = 25.57$; $SD = 5.09$) and the mean reported in a study by Enrici et al. (2015) for samples of 32 PD patients and 25 healthy volunteers ($M = 20.59$; $SD = 5.15$ and $M = 23.40$; $SD = 4.65$, respectively)⁽¹³⁰⁾. Results showed that there was no statistically significant difference in social sensitivity and emotional perception between the study sample and the sample of healthy volunteers ($t(6) = 1.13$, $p = .30$, *ns*) and that there was a statistically significant difference between the study sample and the sample of PD patients ($t(6) = 2.59$, $p = .041$).

k. General cognitive ability

Cognitive impairment

To be eligible to take part in the study, the patients were required to have no cognitive impairment. When compared to the published normative data, all ($n = 9$) of the PD patients who completed the MMSE had no cognitive impairment and were thus all included in the study.

Premorbid intellectual ability

When compared to the published categorical measures and cut off scores, three of the seven PD patients who completed the NART were gifted, three were of above average intelligence, and one was of average intelligence for Full IQ. On average patients indicated above average intelligence ($M = 117.00$; $SD = 7.37$).

Current intellectual ability

Because the RCPM does not provide categorical measures or cut off scores for current IQ, a single sample t-test was conducted, after normality of the variable was met, to determine if a statistically significant difference existed between the mean score of the study sample ($M = 30.29$; $SD = 3.90$) and the mean reported in a study by Roca et al. (2012) for samples of 32 PD patients and 22 healthy controls ($M = 27.78$; $SD = 5.98$ and $M = 31.27$; $SD = 3.90$, respectively)⁽¹³¹⁾. Results showed that there was no statistically significant difference in current intellectual ability between the study sample and the samples of PD patients and healthy controls ($t(6) = 1.70$, $p = .14$, *ns* and $t(6) = -0.67$, $p = .53$, *ns*, respectively).

l. Executive functioning

Response inhibition

When compared to the published categorical measures and cut off scores, two of the seven PD patients who completed the HSCT exhibited average ability to inhibit habitual responses, one showed moderate average ability, one showed low average ability, two showed poor ability, and one showed impaired ability. On average the patients showed a low average-ranged capacity to inhibit habitual responses ($M = 4.00$; $SD = 1.83$).

Set-shifting and rule attainment

When compared to the published categorical measures and cut off scores, one of the seven PD patients who completed the BSAT exhibited very superior ability, one showed high average ability, one showed average ability, one showed low average ability, one showed abnormal ability, and one showed impaired ability to attain rules and shift sets. On average the patients showed a moderate average-ranged capacity to attain rules and shift sets ($M = 5.00$; $SD = 3.06$).

2. **Carers**

Carer questionnaire results are summarised in Appendix 42.

a. Mood*Anxiety*

When compared to the published categorical measures and cut off scores, three of the eight carers who completed the HADS were in the normal range for anxiety, three were in the borderline abnormal range, and three were in the abnormal range for anxiety.

Depression

When compared to the published categorical measures and cut off scores, five of the eight carers who completed the HADS were in the normal range for depression, two were in the borderline abnormal range, and one were in the abnormal range.

b. Quality of life

When compared to the published categorical measures and cut off scores, and two of the eight carers who completed the AC-QoL had high quality of life, four had mid-ranged quality of life, and two had a low quality of life.

3.5.5.2 *Correlational analysis*1. **Assumptions of the Pearson Correlation Test****a. Variable Type**

All the variables were scale variables.

b. Normality of predictors and outcome variable

To determine which correlation tests were to be used, normality analysis of the scales of interest was performed. A summary of the results is presented in Table 27 below.

The Shapiro-Wilk test revealed that the distribution of the BIS-11, UPPS-P, ssUPPS-P, BIS, HSCT (total score), HSAT (converted score)¹⁷, SAST-R, and RCPM was not significantly different from that of normal distribution. Hence, normality for the all these variables was met.

The test revealed, however, that the distributions of the BSAT (adherence) and NART were significantly different from normal distribution. Hence, normality for these variable is not met.

¹⁷ Converted score refers to the errors made in Hayling 2 (response inhibition)

Table 27 – Normality analysis (to determine correlation test)

Variable	Shapiro-Wilk
BIS-11	$W(8) = 0.98, p = .96, ns$
UPPS-P	$W(8) = 0.98, p = .97, ns$
ssUPPS-P	$W(8) = 0.97, p = .86, ns$
BIS	$W(7) = 0.97, p = .89, ns$
HSCT (total score)	$W(7) = 0.93, p = .53, ns$
HSCT (converted scaled score)	$W(7) = 0.87, p = .19, ns$
SAST-R	$W(8) = 0.91, p = .33, ns$
RCPM	$W(7) = 0.91, p = .39, ns$
BSAT (adherence)	$W(7) = .80, p = .042^*$
NART	$W(7) = .80, p = .036^*$

BIS: Behavioural Inhibition Scale; BIS-11: Barratt Impulsiveness Scale; BSAT: Brixton Spatial Anticipation Task; HSCT: Hayling Sentence Completion Task; NART: National Adult Reading Test; RCPM: Raven's Coloured Progressive Matrices; SAST-R: Sexual Addiction Screening Test-Revised; ssUPPS-P: Sensation Seeking scale of UPPS-P; UPPS-P: UPPS-P Impulsive Behaviour Scale

*. Significantly different from normal distribution.

A Pearson Correlation (one-tailed) test was thus used to investigate the correlation between the predictors: BIS-11, UPPS-P, ssUPPS-P, BIS, SAST-R, HSCT (total score), HSAT (converted score), URICA, and PDQ-39. Pearson Correlation (one-tailed) test was used because these variables were normally distributed.

A Spearman's Rho (one-tailed) test was conducted to investigate the correlation between the predictors: NART, BSAT (adherence), UPPS-P, ssUPPS-P, BIS-11, BIS, and RCPM. Spearman's Rho (one-tailed) test was used because the NART and BSAT (adherence) variables were not normally distributed.

2. Main analysis

a. Pearson correlation

The results from the Pearson Correlation test performed on the SPSS program is presented in Table 28.

Table 28 – Pearson Zero Order Correlation Matrix

	UPPS-P	ssUPPS-P	BIS	HSCT (total score)	HSCT (converted score)	SAST-R
BIS-11	.89**	.62	-.50	-.54	.79*	.65*
UPPS-P	-	.68*	-.86**	-.35	.45	.67*
ssUPPS-P	-	-	-.53	.00	.21	.45
BIS	-	-	-	-.54	.33	-.50
HSCT (total score)	-	-	-	-	-.75*	.59
HSCT (converted score)	-	-	-	-	-	.64

BIS: Behavioural Inhibition Scale; BIS-11: Barratt Impulsiveness Scale; HSCT: Hayling Sentence Completion Test; ssUPPS-P: Sensation Seeking scale of UPPS-P; UPPS-P: UPPS-P Impulsive Behaviour Scale

** . Correlation is significant at the 0.01 level (one-tailed).

* . Correlation is significant at the 0.05 level (one-tailed).

1. *UPPS-P and BIS-11*
The Pearson correlation test revealed that there was a significant positive and large correlation between the two scales of impulsivity; $r = .89, p < .01$ (one-tailed), indicating excellent construct (impulsivity) validity.
2. *UPPS and ssUPPS-P*
The Pearson correlation test revealed that there was a significant positive and large correlation between the two scores; $r = .68, p < 0.05$ (one-tailed), measured using the same scale, indicating that patients who had higher levels of impulsivity tended to have higher propensity for risk-taking.
3. *UPPS-P and BIS*
The Pearson correlation test revealed that there was a significant negative and large correlation between the two scales; $r = -.86, p < .01$ (one-tailed), indicating that patients who had higher levels of impulsivity tended to have lower sensitivity to punishment.
4. *UPPS-P and SAST-R*
The Pearson correlation test revealed that there was a significant positive and large correlation between the two scales; $r = .67, p < .05$ (one-tailed), indicating that patients who had higher levels of impulsivity tended to be more sexually addicted.
5. *BIS-11 and HSCT (converted score)*
The Pearson correlation test revealed that there was a significant positive and large correlation between the two scales; $r = .79, p < .05$ (one-tailed), indicating that patients who had higher levels of impulsivity tended to make more errors regarding response inhibition.
6. *BIS-11 and SAST-R*
The Pearson correlation test revealed that, similar to the UPPS-P and the SAST-R, there was a significant positive and large correlation between the two scales; $r = .65, p < .05$ (one-tailed), indicating that patients who had higher levels of impulsivity tended to be more sexually addicted.
7. *HSCT (converted score) and HSCT (total score)*
The Pearson correlation test revealed that there was a significant negative and large correlation between the two scores; $r = -.75, p < .05$ (one-tailed), measured using the same scale, indicating that patients who had more errors on the Hayling 2 had a lower score on the overall HSCT.

No other significant correlations were observed.

b. Spearman's Rho correlation

The results from the Spearman's Rho correlation test performed on the SPSS program is presented in Table 29 below.

Table 29 – Spearman’s Rho Zero Order Correlation Matrix

	BSAT (adherence)	UPPS-P	ssUPPS-P	BIS-11	BIS	RCPM
NART	-.55	-.16	-.04	.11	.34	.84**
BSAT (adherence)	-	.69*	.51	.35	-.69*	-.69*

BSAT: Brixton Spatial Anticipation Task; NART: National Adult Reading Test
 **. Correlation is significant at the 0.01 level (one-tailed).
 *. Correlation is significant at the 0.05 level (one-tailed).

1. *NART and RCPM*

The Spearman’s rho correlation test revealed that there was a significant positive and large correlation between the two scales; $r_s = .84, p < .01$ (one-tailed), indicating that patients who had higher premorbid intelligence tended to have higher current intelligence.

2. *BSAT (adherence) and UPPS-P*

The Spearman’s rho correlation test revealed that there was a significant positive and large correlation between the two scales; $r_s = .69, p < .05$ (one-tailed), indicating that patients who had worse rule adherence tended to have higher levels of impulsivity.

3. *BSAT (adherence) and BIS*

The Spearman’s rho correlation test revealed that there was a significant negative and large correlation between the two scales; $r_s = -.69, p < .05$ (one-tailed), indicating that patients who had better rule adherence tended to be more sensitive to punishment.

4. *BSAT (adherence) and RCPM*

The Spearman’s rho correlation test revealed that there was a significant negative and large correlation between the two scales; $r_s = -.69, p < .05$ (one-tailed), indicating that patients who had better rule adherence tended to have higher current intellectual ability.

No other significant correlations were observed.

A Bonferroni Correction for adjusting multiple comparisons was not used to try to decrease possible type I errors (“false positives”) due to the likelihood of creating type II errors (“false negatives”)⁽¹³²⁾. Because this is an exploratory rather than an explanatory study, these possible “false positives” will be considered in exploration of the potential relationships that exist between the variables and their potential associations with hypersexuality.

3.5.6 Triangulation

Triangulation, as previously described, is a technique that facilitates the validation of data through the “convergence of information” from two or more sources⁽¹³³⁾. Four items that were measured in the questionnaires (impulse control disorders, preoccupation with sex, loss of control over sex, and readiness for change), were also asked about in the interview. The answers from both these assessment tools for these items were compared to evaluate consistency between the quantitative and qualitative data collection tools. Further, four couples took part in the study, therefore, the interview answers of the four patients were compared to their carers’ answers using the common themes that emerged during the thematic

analysis: manifestations of hypersexuality, sexual practices, control over hypersexuality, and the impact of hypersexuality.

1. *Impulse control disorders*

The positively-screened ICDs in Section A of the QUIP determined for each patient were compared to the responses of the patients provided during the interview in response to Question 6 which reads: “Did/do you have any other impulse control disorders such as increased gambling behaviour or thought, increased eating behaviour or thought, or increased buying?”. Seven out of the nine patients, as presented in Appendix 43, indicated the same impulse control disorders in both assessment tools, signifying data accordance of 77.8%.

2. *Preoccupation with sex*

The presence of concern in the Preoccupation dimension of the SAST-R was compared to the responses the patients provided during the interview in response to Question 24, measuring the same construct, which reads: “Did/do you find it hard to concentrate on other areas of your life because of constantly thinking about sex?”. Seven out of the eight patients who completed the questionnaire, as presented in Appendix 44, indicated the same notion in both assessment tools, signifying data accordance of 87.5%.

3. *Loss of control over sex*

The presence of concern in the Loss of control dimension of the SAST-R was compared to the responses the patients provided during the interview in response in Question 25, measuring the same construct, which reads: “Did/do you feel that you had/have no control over your hypersexuality?”. Seven out of the eight patients who completed the questionnaire, as presented in Appendix 45, indicated the same notion in both assessment tools, signifying data accordance of 87.5%.

4. *Readiness for change*

Each patient’s stage of readiness for change assessed by the URICA¹⁸ was compared to the theme of Insight in the qualitative analysis section of this dissertation. Having insight may suggest being in the contemplation (C) stage where the hypersexuality is recognised as a problem and a desire to change/overcome it exists, which mirrors the definition of insight⁽¹³⁴⁾. On the other hand, having no insight suggests being in the precontemplation (PC) stage, where the patient does not recognise hypersexuality as a problem and does not have an intention of changing/overcoming it. Seven out of the eight patients who completed the questionnaire, as presented in Appendix 46, indicated the same notion in both assessment tools, signifying a data accordance of 87.5%.

The results from the four triangulations demonstrated that, on average, there was an 85.1% consistency between the quantitative and qualitative data collection tools.

5. *Comparison between patient and carer accounts about patient’s hypersexuality*

As aforementioned, four couples took part in the study. The themes that were common to both patients and carers are: (1) manifestations of hypersexuality; (2) sexual practices; (3) control over hypersexuality; and (4) impact of hypersexuality.

The following legend shows the patients who took part and their corresponding carers:

¹⁸ Although the URICA is generic and not hypersexuality-specific, the patients were asked to think about hypersexuality as being the “problem” while completing it.

Patient 2 – Carer 2
Patient 5 – Carer 4
Patient 7 – Carer 3
Patient 8 – Carer 5

a. Patient 2 and Carer 2

Of the twenty-one items, disparity was evident in seven (Appendix 47), indicating that there was 66.7% accordance between their accounts about Patient 2's hypersexuality. It is important to note that for some items (that may or may not have showed disparity), the carer provided more information than did the patient.

b. Patient 5 and Carer 4

Of the twenty-one items, disparity was evident in ten (Appendix 48), indicating that there was 52.3% accordance between their accounts about Patient 5's hypersexuality. It is important to note that for some items (that may or may not have showed disparity), the carer provided more information than did the patient.

c. Patient 7 and Carer 3

Of the nineteen items, disparity was evident in five (Appendix 49), indicating that there was a 73.6% accordance between their accounts about Patient 7's hypersexuality.

d. Patient 8 and Carer 5

Of the twenty-one items, disparity was evident in ten (Appendix 50), indicating that there was 52.3% accordance between their accounts about Patient 8's hypersexuality. It is important to note that for some items (that may or may not have showed disparity), the carer provided more information than did the patient.

3.6 Discussion

3.6.1 Introduction

This chapter aimed to assess the prevalence, clinical phenomenology, and impact of hypersexuality in PD and FTD using qualitative and quantitative analysis. These aims are important as there is a lack in published research systematically assessing hypersexuality in neurological disorders. Although the research is focused on sexual behaviour and sexuality, which are sensitive topics, it was important to systematically explore hypersexuality to (1) inform the understanding of the factors and characteristics of hypersexuality and the ways it can manifest, (2) explore the impact hypersexuality has on patients and spousal carers both to help raise awareness about the issue, and consequently (3) help mitigate the stigma surrounding sex.

3.6.2 Interpretation of the findings

3.6.2.1 Prevalence of hypersexuality in PD

Although the research team was aware of the possible difficulties, they thought it interesting/important to attempt it first-hand and see what challenges might arise in the process. These challenges initially became apparent during the process of setting up the study. Both the PD and dementia teams voiced their concerns about assessing the patients and carers and, for the most part, did not agree. They did not want to make the patients and carers uncomfortable and did not want them to feel challenged. The second challenge became apparent when the study team were informed of the hesitation of patients with regards to completing the

QUIP questionnaire at the ECH, which was evident in the low return rate of the questionnaires; only 33 out of 251 questionnaires were completed and returned.

The prevalence figure for hypersexuality in PD of 12.22% determined in the study shows that hypersexuality is not uncommon in PD. However, the fact remains that there have been many reported prevalence figures in the literature, as represented in the previous chapter, so it is difficult to draw any definitive conclusions. These prevalence figures range from 1.8% as reported by Wang et al. (2016)⁽¹³⁵⁾ to 19.8% found in a study by Solla et al. (2011)⁽¹³⁶⁾. The results from the QUIP also challenge the literature in that they show that hypersexuality is the most prevalent in patients with PD whereas other studies such as the DOMINION⁽¹³⁷⁾ showed compulsive gambling behaviour as the most prevalent and hypersexuality, typically, coming second. Reasons for these inconsistencies may involve different samples, sample size and gender differences, different tools used, lack of insight, as well as inherent challenges associated with discussing matters relating to sex and/or sexuality and the stigma associated with it, which might make it difficult for patients to disclose such information. This is consistent with a study by Baumann-Vogel et al. (2012) showing that ICDs, including hypersexuality, are much more frequent than reported⁽¹³⁸⁾. Therefore, similar to the conclusions presented in the previous chapter, one might argue that there is a challenge in determining a prevalence figure for hypersexuality in PD, which remains unresolved. This raises questions as to whether prevalence of hypersexuality in PD or other neurological disorders could ever be measured accurately.

3.6.2.2 *Implicated factors contributing to the development of hypersexuality*

All PD patients implicated dopaminergic medications used to manage PD as the primary cause of their hypersexuality. A review of the pharmacological history of the PD patients from clinical notes showed that dopamine agonists, especially ropinirole ($n = 6$), were most likely contributing to the development of hypersexuality. This is consistent with the literature that reports dopamine agonists, as possibly causing more cases of hypersexuality than other dopamine replacement therapy options^(139, 140). It is common clinical practice to either reduce or discontinue the implicated hypersexuality-inducing medication⁽¹⁴¹⁾. At time of assessment, six patients indicated either reducing or stopping the implicated medication. This proved successful for only one patient (Patient 5) in the study (as determined by clinical notes), whose hypersexuality resolved completely, and partially successful for another patient (Patient 1) whose hypersexuality was slightly reduced after discontinuing the medication, although the effects of the hypersexuality are still potent in his life. The remaining patients did not indicate decrease/cessation of hypersexuality. One participant (Patient 7) claims: "I am off the dopamine... but it is not off me". The lack of consistency in success rates can possibly be explained by four reasons. First, not all the cases of hypersexuality are necessarily attributable to dopamine therapy. This is consistent with a study by Young et al. (2016) suggesting that not all ICD behaviour, including hypersexuality, are attributable to dopamine therapy⁽¹⁴²⁾. Their study described hypersexual patients with PD who were unresponsive to reduction in dopamine therapy⁽¹⁴²⁾. Although this suggests that dopamine therapy might not be attributable to the hypersexuality, one might also argue that failure to extinguish a newly-acquired habitual response following reduction of dopamine agonists may reflect the hard-wiring of the behaviour by repeated excessive dopaminergic stimulation. Many patients continue to demonstrate (perhaps a sub-clinical level of) ICD, including hypersexuality, even after the reduction of dopamine agonists. Third, the patients might implicate the wrong medication. It is thus the clinician's duty to meticulously investigate the medications the patient is taking and their potential effects. Gupta et al. (2015) showed that while ICD expression may be an effect of dopaminergic medication, it does not appear to demonstrate "dose-related or medication-specific effects" and may be influenced by polypharmacy⁽¹⁴³⁾. It is thus important to consider non-PD-specific medication such as antipsychotics and antidepressants, which have been reported to possibly cause hypersexuality⁽¹⁴⁴⁾. Fourth, Codling et al. (2015) claimed that "therapeutically, reduction of dopaminergic medication is only one component of treatment and future therapies based on an appreciation of the cognitive substrate of the problem may be more effective"⁽¹⁴⁰⁾.

Moreover, findings indicated varying accounts of the effect of DBS on hypersexuality. Although there were no cases where DBS was implicated in contributing to the development of hypersexuality, DBS was implicated in either exacerbating or reducing the symptoms of hypersexuality. This inconsistency is mirrored in the literature. A study by Kasemsuk et al. (2017) showed that there is still no consensus on the effect of DBS as some studies show improvement of ICDs following DBS while others show worsening of ICDs following DBS⁽¹⁴⁵⁾. Specifically, Gee et al. (2015) reported reduced hypersexuality following DBS⁽¹⁴⁶⁾, while Demetriades et al. (2011) reported cases of worsening hypersexuality following DBS⁽¹⁴⁷⁾. It is important to note, however, that DBS is often associated with worsening of impulsivity shortly after surgery, which likely reflects the oedema¹⁹ on the frontal lobes⁽¹⁴⁸⁾, leading to disinhibition and the unmasking of the impulsivity. This might explain why the hypersexuality immediately worsened for Patient 2 (e.g. demanding blowjobs in hospital room after surgery), but then levelled off²⁰. It is thus important to follow up the patients to see whether the hypersexuality resolves over time in order to make definitive conclusions. DBS might also allow for the patients to refrain taking the offending drug which also allows reduction of hypersexuality, as suggested by Bronner et al. (2017)⁽¹⁴⁹⁾.

The carers of FTD patients who took part in the study all implicated the dementia as having contributed to the development of hypersexuality. This is consistent with the literature reporting that hypersexuality in dementia likely develops in FTD due to frontal lobe damage and temporal involvement⁽¹⁵⁰⁾.

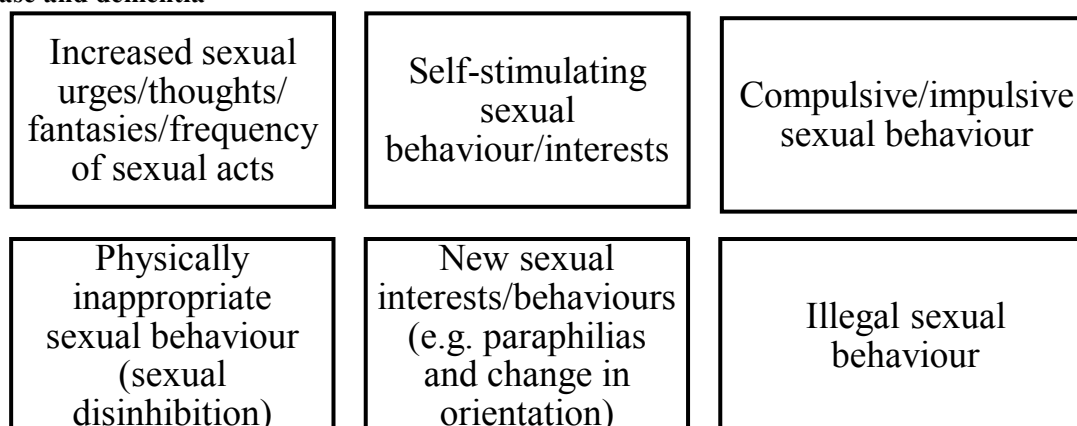
Although these factors are implicated in contributing to the development of hypersexuality, no causality can be determined as research still needs to be conducted into the actual causes and neurobiology/neuropsychology of hypersexuality.

3.6.2.3 *Clinical phenomenology of hypersexuality*

Sexual changes

Both patients and carers showed that hypersexuality does not manifest in the same way amongst all patients. Changes were observed in patients' sexual cognitions and behaviours. The changes include but are not limited to the preoccupation with sex, change in sexual orientation, commenting about other women's underwear, pretending to be wife on dating sites, and transvestic fetishism. These changes can be summarised using the categories presented in Figure 19.

Figure 19 – Summary of categories for clinical phenomenology of hypersexuality in Parkinson's disease and dementia



¹⁹ Oedema: build up of fluid which causes affected tissue to become swollen.

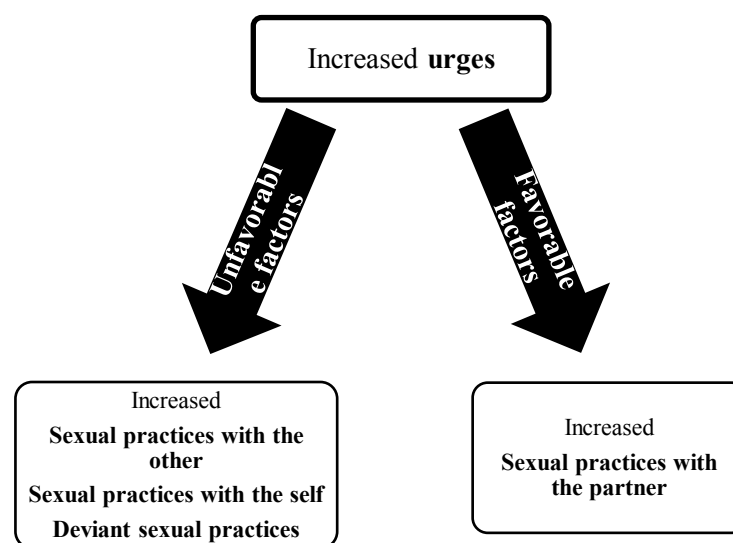
²⁰ Patient 2 (worsening of hypersexuality after DBS) because more recently underwent DBS than Patient 6 (reduced hypersexuality symptoms).

The findings are consistent with the results of the previous chapter as well as the systematic review by Codling et al. (2015) documenting similar sexual changes⁽¹⁴⁰⁾. Furthermore, the literature suggests that PD patients with hypersexuality express sexual impulsivity and compulsivity⁽¹⁴⁰⁾ while dementia patients with hypersexuality express sexual disinhibition and inappropriateness⁽¹⁵¹⁾ and this distinction was observed, albeit to a small extent, in the findings of the study. Sexual compulsivity was characteristic of the PD patients (e.g.: having sex with up to 15 different men in one day; increased requests for sex) and sexual disinhibition, although indicated by the carers and not the patients themselves, was characteristic of FTD patients (e.g.: commenting on the length of wife's sister's skirt; wearing women's underwear to masturbate; commenting to wife about seeing other women's underwear; taking "expired" meat over to a woman he did not know). The FTD carers specifically used the term "disinhibited" to describe their partners' behaviour. It is important to note, however, that there was some overlap and it is possible for the behaviours to cross over between neurological disorders (e.g. sexual preoccupation was common to both and sexual compulsivity was part of the FTD patients' lives). One can argue that if the sample size of the FTD patients was greater, a clearer distinction between the disorders could have been drawn²¹.

Sexual practices

Findings showed that increased urges/desires were the common denominator among all the patients, even for the partners of the carers in the study. This heightened sexual desire, for the most part, translated into several different sexual practices. Although some may believe that an increased desire for sex inherently means an increased frequency of sex with the partner, findings showed that most of the patients expressed either a decreased or similar frequency of sex as compared to the frequency prior to developing hypersexuality. This is seemingly due to the lack of partner or discontent of the partner with the hypersexuality. In this case, patients appeared to seek sexual gratification from themselves, in the form of masturbation or use of pornographic materials, and/or from others, in the form of prostitution, promiscuity (indiscriminate sexual encounters), or affairs. Although it is impossible to make firm associations between variables on the basis of a small sample and qualitative data collection, the research data does suggest that there may be a connection between patients' increased urges for sex and actual sexual practices, and that this relationship may be mediated by external factors. In the presence of favourable factors, which signify a content and accepting partner, the sexual practices of the patients were primarily focused on the partner, whereas in the presence of unfavourable factors, which signify lack of partner or discontent partners, the sexual practices of the patients were primarily focused elsewhere (practices with self and others and deviant sexual practices). This possible connection is presented in Figure 20.

Figure 20 – Possible connection between sexual urges and sexual practices



²¹ Not an aim of this research.

Although this relationship has not been specifically investigated in the literature on hypersexuality in neurological disorders, it has been intimated in research regarding marriage and the family. Knox and Schacht (2016) suggest that individuals who have sexually unwilling partners might be driven to seek sexual fulfilment elsewhere⁽¹⁵²⁾.

Emotional triggers

A few PD patients indicated that negative feelings, such as sadness, triggered their hypersexual episodes. Although this has not been investigated within the context of neurological disorders in the literature, the same notion is paralleled in the sex addiction literature. Research suggests that sexually compulsive individuals “reported engaging in sexual behaviour in response to specific negative emotional states”⁽¹⁵³⁾. Although this was not a salient theme that emerged from the data, it is important to mention as it helps draw comparisons with the literature on sex addiction.

Sexual functioning

Results showed that the male patients, on average, had mild to moderate erectile dysfunction, while results for the female patients showed low sexual functioning. These findings are important in that they show that even patients with erectile dysfunction and low sexual functioning can still develop hypersexuality and vice versa⁽¹⁵⁴⁾.

3.6.2.4 Compulsivity and hypersexuality

Results showed that all the PD patients had compulsive sexual behaviour, as measured by the QUIP, suggesting that compulsivity is a behavioural correlate of hypersexuality⁽¹⁵⁵⁾. This finding is consistent with the available literature that has interchangeably used the terms hypersexuality and compulsive sexual behaviour and that has shown that PD patients do develop compulsive behaviours including hypersexuality^(156, 157). Screening tools, however, should not be used as definitive diagnostic measures, highlighting the need for a clinical interview. “As a screening instrument, the QUIP has limitations including that 40% of patients without an ICD diagnosis screen positive for an ICD”⁽³⁰⁾.

3.6.2.5 Impulsivity and hypersexuality

Results of the study showed that the PD patients were not more impulsive than younger, healthier people and that the patients were in the normal range for impulsivity, as measured by the BIS-11 and the UPPS-P. Research suggests an existing association between impulsivity and hypersexual behaviour⁽¹⁴⁰⁾; however, there have been no studies assessing sexual impulsivity in a population of hypersexual patients with PD or other neurological conditions. One may thus suggest that impulsivity is a dissociable factor of hypersexuality²².

3.6.2.6 Addiction and hypersexuality

Only half of the PD patients in the study were sexually addicted, as measured by the SAST-R. Some research considers sex addiction synonymous with hypersexuality⁽¹⁵⁸⁾; however, other research has argued that, while there do exist parallels between them, including perpetuated behaviour despite adverse effects, appetitive urges, and reduced self-control⁽¹⁴⁰⁾, “much remains to be learned before definitively characterizing [hypersexuality] as an addiction”⁽¹⁵⁹⁾. One may thus suggest that addiction is also a dissociable factor of hypersexuality. It is important to note, however, that there is no research to date directly comparing the phenomenology of sex addiction in the general population with the phenomenology of hypersexuality in PD or other neurological conditions. Interestingly, however, correlational analysis performed in the study showed a relationship between impulsivity and addiction: patients who had higher levels of impulsivity tended to be more sexually addicted. The literature, however, highlights a need for further research to try and resolve the discrepancies present when describing the potential relationship

²² It is important to note that the questionnaires used to assess impulsivity were not sexuality-specific.

between compulsivity, impulsivity, and addiction⁽¹⁶⁰⁾. For this reason, no definitive conclusions can be drawn. There were no addictive personalities/tendencies according to patient demographic data.

3.6.2.7 Risk-taking and hypersexuality

Results showed that the PD patients' propensity for risk-taking, as measured by the UPPS-P, was similar to that of pathological gamblers and healthy controls. Since there is still no consensus on whether or not pathological gamblers express a higher or lower tendency for risk-taking⁽¹⁶¹⁾, the finding relating to the healthy controls will be considered. The finding that the patients are not significantly different than healthy controls suggests that risk-taking is not necessarily associated with hypersexuality and is thus a dissociable factor, although research has not specifically investigated risk-taking in a population of hypersexual patients with PD or other neurological conditions²³. Codling et al. (2015) suggest that risk-taking might share elements with decision-making⁽¹⁴⁰⁾. They showed that hypersexuality can be included in the list of impulse control and substance misuse disorders where deficits in the Iowa Gambling Test have been reported, implicating ventromedial prefrontal cortex dysfunction in their pathogenesis⁽¹⁴⁰⁾. Using a novel risk-taking task while performing functional magnetic resonance imaging, Voon et al. (2011) investigated the relationship between risk taking and dopamine agonists in patients with and without ICDs. In patients with ICDs, dopamine agonists were associated with enhanced sensitivity to risk along with decreased ventral striatal activity. Patients with ICDs appear to have bias towards risky choices (by impairing risk evaluation in striatum)⁽¹⁶²⁾. Another study by Pineau et al. (2016) showed similar executive functioning and risk-taking between PD patients with ICDs and PD patients with no ICDs⁽¹⁶³⁾.

3.6.2.8 Sensitivity to reward/punishment and hypersexuality

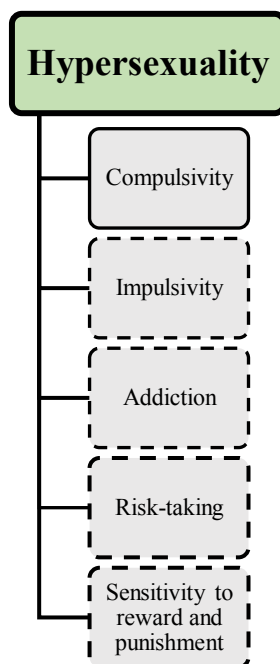
Results showed that the PD patients had similar sensitivity to reward but higher sensitivity to punishment, as measured by the BIS/BAS, than PD controls and healthy controls. This is interesting because patients with hypersexuality, though reward-driven, still seem to be sensitive to punishment. This suggests that the patients' inhibition is still intact and that disinhibition is not necessarily an underpinning of hypersexuality. One may thus suggest that sensitivity to reward and punishment are dissociable factors of hypersexuality, although research has not specifically investigated sensitivity to reward and punishment in a population of hypersexual patients with PD or other neurological conditions²⁴. Furthermore, correlational analysis performed in the study showed the relationship between impulsivity and sensitivity to punishment consistent with findings in the literature⁽¹⁶⁴⁾: patients who had higher levels of impulsivity tended to be less sensitive to punishment. The literature, however, has not considered the relationship between these two constructs in a population of hypersexual PD patients or patients with other neurological disorders.

Figure 21 presents a summary of the behavioural profile of PD patients with hypersexuality as presented in the study. As visually represented, compulsivity is outlined with a continuous black line unlike impulsivity, addiction, risk-taking, and sensitivity to reward and punishment, which have been outlined in dotted lines to distinguish between determined correlates and dissociable factors of hypersexuality as per the results of the study.

Figure 21 – Behavioural profile of Parkinson's disease patients with hypersexuality

²³ It is important to note that the questionnaire used to assess risk-taking was not sexuality-specific.

²⁴ It is important to note, however, that the questionnaire used to assess sensitivity to reward and punishment was not sexuality-specific.



3.6.2.9 Mood and hypersexuality

On average, the PD patients in the study were in the normal range for depression²⁵ but in the abnormal range for anxiety, as measured by the HADS. This is consistent with other research that has shown that a high rate of comorbidity between anxiety and hypersexuality has been observed⁽¹⁴⁰⁾, although the exact relationship has not been examined. It is difficult, however, to determine the relationship between anxiety and hypersexuality due to the presence of PD. Research has shown that disturbances in anxiety are common in PD⁽¹⁶⁵⁾, occurring in up to 20-50% of patients^(165, 166). For this reason, it would be challenging to distinguish the effect of the hypersexuality from the effect of the neurological disorder itself on the aspects of mood. This challenge is further exacerbated by the possibility that some hypersexual PD patients may not have insight and may thus attribute their anxiety to the PD when it might actually be due to the hypersexuality. More research needs to be done regarding the relationship between mood and hypersexuality before any definitive conclusions can be drawn. The patients were assessed only once and the lack of follow-up may have made the distinction unclear. For this reason, this research issue could greatly benefit from a hypersexuality-specific questionnaire.

3.6.2.10 Quality of life and hypersexuality

The PD patients in the study had a similar quality of life to PD controls, as measured by the PDQ-39. One must consider, however, that the scale aims to assess quality of life of patients living with PD and might thus not be sensitive enough to capture the effects of other changes in the patients' lives, such as hypersexuality. For this reason, it would be challenging to determine the effect of hypersexuality on the quality of life of PD patients. More research needs to be done regarding the relationship between quality of life and hypersexuality before any conclusions can be drawn. Perhaps it would be beneficial to develop a quality of life assessment tool that is hypersexuality-specific.

3.6.2.11 Social cognition and hypersexuality

The PD patients in the study were not significantly different than healthier individuals in their social cognition, as measured by the IRI and RMET. This suggests that the patients still retain their ability for emotional perception and empathy. This finding is important because the ability to "understand what the other is thinking, put oneself in the other's place, and intellectually understand another's condition without

²⁵ Could be due to small sample size.

vicariously experiencing their emotions” is essential for well-adjusted, stable relationships⁽¹⁶⁷⁾. This might be indicative that the patients can be aware of how the hypersexuality is affecting those around them, which was evident in the study to some extent. There is no evidence, however, to suggest that there is a relationship between hypersexuality and social cognition; however, one might argue the benefit of having operational social cognition on the outcomes of possible psychological interventions to manage the negative effect the hypersexuality has had on the patients, their partners, and their relationships.

3.6.2.12 *General cognitive ability and hypersexuality*

On average, the PD patients in the study were not cognitively impaired, were of above average intellectual ability, and were not significantly different than healthier individuals, as measured by the MMSE, NART and RCPM. There is no evidence to suggest that there is a relationship between hypersexuality and cognitive ability and “studies exploring cognitive underpinnings of specific ICDs are rare”⁽¹⁴⁰⁾; however, one might argue the benefits of having sound cognitive ability in order to understand and be educated about the hypersexuality and its impact, as well as on the outcomes of possible psychological interventions considered to manage the consequences of hypersexuality. This is consistent with the literature indicating that better cognitive ability yields better intervention outcomes⁽¹⁶⁸⁾.

3.6.2.13 *Executive functioning and hypersexuality*

Results showed that the PD patients had low to moderate average executive functioning, as measured by the HSCT and BSAT. There is very limited evidence to suggest that there is a relationship between hypersexuality and executive functioning (specifically response inhibition, set-shifting, and rule attainment). Codling et al. (2015) reported that in studies comparing patients across ICDs, those with hypersexuality were more impaired on response inhibition⁽¹⁴⁰⁾. One may also argue the challenges with having worse executive functioning on treatment outcomes, as is suggested in the literature^(169, 170). It would be difficult to implement therapeutic changes in patients with worse executive skills without a lot of support. Furthermore, correlational analysis showed the relationship between executive functioning and impulsivity, as well as between executive functioning and sensitivity to punishment. The former suggests that patients who had higher levels of impulsivity tended to have worse ability to inhibit habitual responses (more errors) and had worse rule adherence. Although this has yet to be studied in a population of PD patients with hypersexuality, there is some research to support this correlation. A study by Christodoulou et al. (2006)²⁶ showed that individuals who scored higher on the impulsivity scale were associated with more errors on the HSCT, which measures response inhibition⁽¹⁷¹⁾. Impaired response suppression may indicate impaired strategy implementation; “this may prevent [patient] from a proponent or habitual response, all the patient’s [hypersexuality] to persist”⁽⁸⁰⁾. Similarly, a study by Bagshaw et al. (2014) found that individuals with impulse control disorders commonly produced rule adherence errors possibly due to their rapid responses⁽⁸⁶⁾. One might thus argue that impulsivity is a by-product/dissociable aspect of executive functioning. The latter suggests that patients who had better rule adherence tended to be more sensitive to punishment. Although this has yet to be studied in a population of PD patients with hypersexuality, it is consistent with the literature on crime⁽¹⁷²⁾ and is common sensical. If an individual is sensitive to punishment, they will likely adhere to rules so as not to be placed in an uncomfortable, punishable position.

3.6.2.14 *Insight*

Most of the PD patients did not have insight, as measured by the interview and the URICA. To determine whether the PD patients had insight, they had to first acknowledge the presence of the problem, understand that their hypersexuality was unnatural, have awareness with regards to what contributed to its development, and have a true desire to overcome the problem. The findings showed that, although all the

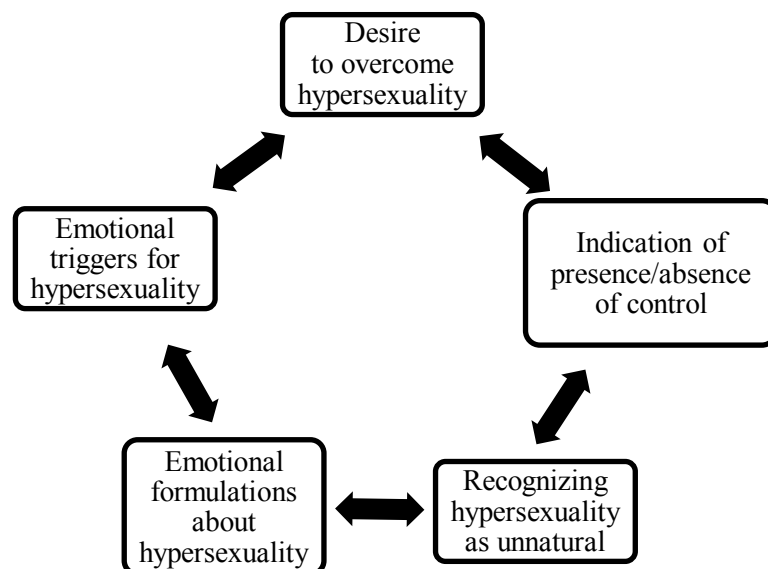
²⁶ Twenty-five remitted patients with bipolar disorder completed the BIS-II; healthy participants were not included in the study and patients were medicated⁽¹⁷¹⁾.

patients acknowledged the presence of hypersexuality and were aware that the PD and the medication may have contributed to its development, only three of the patients appeared to have accurate and intuitive understanding of the problem and who were consequently determined as having insight, while the remaining six were not.

Results assessing readiness for change using the URICA showed that most of the patients were still in the precontemplation stage, where the hypersexuality is not recognised as a *problem* and where no desire to change/overcome it exists. This seems to relate directly to the issue of insight as the patients who indicated insight in the interview were determined to be in the contemplation phase while the patients who indicated no insight in the interview were determined to be in the precontemplation phase, save for Patient 2 without insight who reported being in the contemplation stage. A reason for this discord in the case of Patient 2 might be that his wife was present during his evaluation, which may have prompted him to respond to the questionnaire in a manner appeasing his distraught wife. His answers, therefore, may not have reflected his true condition. This supports the claim that insight should not be determined only using quantitative measures. Quantitative measures may not be sensitive enough and some patients might not be fully forthcoming in their answers as was evident in the study. Interviews, on the other hand, allow a critical researcher to determine insight from the vastness and breadth of the results. Insight and readiness for change are important if any psychological intervention is to be considered for the patients, as research shows that poor insight is associated with poorer outcome^(168, 173).

The findings from the interview regarding the patients with insight suggest a relationship between five emerging variables in the thematic analysis: recognizing hypersexuality as unnatural, emotional formulations about hypersexuality, emotional triggers for hypersexuality, desire to overcome hypersexuality, and indication of presence or absence of control over hypersexuality.

Figure 22 – Factors (determined by thematic analysis) contributing to patient insight into hypersexuality



The three patients with insight seemingly recognised the hypersexuality as unnatural, had negative emotional formulations about their hypersexuality, indicated negative emotional triggers for hypersexuality, expressed a true desire to overcome it, and indicated a lack of control over their hypersexuality. No such relationship has been documented in the literature as there are no studies to date assessing insight and its constituents regarding hypersexuality or other impulse control behaviours in PD or neurological disorders.

Interview data also showed that hypersexuality has negatively impacted almost all the areas of patients' daily living. This is consistent with Mendez and Shapira (2013) who conclude that the hypersexuality does cause substantial "personal distress or impairment in social occupational or other important areas of functioning"⁽¹⁵⁰⁾. Interestingly, the patients who did not have insight into the hypersexuality were still aware that the hypersexuality has had a negative impact on at least one area of their daily living. Some of the patients have acknowledged that the hypersexuality has had a negative effect on the spousal relationship and has caused the partner distress. This indicated that the patients, although lacking insight into the hypersexuality, may not lack insight into what is happening around them (reflective of empathy scale), which might consequently affect their mood and quality of life. Clinicians must be able to make this distinction.

A reason for the lack of insight into the hypersexuality, however, could be that the impact was not severe enough to warrant a change in insight.

It is thus conceivable that the profile of a patient with insight into hypersexuality would look like the following:

Profile of a patient with insight about their hypersexuality

1. *Acknowledgement of the presence of hypersexuality*
2. *Recognition that hypersexuality is unnatural*
3. *Presence of negative emotional formulations around hypersexuality*
4. *Indication of loss of control over hypersexuality*
5. *Awareness regarding the factors contributing to the development of hypersexuality*
6. *Presence of true desire to overcome hypersexuality*
7. *Indication of negative impact of hypersexuality on quality of life/daily living*
8. *Hypersexuality triggered by negative emotions*

One might ask: what determines insight? In the research student's unpublished MSc thesis⁽²²⁾, it was suggested that patients who reduced their dopaminergic medication believed to have contributed to the development of hypersexuality were able to develop insight. This finding was not consistent with the current study's. The three patients who had insight included two patients whose implicated medications were discontinued and one who had no changes in medication regimen (as he had not disclosed his hypersexuality to his consultant or GP). It is difficult to assess, however, whether they developed insight before stopping medications because they were only assessed after stopping them. Further, the remaining six patients included four who had their medication reduced/stopped. This reduction/cessation in medication did not allow them to develop insight. The discrepancy in the findings can be explained by two reasons. First, the patients might implicate the wrong medication. Second, insight into hypersexuality may not relate to medication. For instance, "presentation of hypersexuality may be gender-dependent. Male patients may consider the increased libido as a sign of well-being"⁽¹⁴¹⁾.

Moreover, data from the four couples who took part in the study together showed that the carers provided more information about the hypersexuality than did the patients. This may be due, in large part, to the patients' lack of insight. This is supported by the fact that the one patient (Patient 7) with insight who came with their carer (Carer 3) showed the highest level of accord between the two accounts about

hypersexuality. It is important to note, however, that another reason for the discrepancy in accounts could be social desirability, which refers to instances where participants respond to questions on questionnaires and/or interviews in a manner that make themselves or the situation they are in appear better than it really is in order to reflect a more ‘desirable’ self⁽¹⁷⁴⁾. These findings indicate the importance of including carers in such studies for a better understanding of the phenomenon. This is mirrored in the literature. A study by Rana and Gangat (2011) showed that when asked about ICDs directly, patients denied while carers provided affirmation and details of the ICDs, which were later confirmed by the patients⁽¹⁷⁵⁾.

It is important to note that “patients with excessive sexual thoughts who deny distress or interference with their daily life may be diagnosed as ‘subclinical’ and therefore not captured in epidemiological studies”⁽¹³⁹⁾ and thus overlooked.

3.6.2.15 Stigma

“All societies will always stigmatise some conditions and some behaviours because doing so provides for group solidarity by delineating ‘outsiders’ from ‘insiders’”⁽¹⁷⁶⁾. The stigma associated with hypersexuality may be an “existential stigma”, which sociologist Gerhard Falk defines as “stigma deriving from a condition which the target of the stigma either did not cause or over which he has little control”⁽¹⁷⁶⁾. Sex has long been regarded as a taboo subject with roots in religion and culture, which appear to influence the nature and frequency of sex and its practices. Religion and historical literature portray women having sex out of wedlock as impure, and sexual practices were thus limited to acts occurring only between married people. Further, sexual practices beyond the straightforward, missionary, ‘penis-in-vagina’ paradigm were frowned upon and only heterosexual relationships were accepted. Historically, sexual relationships outside the heterosexual norm were punished, condemned, and ridiculed⁽¹⁷⁷⁾. There was no room socially, culturally, religiously, or biologically for bisexual or homosexual relationships. These values have instilled in people, even years later, a fear of sexual expression and exploration, which has yielded sexual stigma, secrecy, and shame. In an online article by Earp (2015) titled “People Are Terrified of Sex”, he quotes a philosopher who, on the discussion of sexuality, said “I’m not sure if it relates to our Puritan values... but I do think the stigma is a proxy for moral judgement. Sexuality has always had to do with one’s moral character, and so if one has an STI, it suggests that one’s character is ‘infected’ as well”⁽¹⁷⁸⁾. Although cultures and societies have since evolved and become more tolerant⁽¹⁷⁷⁾, the taboos are deep-rooted enough in that their effects can still be observed in present day and were observed in the patients and carers who took part in the study. During the interviews, most of the patients and carers expressed stigma regarding their hypersexuality. Some referred to being older as a reason for their embarrassment about the hypersexuality. This is consistent with the literature on stigma and sexuality in old age. A study by Dominguez and Barbagallo (2016) showed that sexuality in old age is “still conditioned by biases, prejudices”, and borne from “stereotyped vision” which considers older people as “asexual” although older people do have “sexual potential to express”⁽¹¹⁵⁾. Moreover, patients and carers also appeared to laugh or apologise when describing sexually explicit details of the patients’ experience with hypersexuality. Apologizing and nervous laughter may be methods used to try to balance anxiety or embarrassment and mask discomfort⁽¹⁷⁹⁾. Some patients and carers explicitly expressed shame due to the sexual behaviour. The following quotes from the patients and carers seem to characterise the issue of sexual stigma:

“Hypersexuality has not crossed the threshold where people can talk about it... it’s really embarrassing to discuss...”

“Sort of sex is a... it’s not easy for people to discuss... I don’t find it easy...”

“If I walked out of this naturist club straight into the arms of a friend I’d be so embarrassed... it would be terrible... I just worry that people will think I’m a weirdo...”

“I was worried that people would laugh at me... because... pride always comes before a fall... I’d always been proud of my happy marriage... we’d worked at it and the thought that my husband was gay and might be discovered to be gay... that did worry me...”

“I can’t really spread the word [about hypersexuality] ... I would... but because of the children and the embarrassment of you know having a father do that which is difficult...”

One might raise the question about how stigma might drive behaviour. Result showed that sexual stigma drove patients and carers to attempt to hide the patients’ hypersexuality and caused them to worry about others finding out about it. This was not only evident in the interviews but rather in the process of assessing prevalence. The research team was informed that the patients were hesitant in completing the screening questionnaires, although anonymous, and the reason likely driving their resistance is fear of being stigmatised. Similarly, patients and carers who declined participation in the study indicated embarrassment as their reason for choosing not to partake, which may also be directly related to fear of being stigmatised. It is also possible that the patients and carers who did not attend their scheduled appointments and did not schedule appointments after indicating interest may have done so out of fear and embarrassment of discussing this issue. This was also evident in the refusal of some patients and carers to having their interviews recorded, despite ensured deletion and confidentiality.

3.6.2.16 Professional help-seeking barriers

Although the patients and carers were not directly asked about their professional help-seeking behaviour or the barriers associated with professional help-seeking, they did express their discontent with the services, or lack thereof, that were provided to them. Professional help-seeking barriers may stem from the stigma⁽¹⁸⁰⁾ associated with sex and the difficulties associated with the discussion of such a sensitive topic for the patients and carers as well as the health professionals. One might argue that health professionals do not want to upset their patients or cause them discomfort, do not know how to broach the subject, and/or do not know what resources to provide if hypersexuality is presented as an issue. The findings showed that neither the patients nor carers are getting the adequate and necessary information and help for the newly-developed hypersexuality. Evidently, the professional help-seeking barriers impeding the patients and carers’ ability to express their concerns about hypersexuality include the lack of communication, lack of understanding, lack of education, neglect by the health professionals, and difficulties discussing sex. Although there is no research to date specifically examining the professional help-seeking barriers for sex-related issues, the findings are consistent with a study by Hinchcliff et al. (2005) exploring the perspectives of general practitioners on the challenges associated with the discussion of sexual health issues⁽¹⁸¹⁾. Some of the challenges that were established included practitioners’ unawareness of the sexual lifestyles and practices, and “concerns about the appropriate language to use” when discussing sex⁽¹⁸¹⁾. One GP says: “I daresay I might find it embarrassing”⁽¹⁸¹⁾. Although this study focuses primarily on homosexuality, one might be able to draw comparisons with hypersexuality as both notions can be regarded as being ‘outside the sexual norm’. Findings from the current study showed that these professional help-seeking barriers cause further distress to the patients and carers and have caused them to suffer longer in silence of the issue. The following quotes from the patients and carers seem to characterise the issue of professional help-seeking barriers:

“The doctor’s reaction was quite... got me really depressed because I didn’t get an answer for any of my worries... my inquiry... for my worries about my body and I felt like I... either neglected or denied or... haven’t been believed... I thought... and I started to reflect on my personality. I used to say I’m an evil... I’m anonymous... I’m just horrible person... I’m just horrible person because I’m doing things no... nobody is doing and I always used to push it back on myself...”

“Did the psychiatrist know anything more than I knew? I don’t think so... feels horrible being at consultation where everything is being discussed but this... the doctors don’t know what to do...”

“I really query the ethics of not asking patients about this... I think it’s staggering... if somebody had said... well warning you that this might happen when he went on these drugs... I mean it says in the leaflets... it talks about hypersexuality... and I said to... I think it was the professor... I can’t remember now... I looked at it and read the sheets through and I said ‘Oh hypersexual... he’ll be a bit frisky and that’ll be alright’... you know... the horrors of what were to come never occurred to me... if nobody speaks out then this will go on and other marriages will be ruined like mine was ruined... at least had we’ve been told it wouldn’t have been such a terrible shock...”

“I do a bit more than hint at the problems now and again but he never sort of takes it and runs with it... it’s difficult... the only way it would continue is if I kept saying things... I don’t think he think it’s funny necessarily but that it isn’t serious... we’ve been seeing him for ten years and not once has he asked about hypersexuality... or hinted... that it could be a problem... he would spend more time talking about gambling...”

“Feels like no one cares enough... you just don’t feel listened to... carers see everything... I gave up... the overwhelming feeling is of not being believed... by the professionals... the GPs and... it is quite awful... they don’t know... I’m part of our patient liaison committee at the local surgery and I said that I was interested in [hypersexuality]... because of what happened... and there was almost a sort of ‘Would you please lead a group?’ and I said ‘No I can’t’ but they were aware... completely aware... as almost undoubtedly a lot of people are... but even neurologists... even psychoneurologists... don’t know enough about it...”

3.6.2.17 Caregiver burden

All the carers, except one, expressed negative emotional formulations around hypersexuality which suggests the struggles associated with the development of hypersexuality not just on the patients but rather on the carers as well. This finding is mirrored in the literature where this is termed “caregiver burden”^(182, 183). Research has shown that hypersexuality has had a substantial effect on the carers’ lives⁽¹⁸⁴⁾. Findings of the study showed that hypersexuality had an overwhelmingly negative effect on the carers and their relationships with their partners. Some of the words used by the carers to describe their feelings about their partners and the hypersexuality include:

- | | |
|------------------------|-----------------------|
| ▪ <i>shocked</i> | ▪ <i>despair</i> |
| ▪ <i>cheapened</i> | ▪ <i>embarrassed</i> |
| ▪ <i>uncomfortable</i> | ▪ <i>repulsed</i> |
| ▪ <i>hopeless</i> | ▪ <i>broken heart</i> |
| ▪ <i>abandoned</i> | ▪ <i>angry</i> |
| ▪ <i>stupid</i> | ▪ <i>betrayed</i> |
| ▪ <i>hurt</i> | ▪ <i>rejected</i> |
| ▪ <i>sad</i> | ▪ <i>confused</i> |
| ▪ <i>cross</i> | ▪ <i>worthless</i> |
| ▪ <i>used</i> | ▪ <i>disregarded</i> |

Furthermore, of the things the carers said to describe the impact hypersexuality had on their relationships were:

“Made a mockery of the last twenty years together...”

“I need to walk before I can run again and I don’t know whether I’ll ever really want to run...”

“My marriage was wrecked... and he died among the wreckage...”

“Like someone telling you they have a cold constantly and you can’t do anything about it... becomes an irritation...”

The data showed that some carers, due to their frustration and despair from dealing with their partners and the hypersexuality, had desires or actual instances where they had an aggressive response to their partners’ hypersexuality. The following quote characterises the despair: *“I think the worst thing was that on one occasion I actually momentarily considered violence towards him... he’d had one of his trips to the sex shop... he got stuff... I’d been out in the garden... and I’d seen him through the window of his office... obviously he was busy looking at some stuff... and it was lunch time and I came in to give him his lunch... and I stood behind him and I really can’t believe it now but I’ve got to tell you... it’s the truth... I stood behind him with this big hammer in my hand... and I thought quite clearly ‘A couple of blows to your skull with this and this would all be over’... and then I put the hammer away and served his lunch...”*

Moreover, although the carers tried, to the best of their ability, to deal with the hypersexuality, they were faced with challenges with coping with it. Some carers expressed feelings of responsibility and guilt while other carers expressed a desire not to exist. These difficulties with coping further support the claim that the carers might suffer as much as the patients themselves, if not more because there is no question of insight for the carers as is the case of the patients. These findings are consistent with the literature. A study by Kaizik et al. (2016) showed an association between hypersexual behaviour and carer distress⁽¹⁸⁵⁾. Themes of “grief and loss”⁽¹⁸⁵⁾ and “changed role”⁽¹⁸⁵⁾ emerged from the carers’ accounts as in the study. Other research shows that hypersexuality is a “source of suffering and hardship to patient’s entourage”⁽¹⁸⁶⁾ and affect spouses’ well-being and physical health⁽¹⁸⁷⁾. The findings of the study are also consistent with the literature on sex addiction. One may thus draw comparisons with the literature on sex addiction which also leaves the carers “overlooked”⁽¹⁸⁸⁾. Praver (2011) states that “many people married to sex addicts are left traumatised [and] devastated”⁽¹⁸⁹⁾. Furthermore, Wadleigh (2017) concludes that the experience may leave the carers feeling “alone and ashamed... trust is severely damaged, which cripples emotional intimacy and creates distance and a breakdown in communications”⁽¹⁸⁸⁾, which was evident in the study. Results also showed that the carers were in the borderline abnormal range for anxiety⁽¹⁹⁰⁾ and had mid-range quality of

life⁽¹⁹¹⁾, as measured by the HADS and AC-QoL, respectively. Research has shown that carers of individuals with neurological disorders can experience anxiety and a reduction in quality of life; therefore, it would be difficult to distinguish between how much of the effect on the carers' mood and quality of life was due to living with an individual with neurological disorders and how much, if any, it was exacerbated by the hypersexuality. Also, the carers were expected to spend around 2 hours in assessment; however, the carers tended to spend more time discussing the hypersexuality, with one carer spending almost 3 hours and a half. This may suggest that the carers' distress is undermined and that, in actuality, they need time just to express the way they feel and talk about their experience.

Although this study focused primarily on spousal carers, this burden may also be experienced by other members of the family who are affected by the hypersexuality. Also, the impact and burden on the carers may be exacerbated due to the presence of a neurological disorder with the hypersexuality that they are also expected to come to terms with. This sentiment is echoed by Carer 2 who said in her interview: "Had it been just the hypersexuality, it might've been easier than the hypersexuality and PD together".

It is important to note that there was no significant distinction between the burden experienced by the PD and FTD carers and no correlation between quality of life and depression score of carers. This may be due to small sample size and some patients deceased. It might be worthwhile to consider sex-specific QoL scales.

3.6.2.18 *Past experiences and hypersexuality*

Although all the carers attributed the onset of their partners' hypersexuality to the neurological diseases, some carers believe the nature in which the hypersexuality developed is related to some of the patients' past experiences. There were four examples of this in the study. The first carer indicated that her hypersexual husband had a homosexual experience at the age of fifteen with a school friend. She claims that her husband "might have been a repressed homosexual and the hypersexuality had overridden his control of that and was forcing him... allowing him... stimulating him to pursue the homosexuality as he had never done" before. The second carer indicated that her hypersexual husband had an ex-girlfriend during his twenties who was of Indian descent and who tragically died in a car accident. She claims that both prostitutes he was involved with, and one of whom he fell in love with, were dark-skinned. The third carer's hypersexual husband put on women's makeup and clothing as a teenager and used to masturbate while wearing his mother's underwear at eleven years of age. She believes that this behaviour had "come back" from his early years and claims that he had consequently "reverted to factory settings". The fourth carer indicated that, after developing hypersexuality, some of her husband's old behaviours that he seemed happy not to do had "rekindled" such as swallowing and anal and oral sex. There has been no research exploring this possible link in either the hypersexuality in neurological diseases literature or the sex addiction literature; however, one might argue that there may be two potential reasons for this. The first involves the patient's lack of disclosure. Two of the above carers claim that the behaviour their partners once experienced seemed to come back after long years of absence; however, it is a possibility that these behaviours had never gone but rather their partners had been successful in suppressing them. It is conceivable that because of the neurological disorders, their inhibitions might have been affected which allowed these behaviours to manifest. The second possible reason involves molecular and biological underpinnings of the medications used to manage the neurological disorders, namely PD. Although this has not been investigated and is beyond the scope of this research, it is conceivable that latent tendencies become manifest due to chemical changes following the use of certain medications.

3.6.2.19 *Advantages of having mixed method research design*

Results from triangulation of the data showed that the qualitative assessment tool has provided more information than the quantitative assessment tools in some instances. For instance, when comparing assessment tools for impulse control disorders, two patients appeared to express eating as an impulse

control disorder in the interview that was not picked up in the questionnaire. Similarly, one patient expressed preoccupation with sex in the interview that was not picked up in the questionnaire. This suggests the possibility that the questionnaires may not be as sensitive as qualitative tools, which supports the employment of a mixed methods research design. Because research into the phenomenology of hypersexuality in neurological disorders is in its infancy, mixed methods research design is beneficial as it increases comprehensiveness and completeness of overall findings and the expansion of the dimensions of the research topic⁽¹⁹²⁾.

3.6.3 Limitations

Due to the preliminary nature of this study, there are several limitations:

1. Lack of prior research on hypersexuality

A major limitation of the study is the lack of available prior research on hypersexuality in neurological disorders. More research has been done into sexual dysfunction (outside of hypersexuality) in neurological disorders such as erectile dysfunction and hyposexuality. In PD research, most mention of hypersexuality has been in conjunction with the other impulse control disorders and has therefore not been examined in depth on its own. Although in recent years hypersexuality has become more recognised as an issue in research, there is still very limited information regarding its manifestations, impact, and correlates. This limited research primarily limits the comparison of results from this data to other similar data to see how different patients fare. Further, there has been no research directly comparing hypersexuality in PD to hypersexuality in dementia.

2. Sex research

Hypersexuality is likely underreported due to patient and/or carer stress and shame which complicates the identification and assessment of the behaviour⁽¹⁹³⁾. Patients and carers tend to be too ashamed to divulge information about the patients' sexual behaviour and pursuits⁽¹⁹⁴⁾, especially in older populations⁽¹⁹⁵⁾. Research into sex warrants its own set of limitations including but not limited to fearful and hesitant participants⁽¹⁹⁶⁾. Sexuality is considered a sensitive and private topic, which is fed into by social, cultural, moral, and legal norms and restraints⁽¹⁹⁶⁾, and may involve stigmatised and/or illegal behaviour⁽¹⁹⁷⁾. This limits the number of individuals willing to speak of their sexuality with health professionals, which may explain the modest number of patients who completed the QUIP at ECH. Consequently, it is seemingly very difficult to ensure the size and boundaries of a study population which, in turn, makes it difficult to get a representative sample⁽¹⁹⁷⁾. Concerns also arise with regards to privacy and confidentiality and are often "difficult to resolve"⁽¹⁹⁷⁾. Another limitation is having unbiased and precise measures of sexuality as errors may arise due to "participation bias, recall and comprehension, problems, and respondents' willingness to report sensitive and sometimes socially censured attitudes or behaviours"⁽¹⁹⁶⁾. Conclusively, as with research on any sensitive and private matter, there are no guarantees with regards to participants or what information they should and are willing to divulge.

3. Mixed methods research design

There are several challenges with using both qualitative and quantitative methodology in research. First, the research design can be very complex⁽¹⁹⁸⁾. Second, it is more time-consuming⁽¹⁹⁸⁾. Third, it may require more resources to implement⁽¹⁹⁹⁾. Fourth, it may be difficult to resolve discrepancies between the two methods because they are operationally different⁽¹⁹⁹⁾. Fifth, it may be difficult for "quantitative" researchers to cross over and see the merit and validity of qualitative research⁽²⁰⁰⁾.

4. Non-experimental research design

The non-experimental nature of the study allowed the researcher to establish correlational relationships between scales and constructs. Correlational analyses, however, can only generate a predictive relationship between variables which suggests that causation cannot be inferred from such relationships⁽¹⁷⁴⁾.

5. Sample size

Quantitatively the limitations include the effect the small sample has on statistical power. Statistical power refers to the ability of a statistical test to discover effects that truly exist in the population⁽²⁰¹⁾. Lower sample sizes typically suggest lower statistical power⁽²⁰¹⁾. Moreover, the small sample size may affect correlational analyses and may thus produce overestimations in the magnitude of the relationship in the data⁽²⁰²⁾. There is also a possibility that if the sample size had been larger, more correlations between the questionnaires and the constructs could have been established. Furthermore, the small sample size did not allow the exploration of gender differences. However, because no other systematic investigations of hypersexuality in neurological disorders exist, the limitation of small sample size is not significant enough to minimize and undermine the results and value of the study as it provides a basis for future research. A study by Maxwell (2004) actually suggests that there is persistence of underpowered studies in research⁽²⁰³⁾. A reason for this may be that the current state of academia supports novel studies that provide new insights and angles.

Qualitatively, on the other hand, saturation is a highly debated subject in qualitative research. Saturation cannot be measured and is a subjective decision based solely on researcher judgment. It can be argued, therefore, that there was enough data from the interviews to ensure that the research questions were answered (not saturated for comparison between FTD and PD, however).

6. Recruitment methods

Due to the challenges encountered in initial plans of recruitment, the recruitment methods that were used were limited to leaflets and blurbs of the study distributed with the QUIP at ECH, at one seminar, included in a dementia newsletter, and circulated online by Parkinson's UK and having consultants, psychologists, and nurses inform patients presenting with hypersexuality and/or their carers about the study, which may have contributed to the small sample size.

7. Inclusion of only two neurological disorders

A further limitation of the study was the inclusion of only two neurological disorders, PD and dementia, which may have limited the scope of the study, however, other neurological disorder groups were approached by the researcher and the supervisors to no avail possibly due to the challenges associated with discussing sex, as well as the desire to avoid making patients uncomfortable, which this study hopes to help minimise.

8. No dementia patients

The research team was informed that dementia patients could not be approached about taking part in the study due to their research fatigue which may have weakened the comparisons between hypersexuality in PD and dementia as any comparison was contingent upon the carers' accounts of their partner's hypersexuality, generating possible bias.

9. No Alzheimer's disease carers

Although FTD carers were successfully recruited in the study, no AD carers indicated or contacted the research team about their partners having hypersexuality. Had there been an AD carer group,

comparisons could have been made between the two dementia groups and the PD group. It is important to note, however, that the prevalence of hypersexuality in AD is lower than in FTD, as presented in the previous chapter, which may have contributed to this.

10. Lack of control group

There were no age-matched, disease-matched control groups included in the study to compare the quantitative data to, which could have made the results of the study more significant. The results, however, were compared to similar data found in the literature. Because this study is exploratory rather than explanatory, the lack of control groups for comparison does not undermine the significance of this research.

11. Sample descriptives

The first limitation associated with the sample descriptives in the study relates to missing information from ECH. Although ECH was a site of recruitment for the study, the research team had no access to patient history and clinical notes and, thus, could not obtain medication history for the one patient from there who partook in the study, although the research team had requested that he bring his clinical notes with him. The second limitation of the sample descriptives relates to missing Hoen and Yahr stages which limits possible comparability, although not within scope of this particular research.

12. Missing values

Two of the patients did not complete the full set of questionnaires. This created missing values in the data which may have impacted the quantitative results and consequently the statistical analyses. One of the patients did not complete the full set of assessment because of her “PD attack”, while the other did not complete it due to embarrassment and fatigue from the long battery of questionnaires.

13. Qualitative research

Although rigour was discussed in the qualitative analysis methodology section, there are inherent limitations associated with qualitative research. First, the quality of the research relies heavily on the researcher’s skills and may be influenced by the researcher’s “personal bias and idiosyncrasies”⁽²⁰⁴⁾. Second, the “volume of data” generated in qualitative research makes analysis and interpretation time-consuming⁽²⁰⁴⁾. Third, the presence of the researcher during data collection may influence participants’ responses⁽²⁰⁴⁾. Fourth, characterizing the findings in a visual manner may be more challenging and time-consuming⁽²⁰⁴⁾. Fifth, qualitative research is “not as well understood and accepted as quantitative research within the scientific community”⁽²⁰⁴⁾. Sixth, qualitative research is not easily generalizable “with the same degree of certainty that quantitative analyses can”, which may limit its replicability⁽²⁰⁵⁾ and its ability to make predictions. Seventh, the only way the participants could interact with the researcher was through language, which could be limiting. Carla Willig (2008) claims that language can often precede or construct reality for an individual so that the words one chooses to describe their experience may construct just one version of that experience and consequently the real essence of the experience may get “lost in translation” between participants and researcher⁽²⁰⁶⁾.

14. Semi-structured interviews

The use of semi-structured interviews was necessary to fulfil the aim of the research; however, it does present with its own set of limitations. First, the interviewer cannot ensure total honesty of the participants and thus cannot ensure validity of the interview⁽²⁰⁷⁾. “Each individual’s experience of truth will be influenced by their own subjective construction of that truth”⁽²⁰⁸⁾. Second, flexibility of the interview may reduce reliability, which makes it difficult to replicate as the

interviewer may ask different participants different questions based on their responses⁽²⁰⁷⁾. The interviewer might also inadvertently influence participants to respond in a certain manner, which may also challenge the reliability⁽²⁰⁷⁾. Third, open-ended questions are difficult to analyse due to the volume and breadth of the qualitative data⁽²⁰⁷⁾, and as was observed in the study, some participants talked about things that other did not. Fourth, it is challenging to compare answers, which may give rise to research bias⁽²⁰⁷⁾. Fifth, the articulacy of the participants may challenge the data collected⁽²⁰⁷⁾. Sixth, semi-structured interviews may be time-consuming⁽²⁰⁷⁾. Seventh, the interviews may constitute personal questions, which may cause some participants discomfort⁽²⁰⁷⁾. Eighth, participants' answers may be influenced by their mood on the day of participation.

15. Patient/Carer Assessment Interviews

It is important to note that the research student developed the semi-structured interviews that were used because there were no interview schedules available that would have fulfilled the aims of the study. The Minnesota Impulsive Disorders Interview (MIDI) is often used; however, it is not extensive and thorough enough. The questions used in the interviews of the patients and carers were informed by the MSc thesis and data on sex addiction. After the appropriate thematic analyses were carried out and significant information emerged about hypersexuality, there appeared to be some limitations associated with the interviews. First, the patients were asked what was unusual about their sexual behaviour rather than what was different, which would have been more appropriate since some patients do not regard their sexual changes as 'unusual'. Second, the interviews did not ask about experience with professional help or about what the participants hoped to achieve or overcome moving forward with the hypersexuality, both of which were salient themes. Third, the interviews did not appear systematic enough; questions were not grouped appropriately, which may have caused the participants some confusion. Moreover, there is no interview schedule aimed at the assessment of hypersexuality in patients with neurological disease; therefore, it was necessary to develop one to achieve the aims of this study.

16. Questionnaires

One limitation is that some tests did not provide cut off scores or categorical measures making it difficult to classify the patients/carers. This prompted the use of a single sample t-test to measure statistical significance as compared with normative data. Although the normative data to which the results were compared did not always provide age-matched samples, it was necessary to be able to see where the study sample fit. Another limitation is that there are no questionnaires specifically assessing hypersexuality in neurological disorders. Because of this and because this is the first study to systematically investigate hypersexuality in neurological disorders, the researcher had to ensure that the battery of questionnaires used assessed a wide range of constructs from sex addiction to executive functioning to ensure breadth and depth of the analysis of hypersexuality and its manifestations, which could in the future facilitate the creation of hypersexuality-specific questionnaires. Moreover, some questionnaire such as the HADS, IIEF, and FSFI require participants to respond according to how they have been feeling within a certain time frame, which may not grasp the full extent of the phenomenon. For instance, a carer participant indicated that her responses to the HADS would have been different had it been further back than the week time frame.

17. Self-reporting

The interview as well as almost all the questionnaires that were used in the study relied on self-reporting. The main limitation associated with self-reporting is that the information collected cannot be verified. Other limitations include selective memory, telescoping, and exaggeration⁽²⁰⁹⁾. Selective memory refers to a participant "remembering and not remembering" past experiences or events⁽²⁰⁹⁾. Telescoping refers to a participant "recalling events that occurred at one time as if they

occurred at another²⁷(209). Exaggeration refers to participants “embellishing” events and experiences⁽²⁰⁹⁾.

18. Social desirability²⁷

This limitation was especially evident when some of the carers of the patients who took part in the study informed the researcher that their partners had not been as forthcoming and honest in their answers as they could have been. This, however, could also relate back to the stigma and challenges associated with the discussion of sex.

19. Dynamics of data collection

Apart from the interview, the patients had to complete seventeen questionnaires. Although most were relatively short in length (on average 5-15 minutes per questionnaire/test), the limitation associated with a long battery of questionnaires is patient fatigue and boredom which might have affected their answers. Furthermore, the questionnaires had been given in the same order to all the patients, so there is a possibility that due to the boredom and fatigue the patients may have inadvertently scored worse on the tests that were completed towards the end potentially showing greater deficits than they actually have. For purposes of the study, however, these tests were necessary to complete in the same day because there were no guarantees of having the patients come in on two or more separate days to complete the questionnaires.

20. Collecting data from patients with neurological disorders

There are limitations associated with assessing individuals with neurological conditions. Patients with PD and dementia may have cognitive deficits which might impact their understanding of the questions. They may also suffer from memory problems which could affect their recall of certain events and experiences. In the study, some of the patients with PD required multiple breaks in order to get their tremors under control and in order to take their medications at specified times. One of the PD patients had to stop the interview because she had had a “PD attack”, a term she uses to describe a flare-up of her symptoms, requiring her to stop. Also, one of the patients suffers from slurring of his speech as a result of his PD which made it a bit difficult to understand him.

21. Dictaphone

Some of the participants of the study did not consent to having their interviews be audio-recorded using a Dictaphone although absolute confidentiality was ensured and they were informed that the recordings would be deleted immediately at the end of transcription. The researcher was thus required to ensure thorough, accurate, and complete note-taking during the interviews to guarantee all important information was collected. Although this was done to a high degree of diligence, there are obviously limitations to not having actual transcripts of the interviews such as the lack of verbatim quotations. Also, there is always a possibility that something might have been left out or overlooked.

22. Patient assessed with wife

Although patients and carers who came together were advised to complete their assessments separately, one PD patient requested his wife be present, which may have affected his responses. After his assessment, his wife indicated that much of what her husband had said about his hypersexuality was down-played to possibly appease her discontentment with it.

23. Deceased partners

Two of the carers who took part in the study indicated that their husbands had passed away.

²⁷ To appear more socially ‘attractive’.

Although one of these carers indicated that she still suffers from the effects of her husband's hypersexuality, the other claims that her answers on the HADS for depression and anxiety would have been different had her husband still been alive (as she has since had time to process and recover from the effects of the hypersexuality). This may have influenced the results and the consequent statistical analyses regarding the impact hypersexuality has had on carers' mood.

24. Variable quality of interviews

As highlighted in section 3.4.10.8, the researcher was responsible for modifying, changing, or skipping questions during the interview process according to participants' reactions. This resulted in variable quality of interviews, especially for the patient group. Although analysis of the interviews was as thorough as possible, this might have affected the quality of analysis.

3.6.4 Implications

“Stigmatizing behaviours does not prevent [sexual] activities from occurring”⁽¹⁷⁸⁾. This statement reflects the main implication of this research, which requires health professionals to help mitigate the stigma associated with sex. Health professionals, including consultants, psychologists, nurses, and GPs, must be educated about hypersexuality and the negative impact it has in order to then educate the patients and their carers/families. Perhaps in doing so (as well as having appropriate communication skills), they can attempt to normalise hypersexuality, explain it, and provide reassurance, if nothing else. This would help alleviate the patient and carer burden of living with hypersexuality and consequently facilitate better help-seeking behaviour. It is necessary for health professionals to explain to the patients with neurological disorders and especially PD, as well as their carers that hypersexuality, for the most part, is a “chemical disorder linked to the effects of neurotransmitters and not to behaviour or personality changes caused by the disease”⁽¹⁴⁹⁾. Clinicians may choose to consider the OSEC model, discussed in Chapter 1, which has been indicated as being effective in overcoming difficulties in talking about sexual disorders^(210, 211). The OSEC comprises four steps, which allows clinicians to begin the “sex talk” with patients to pinpoint apprehensions they might have and then attempt to find suitable interventions⁽²¹⁰⁾. A sexual history must then be taken and clinicians must understand how sensitive the issue is while doing so⁽²¹⁰⁾. “The importance of a thorough clinical assessment cannot be underestimated”⁽¹³⁹⁾. Moreover, health professionals who do not feel equipped or comfortable enough to tackle this issue on their own or are too busy to, should consider identifying one individual from their multidisciplinary team who *is* willing evaluate and treat this complicated and sensitive issue and who patients/carers can be referred to⁽¹⁴¹⁾. For this type of help to be provided, health professionals must understand the uniqueness and the multidimensionality of hypersexuality.

These implications for health professionals may then lead to implications for carers, which could include understanding the hypersexuality and understanding that it is beyond the patients' control. This does not mean that carers must accept however the hypersexuality manifests, but rather to know that they are able access bodies of help that can provide support and advice if needed.

Further implications may require society to take a step back and reevaluate stigmatised beliefs. Although this is difficult considering the deep-rooted stigmas associated with sex, it is not impossible. Sexual issues “thrive in secrecy and shame, and until we as a society can start talking about it openly and non-judgmentally, the problem is going to continue to grow”⁽²¹²⁾.

3.6.5 Link to upcoming chapter

One of the biggest barriers to result from this chapter is the “professional defensiveness”⁽²¹³⁾ that the patients and carers are subject to. These individuals are being told that their problem “does not really exist or that they simply need to develop more self-control or come to terms with [the] behaviour”⁽²¹³⁾. This might be, in large part, due to the fact that health bodies do not know how to go about treating this

condition. Also, little attention is being paid to carers' emotional and physical health and, therefore, carers are often disregarded. It thus became apparent to the research team the importance of an easily accessible, psychoeducational tool to provide basic, necessary information about hypersexuality in neurological disorders to *both* patients and carers (that health professionals might benefit from also), as well as the investigation/development of feasible psychological/behavioural management pathways that health professionals can consider when faced with this issue, both of which will be explored in the next chapter and will be based on the findings of this chapter and the systematic review chapter.

3.6.6 Recommendations for future research

Because this study is a preliminary study of hypersexuality in neurological disorders, there are several directions for future research (that will not be explored in this dissertation). The recommendations include:

1. Developing hypersexuality-specific questionnaires since there are no such questionnaires. For instance, the URICA used in the study could inspire researchers to create a sexual readiness for change scale, the BIS-11 and UPPS-P could inspire researchers to create sexual impulsivity scales, and the AC-QoL could inspire researchers to create a quality of life scale for carers about dealing with the hypersexuality.
2. Conducting studies to compare the manifestation and impact of hypersexuality within neurological disorders, such as in dementia between FTD and AD, and between neurological disorders, such as PD, dementia, epilepsy, and others. These studies could be beneficial as they could uncover patterns that have yet to be uncovered. This may prove challenging as it could take long to recruit these patients.
3. Conducting studies with PD control group to see what types of differences arise in the quantitative component, for instance.
4. Conducting studies assessing sexual conduct in PD patients not on medication.
5. Conducting studies with large sample size to compare patients with neurological disorders who have hypersexuality to people with no neurological disorders who have sex addiction. This would allow researchers to investigate the differences between these two groups and perhaps specifically assess the patterns of impulsivity, compulsivity, addiction, and risk-taking.
6. Exploring other recruitment methods that could guarantee a higher sample size such as the use of the radio and social media to inform people of the study, as was suggested by one of the participants, or providing study leaflets to every patient and carer attending the clinic. Home visits could also be of benefit.
7. Considering multi-centre studies to further ensure substantial sample size, potentially benefiting prevalence studies.
8. Conducting studies investigating the determinants of insight, as well as the importance of patient insight for the assessment of hypersexuality, which could possibly lead to the development of a more thorough profile of a patient with insight that clinicians can make use of in the future as this has not been investigated yet.
9. Exploring the significance of past experiences and how they affect the nature in which the hypersexuality develops, as was discussed in the findings.

10. Conducting studies to examine, at a neurobiological, molecular, and chemical level, why the PD medications, and mainly the dopamine agonists, cause hypersexuality and other impulse control disorders. This would allow a more holistic picture of the phenomenon to emerge.
11. Not to disregard the carer in any assessment of hypersexuality as they can often provide more information than the patients, as was evident in the study.
12. Conducting studies investigating the professional help-seeking barriers and possibly involving GPs and consultants and considering reasons why they do not broach the subject, as was done the study by Hinchcliff et al. (2005)⁽¹⁸¹⁾, except not just about difficulties with discussing homosexuality.
13. The use of the following newly-developed patient and carer semi-structured interview schedules to assess past and current hypersexuality in neurological disorders that have been informed by the detailed findings of the thematic analyses:

a. *Patient Assessment Interview*

Interview length: 60-90 minutes

Introduction (to read aloud to the patient):

Thank you for agreeing to take part in this interview.

This interview will be audio recorded, unless you have specified otherwise.

All data collected is confidential. No records of this interview will be kept with your name or any other identifiable data on it.

The following sections include questions about the increase in your sexual thoughts, desires, and/or behaviour since getting [insert name of neurological disorder]. This is called hypersexuality. Please remember that sexual acts involving physical harm to others or child abuse is against the law. For this reason, please do not answer any questions that show that your sexual behaviour has been a threat to others or that you have had sexual relationships with minors.

I completely understand how sensitive this topic is and how challenging it may be to discuss. If any questions make you uncomfortable, you are entirely free not to answer them. Also, if any questions are not understandable, please ask and they will be explained.

This research into hypersexuality will, hopefully, help mitigate the stigma around sex. This interview is, therefore, not intended to serve any judgement towards you regarding your sexuality and how you have expressed it. This is a free space where you can express yourself however you choose. It is an opportunity for us to get to know you in an extremely objective manner. This interview is not intended to cause you any discomfort or upset.

Are you happy to proceed?

Background Information

1. How old are you?
2. How old were you when you got [insert name of neurological disorder]?
3. What is your sexual orientation?
4. Have you ever been sexually abused?
Probe 1: (if yes) By whom?
Probe 2: At what age?
Probe 3: How long did it go on?
5. Did you have any behavioural or cognitive disorders before you got [insert name of neurological disorder]?
Probe: (if yes) What were they?
6. Did you have any previous addictions such as illegal drugs or alcohol?
Probe: (if yes) What were they?
7. Apart from hypersexuality, have you had any other impulse control disorders since developing [insert name of neurological disorder] such as compulsive gambling?
Probe 1: (if yes) When did it start?
Probe 2: How severe do you think it has been?
8. Compulsive eating?
Probe 1: (if yes) When did it start?
Probe 2: How severe do you think it has been?
9. Compulsive buying?
Probe 1: (if yes) When did it start?
Probe 2: How severe do you think it has been?
10. Since developing [insert name of neurological disorder], have you noticed any other changes in your behaviour apart from these?
Probe 1: (if yes) What are they?
Probe 2: When did they start?
Probe 3: How severe do you think they have been?

Cognitions

11. Are you hypersexual?
Probe: How old were you when you first became hypersexual?

12. Since developing hypersexuality, has there been a change in your thoughts about sex?
Probe: (if yes) What was this change?
13. Have you noticed yourself thinking about sex more frequently than before?
14. Is the change in your thoughts about sex still present to this day?
Probe: How has the change in your thoughts made you feel?
15. Since developing hypersexuality, have there been a change in your sexual desire?
Probe 1: (if yes) What was this change?
Probe 2: Did/do you desire the things you used to more than you did before developing hypersexuality?
Probe 3: Have you developed new sexual desires that were not there before?
16. Is the change in your sexual desires still present to this day?
Probe: How has the change in your desires made you feel?
17. Would you say your sexual desire is insatiable?
Probe: (if yes) How so?
18. Have you noticed other people becoming more sexually attracted to you?
Probe: (if yes) How so?
19. Have you noticed yourself becoming more sexually attracted to other people?
Probe: (if yes) How do?
20. Have you felt sexually aroused by any inanimate objects?
Probe: (if yes) Which objects?

Behaviours

21. Since developing hypersexuality, has there been a change in your sexual behaviour?
Probe: (if yes) What was this change?
22. Have you developed new sexual behaviours that you did not have before developing hypersexuality?
Probe: (if yes) What were they?
23. Would you say your sexual behaviour was unusual?
Probe: (if yes) How so?
24. Would you say your sexual behaviour was risky?
Probe: (if yes) How so?
25. Is the change in your sexual behaviour still present to this day?
Probe: How has the change in your behaviour made you feel?

Preoccupation

26. Since developing hypersexuality, how often have you thought about sex?
Probe: Can you quantify how much time?
27. Since developing hypersexuality, have you found it hard to concentrate on other areas of life because of thinking about sex?
Probe: (if yes) What areas of life?
28. Since developing hypersexuality, have you felt a lot of time has been spent on sexual thoughts that you would have rather used on other things?
Probe: (if yes) How much time?

Compulsivity

29. Do you believe your behaviour was/is compulsive?
Probe: (if yes) How so?
30. Since developing hypersexuality, have you felt a lot of time has been spent on sexual behaviour that you would have rather used on other things?
Probe: Can you quantify how much time?

Impulsivity

31. Do you think your behaviour was/is impulsive?
Probe: (if yes) How so?

Addiction

32. Do you believe you were/are addicted to sex?
Probe: (if yes) How so?

Triggers

33. Did/does anything trigger your hypersexuality?
Probe: (if yes) What things?

34. Did/do certain feelings trigger your hypersexuality?
 Probe 1: Have you felt more hypersexual when you have had certain feelings such as sadness, happiness, or anger?
 Probe 2: (if yes) Which feelings?

Practices with the partner

35. Do you have a partner?
 Probe: (if yes) Were you together before you developed hypersexuality?
36. Since you developed hypersexuality, has there been a change in the frequency of sexual intercourse with your partner?
 Probe 1: (if yes) What is this change?
 Probe 2: How has your partner responded to this change?
 Probe 2: How has this change in the frequency of sex made you feel?
37. How often were you having sex before developing hypersexuality?
38. How often were you having sex after developing hypersexuality?
39. How often are you having sex now?
40. Since you developed hypersexuality, has there been a change in the nature of sexual intercourse with your partner?
 Probe 1: (if yes) What is this change?
 Probe 2: How has your partner responded to this change?
 Probe 3: How has this change in the nature of sex made you feel?
41. Since developing hypersexuality, have you asked for new things during sex you did not care for before?
 Probe: (if yes) What things?
42. Since developing hypersexuality, have you been more sexually aggressive with your partner?
 Probe: (if yes) How so?
43. Since developing hypersexuality, have you asked your partner to be sexually aggressive with you?
 Probe: (if yes) How so?

Practices with themselves

44. Since developing hypersexuality, have you chosen to please yourself sexually?
 Probe 1: (if yes) How often?
 Probe 2: Has there been a change in your frequency of pleasing yourself since developing hypersexuality?
 Probe 3: Has it left you feeling satisfied?
 Probe 4: (if no) Why?
45. Since developing hypersexuality, have you used pornographic material?
 Probe 1: (if yes) How often?
 Probe 2: Has there been a change in your frequency of using porn since developing hypersexuality?
 Probe 3: Has it left you feeling satisfied?
 Probe 4: (if no) Why?

Practices with others

46. Promiscuity can be defined as having indiscriminate sex with many different people. Since developing hypersexuality, have you felt promiscuous?
 Probe: (if yes) How so?
47. Since developing hypersexuality, have you paid for sex?
 Probe 1: Have you had sex with prostitutes?
 Probe 2: Have you visited massage parlours?
 Probe 3: Have you visited strip clubs?
 Probe 4: Have you used dating sites looking for sex?
 Probe 5: Have you called sex phone lines?
48. Since developing hypersexuality, have you had anonymous sexual encounters?
 Probe 1: Have you had one night stands?
 Probe 2: Have you visited saunas?
 Probe 3: Have you visited bath houses?
49. Since developing hypersexuality, have you had any affairs?
 Probe 1: (if yes) Was/is it sexual in nature?

Probe 2: What were/are you getting from your affair that you are not getting from your relationship with your partner?

Probe 3: Has your affair ended?

Probe 4: Does your partner know about it?

Probe 5: (if yes) How has your partner felt about it?

50. Since developing hypersexuality, have you had sex with anyone of a different gender than the one you are typically interested in?

Probe: (if yes) Would you say your sexual orientation has changed?

Deviant practices

51. Since developing hypersexuality, have you gotten sexual satisfaction from spying on sexual acts (not pornography; sexual acts in real life, in real time)?

52. Since developing hypersexuality, have you showed your genitals to strangers?

53. Since developing hypersexuality, have you had sex with animals?

Emotional formulation

54. How has your hypersexuality made you feel?

55. Have you ever felt happy with your hypersexuality?

56. Since developing hypersexuality, has your image of yourself changed?

Probe: (if yes) How so?

Insight

57. Do you believe hypersexuality is a problem?

58. Do you believe your hypersexuality is unnatural?

Probe 1: (if yes) Did/does your hypersexuality match your personal values and beliefs?

Probe 2: How so?

59. What do you believe was the cause of your hypersexuality?

60. Do you believe your [insert name of neurological disorder] caused your hypersexuality?

Probe: (if yes) Why do you think so?

61. (if patient has PD) Do you believe the PD medication caused your hypersexuality?

Probe 1: (if yes) Why do you think so?

Probe 2: Which medication?

62. Have you wanted to overcome your hypersexuality?

Probe: Why?

Control

63. Have you had control over your hypersexuality?

Probe: Why do you think so?

64. Have you tried to reduce your hypersexuality or stop it altogether?

Probe 1: (if yes) How so?

Probe 2: Have you been successful?

Probe 3: How has that made you feel?

Impact

65. Has the hypersexuality had an impact on your life in general?

Probe: (if yes) How so?

66. Has the hypersexuality affected your marital life?

Probe: (if yes) How so?

67. Has the hypersexuality affected your family life?

Probe: (if yes) How so?

68. Has the hypersexuality affected your social life?

Probe: (if yes) How so?

69. Has the hypersexuality affected your work and daily activities?

Probe: (if yes) How so?

70. Has the hypersexuality affected your finances?

Probe: (if yes) How so?

71. Has the hypersexuality affected your health?

Probe: (if yes) How so?

72. Has the hypersexuality affected your mood?

Probe: (if yes) How so?

73. Has the hypersexuality affected your sleep?

Probe: (if yes) How so?

74. Has the hypersexuality affected your self-confidence?
Probe: (if yes) How so?
75. Has the hypersexuality affected your overall quality of life?
Probe: (if yes) How so?

Relationship with the partner

76. Since developing hypersexuality, has there been less intimacy between you and your partner?
Probe 1: (if yes) How so?
Probe 2: How has that made you feel?
77. Since developing hypersexuality, has there been more arguments with your partner?
Probe 1: (if yes) Why?
Probe 2: How has that made you feel?
78. Since developing hypersexuality, have you become irritable?
Probe 1: (if yes) Why?
Probe 2: How has that made your partner feel?
79. Since developing hypersexuality, has your partner become more irritable?
Probe 1: (if yes) Why?
Probe 2: How has that made you feel?
80. Since developing hypersexuality, has there been a change in the amount of time you and your partner have spent together?
Probe 1: (if yes) What kind of change?
Probe 2: How has that made you feel?
81. Since developing hypersexuality, has your affection for your partner changed?
Probe 1: (if yes) What kind of change?
Probe 2: How has that made your partner feel?
82. Since developing hypersexuality, has your partner's affection for you changed?
Probe 1: (if yes) What kind of change?
Probe 2: How has that made you feel?
83. How has your partner felt about your hypersexuality?
Probe 1: Have they discussed it with you?
Probe 2: Has the way your partner felt affect you?
Probe 3: (if yes) How so?
84. Have you ever felt your partner was to blame for your hypersexuality?
Probe: (if yes) How are they to blame?
85. Have you ever felt your partner would leave you because of your hypersexuality?
Probe: (if yes) Why?
86. Has sex become an all-consuming part of your relationship with your partner?
Probe: (if yes) How so?

Past experiences

87. Do you believe any of your past experiences have affected the way in which your hypersexuality has developed?
Probe 1: (if yes) Can you specify which experience?
Probe 2: How do you believe this experience has affected the manifestation of your hypersexuality?

Stigma

88. Do you believe it is difficult to discuss your hypersexuality with your partner?
Probe: (if yes) Why?
89. Do you believe it is difficult to discuss your hypersexuality with your family?
Probe: (if yes) Why?
90. Do you believe it is difficult to discuss your hypersexuality with your friends?
Probe: (if yes) Why?
91. Do you believe it is difficult to discuss your hypersexuality with health professionals?
Probe: (if yes) Why?
92. Has your hypersexuality made you feel ashamed or embarrassed?
Probe: (if yes) Why?
93. Have you tried to hide your hypersexuality from your partner?
Probe 1: (if yes) How so?
Probe 2: Why have you tried to hide it from your partner?

94. Have you tried to hide your hypersexuality from your family?
 Probe 1: (if yes) How so?
 Probe 2: Why have you tried to hide it from your family?
95. Have you tried to hide your hypersexuality from you friends?
 Probe 1: (if yes) How so?
 Probe 2: Why have you tried to hide it from your friends?
96. Have you tried to hide your hypersexuality from health professionals?
 Probe 1: (if yes) How so?
 Probe 2: Why have you tried to hide it from health professionals?
97. Have you worried that others would find out about your hypersexuality?
 Probe: What do you think would happen if others found out about it?

Professional help-seeking

98. Have you ever sought help for your hypersexuality from health professionals?
 Probe 1: (if yes) What has been their reaction to your concerns?
 Probe 2: How has that made you feel?
99. How do you believe health professionals should treat the issue of hypersexuality?

Aspirations

100. Has anything positive come out of your experience with hypersexuality?
 Probe: (if yes) What is it?
101. Do you have any hopes moving forward with regards to your hypersexuality?
 Probe: (if yes) What are they?

Conclusion *(to read aloud to the patient):*

We have reached the end of our interview. I would like to thank you for being so patient. However, do you believe there is anything we have missed out that you would like to add?
 Do you have any other comments about what we have discussed, or about the research as a whole?
 We will send you a summary of the research findings when it becomes available. Thank you so much for your participation.

b. Carer Assessment Interview

Interview length: 60-90 minutes

Introduction (to read aloud to the patient):

Thank you for agreeing to take part in this interview.

This interview will be audio recorded, unless you have specified otherwise.

All data collected is confidential. No records of this interview will be kept with your name or any other identifiable data on it.

The following sections include questions about the change in your partner's sexuality since getting [insert name of neurological disorder] and the increase in sexual thoughts, desires, and/or behaviour. This is called hypersexuality. Please remember that sexual acts involving physical harm to others or child abuse is against the law. For this reason, please do not answer any questions that show that your partner's sexual behaviour has been a threat to others or that your partner has had sexual relationships with minors.

I completely understand how sensitive this topic is and how challenging it may be to discuss. If any questions make you uncomfortable, you are entirely free not to answer them. Also, if any questions are not understandable, please ask and they will be explained.

This research into hypersexuality will, hopefully, help mitigate the stigma around sex. This interview is, therefore, not intended to serve any judgement towards you or your partner regarding their sexuality, how they have expressed it, and the manner in which you have responded to it. This is a free space where you can express yourself however you choose. It is an opportunity for us to get to know you in an extremely objective manner. This interview is not intended to cause you any discomfort or upset.

Are you happy to proceed?

Background Information

1. How old are you?
2. How old is your partner?
3. What is your relationship to the patient?
 Probe 1: How long have you been in this relationship?
 Probe 2: (if no longer together) When did the relationship end?
 Probe 3: Was the hypersexuality the reason the relationship ended?
4. How old was your partner when they got the [insert name of neurological disorder]?
5. What is your partner's sexual orientation?
6. Has your partner even been sexually abused?
 Probe 1: (if yes) By whom?
 Probe 2: At what age?
 Probe 3: How long did it go on?
7. Did your partner have any previous behavioural or cognitive disorders before getting [insert name of neurological disorder]?
 Probe: (if yes) What were they?
8. Did your partners have any previous addictions such as illegal drugs or alcohol?
 Probe: (if yes) What were they?
9. Apart from hypersexuality, did your partner have had any other impulse control disorders since developing [insert name of neurological disorder] such as compulsive gambling?
 Probe 1: (if yes) When did it start?
 Probe 2: How severe do you think has been?
10. Compulsive eating?
 Probe 1: (if yes) When did it start?
 Probe 2: How severe do you think has been?
11. Compulsive buying?
 Probe 1: (if yes) When did it start?
 Probe 2: How severe do you think has been?
12. Since developing [insert name of neurological disorder], have you noticed any other changes in your partner's behaviour apart from these?

- Probe 1: (if yes) What are they?
 Probe 2: When did they start?
 Probe 3: How severe do you think they have been?

Indicators

13. Is your partner hypersexual?
 Probe 1: How old was your partner when they first became hypersexual?
 Probe 2: Is your partner still hypersexual to this day?
14. What were the initial indicators that your partner was hypersexual? How did you first notice it?
 Probe: What was your initial reaction to it?

Desires

15. Since developing hypersexuality, has there been a change in your partner's sexual desire?
 Probe 1: Has your partner desired things more than they did before developing the hypersexuality?
 Probe 2: Has your partner desired new things that they did not sexually desire before?
 Probe 3: Would you say your partner's sexual desire was insatiable?
 Probe 4: (if yes) How so?
16. Since developing hypersexuality, has your partner developed a heightened desire for sex with you?
 Probe 1: (if yes) How can you tell?
 Probe 2: (if no) Has your partner's desire for sex with you decreased?
 Probe 3: How can you tell?
 Probe 4: How has this made you feel?
17. Has your partner developed a heightened desire for sex for other people/things apart from you?
 Probe 1: (if yes) How can you tell?
 Probe 2: (if no) Has your partner's desire for sex for other people/things apart from you decreased?
 Probe 3: How can you tell?
18. Has your partner become sexually aroused by inanimate objects?
 Probe: (if yes) Which objects?

Behaviours

19. Has there been a change in your partner's sexual behaviour?
 Probe 1: (if yes) What was this change?
20. Has your partner developed new sexual behaviours that were not there before they developed hypersexuality?
 Probe: (if yes) What were they?
21. Would you say your partner's sexual behaviour was unusual?
 Probe: (if yes) How so?
22. Would you say your partner's sexual behaviour was risky?
 Probe: (if yes) How so?
23. Is the change in your partner's sexual behaviour still present to this day?
 Probe: How has this change in the behaviour made you feel?
24. Has your partner insisted on sexual behaviour with you that you found uncomfortable or unwanted?
 Probe: (if yes) What was this behaviour?

Preoccupation

25. How often do you think your partner has been thinking about sex since developing hypersexuality?
26. Do you believe your partner has found it hard to concentrate on other areas of life because of thinking about sex?
 Probe: (if yes) Why do you believe so?
27. Do you believe your partner has spent a lot of time on sexual thoughts that they should be using on other things?
 Probe: (if yes) How has this made you feel?

Compulsivity

28. Do you believe your partner's behaviour was/is compulsive?
 Probe: (if yes) How so?

29. Do you believe your partner has spent a lot of time on sexual behaviour that they should be using on other things?

Probe 1: (if yes) How much time do you think your partner spends on these behaviours?

Probe 2: How has this made you feel?

Impulsivity

30. Do you believe your partner's behaviour was/is impulsive?

Probe: (if yes) How so?

Addiction

31. Do you believe your partner was/is addicted to sex?

Probe: (if yes) How so?

Triggers

32. Do you believe there were/are things that trigger your partner's hypersexuality?

Probe: (if yes) What things?

33. Do you believe certain feelings have triggered your partner's hypersexuality?

Probe 1: Has your partner felt more hypersexual when they have had certain feelings such as sadness, happiness, or anger?

Probe 2: (if yes) Which feelings?

Practices with the partner

34. Since your partner developed hypersexuality, has there been a change in the frequency of sexual intercourse with them?

Probe 1: (if yes) What is this change?

Probe 2: How has this change made you feel?

35. How often were you having sex before your partner developed hypersexuality?

36. How often were you having sex after your partner developed hypersexuality?

37. How often are you having sex now?

38. Since your partner developed hypersexuality, has there been a change in the nature of sexual intercourse with them?

Probe 1: (if yes) What is this change?

Probe 2: How has this change made you feel?

39. Since developing hypersexuality, has your partner asked for new things during sex that they not care for before?

Probe 1: (if yes) What things?

Probe 2: How have you responded to these demands?

40. Since developing hypersexuality, has your partner been more sexually aggressive with you?

Probe: (if yes) How so?

41. Since developing hypersexuality, has your partner asked you to be sexually aggressive with them?

Probe: (if yes) How so?

Practices with themselves

42. Since developing hypersexuality, has your partner chosen to please themselves sexually?

Probe 1: (if yes) How often?

Probe 2: Do you believe there has been a change in your partner's frequency of pleasing themselves since developing hypersexuality?

Probe 3: Do you believe it has left your partner feeling satisfied?

Probe 4: How has this made you feel?

43. Since developing hypersexuality, has your partner used pornographic material?

Probe 1: (if yes) How often?

Probe 2: Do you think there has been a change in your partner's frequency of using porn since developing hypersexuality?

Probe 3: Do you believe it has left your partner feeling satisfied?

Probe 4: How has this made you feel?

Practices with others

44. Promiscuity can be defined as having indiscriminate sex with many different people. Do you believe your partner has become promiscuous since developing hypersexuality?

Probe 1: (if yes) Why do you believe so?

Probe 2: How has this made you feel?

45. Since developing hypersexuality, has your partner paid for sex?
 Probe 1: Has your partner had sex with prostitutes?
 Probe 2: Has your partner visited massage parlours?
 Probe 3: Has your partner visited strip clubs?
 Probe 4: Has your partner used dating sites looking for sex?
 Probe 5: Has your partner called sex phone lines?
46. Since developing hypersexuality, has your partner had anonymous sexual encounters?
 Probe 1: Has your partner had one night stands?
 Probe 2: Has your partner visited saunas?
 Probe 3: Has your partner visited bath houses?
47. Since developing hypersexuality, has your partner had any affairs?
 Probe 1: (if yes) Was/is it sexual in nature?
 Probe 2: What do you think your partner was/is getting from the affair that they were not getting in your relationship?
 Probe 3: How has this made you feel?
48. Since developing hypersexuality, has your partner had sex with anyone of a different gender than the one they are typically interested in?
 Probe: (if yes) How has this made you feel?

Deviant practices

49. Since developing hypersexuality, has your partner gotten sexual satisfaction from spying on sexual acts (not pornography; sexual acts in real life, in real time)?
 Probe: (if yes) How has this made you feel?
50. Since developing hypersexuality, has your partner showed their genitals to strangers?
 Probe: (if yes) How has this made you feel?
51. Since developing hypersexuality, has your partner had sex with animals?
 Probe: (if yes) How has this made you feel?

Impact

52. Do you believe the hypersexuality has had an impact on your partner's life in general?
 Probe: (if yes) How so?
53. Do you believe the hypersexuality has affected your partner's marital life?
 Probe: (if yes) How so?
54. Do you believe the hypersexuality has affected your partner's family life?
 Probe: (if yes) How so?
55. Do you believe the hypersexuality has affected your partner's social life?
 Probe: (if yes) How so?
56. Do you believe the hypersexuality has affected your partner's work and daily activities?
 Probe: (if yes) How so?
57. Do you believe the hypersexuality has affected your partner's finances?
 Probe: (if yes) How so?
58. Do you believe the hypersexuality has affected your partner's health?
 Probe: (if yes) How so?
59. Do you believe the hypersexuality has affected your partner's mood?
 Probe: (if yes) How so?
60. Do you believe the hypersexuality has affected your partner's sleep?
 Probe: (if yes) How so?
61. Do you believe the hypersexuality has affected your partner's self-confidence?
 Probe: (if yes) How so?
62. Do you believe the hypersexuality has affected your partner's overall quality of life?
 Probe: (if yes) How so?

Control

63. Do you believe your partner is aware that their hypersexuality was/is a problem?
 Probe: (if yes) Why do you believe so?
64. Do you believe your partner has had no control over their hypersexuality?
 Probe: (if yes) Why do you believe so?
65. Do you believe your partner has tried to reduce their hypersexuality or stop it altogether?
 Probe 1: (if yes) How so?

- Probe 2: Has your partner been successful?
 Probe 3: How has this made you feel?
66. Do you believe your partner has wanted to overcome their hypersexuality?
 Probe 1: How do you know?
 Probe 2: How has this made you feel?

Emotional formulation

67. Try to consider the hypersexuality and your partner as two different entities. How have you felt about the hypersexuality itself?
 Probe 1: Does your partner know this?
 Probe 2: Have you tried to make them aware of your feelings?
 Probe 3: What has been your partner's reaction?
68. How do you feel about your partner after they developed hypersexuality?
 Probe 1: Does your partner know this?
 Probe 2: Have you tried to make them aware of your feelings?
 Probe 3: What has been your partner's reaction?

Attributions

69. What do you believe was the cause of your partner's hypersexuality?
 70. Do you believe the [insert name of neurological disorder] has caused your partner's hypersexuality?
 Probe 1: (if yes) Why do you believe so?
 Probe 2: (if patient has PD) Do you believe the PD medication caused your partner's hypersexuality?
 Probe 3: (if yes) Which medication?
71. Have you ever blamed your partner for their hypersexuality?
 Probe: (if yes) Why?
72. Have you ever blamed yourself for your partner's hypersexuality?
 Probe: (if yes) Why?

Relationship with the partner

73. Since your partner developed hypersexuality, has your relationship changed?
 Probe 1: (if yes) How was it before?
 Probe 2: How is it now?
 Probe 3: How has this change made you feel?
74. Since your partner developed hypersexuality, have the physical aspects of your relationship changed?
 Probe 1: (if yes) How so?
 Probe 2: How has this change made you feel?
75. Since your partner developed hypersexuality, has sex become an all-consuming part of your relationship?
 Probe 1: (if yes) How so?
 Probe 2: How has this made you feel?
76. Since your partner developed hypersexuality, have you felt there was less intimacy between you when you have sex?
 Probe 1: (if yes) Why?
 Probe 2: How has this made you feel?
77. Since developing hypersexuality, has your partner been less affectionate with you in non-sexual ways?
 Probe 1: (if yes) How so?
 Probe 2: How has this made you feel?
78. Since your partner developed hypersexuality, have you been less affectionate with them?
 Probe: (if yes) How so?
79. Since your partner developed hypersexuality, has there been more arguments with them?
 Probe 1: (if yes) Why?
 Probe 2: How has this made you feel?
80. Since your partner developed hypersexuality, have either of you become more irritable?
 Probe 1: (if yes) How so?
 Probe 2: How has this made you feel?

81. Since your partner developed hypersexuality, has there been a change in the amount of time you spend together?
Probe 1: (if yes) What kind of change?
Probe 2: How has this made you feel?
82. Since your partner developed hypersexuality, have you feared they would leave you?
Probe: (if yes) Why?
83. Do you believe your partner has feared that you would leave them because of their hypersexuality?
Probe: (if yes) Why do you believe so?
84. Since your partner developed hypersexuality, have you found them repulsive?
Probe 1: (if yes) Why?
Probe 2: Have you told your partner?
Probe 3: What was their reaction?
85. Since your partner developed hypersexuality, have you lost respect for them?
Probe 1: (if yes) Why?
Probe 2: Have you told your partner?
Probe 3: What was their reaction?
86. Do you still feel the same way about your partner that you did before they developed hypersexuality?
Probe 1: (if no) How has it changed?
Probe 2: Have you told your partner?
Probe 3: What was their reaction?
87. Do you believe your partner has felt the same way about you that they did before they developed hypersexuality?
Probe 1: (if no) How has it changed?
Probe 2: How has this made you feel?
88. Has your partner ever apologised for their hypersexuality?
Probe 1: (if yes) Do you think it was sincere?
Probe 2: Have you accepted your partner's apology?
89. Since your partner developed hypersexuality, has your image of them changed?
Probe: (if yes) How so?
90. Since your partner developed hypersexuality, do you believe your partner's image of you has changed?
Probe 1: (if yes) How so?
Probe 2: How has this made you feel?
91. Have you ever confronted your partner about their hypersexuality?
Probe 1: (if yes) What did you say?
Probe 2: How did your partner react?
Probe 3: Have you regretted confronting your partner about it?

Past experiences

92. Do you believe any past experiences of your partner's have affected the manifestation of their hypersexuality?
Probe 1: (if yes) Can you specify which experience?
Probe 2: How do you believe this experience has affected the manifestation of your partner's hypersexuality?

Aggression

93. Since your partner developed hypersexuality, have you ever contemplated physically harming them?
Probe 1: (if yes) When?
Probe: What kind of thoughts have you had?
94. Since your partner developed hypersexuality, have you ever actually physically harmed your partner?
Probe 1: (if yes) How so?
Probe 2: Why did you do it?
Probe 3: How did they react?
Probe 4: How did it make you feel?
Probe 5: Have you regretted doing it?

Dealing with hypersexuality

95. Have you tried to limit your partner's hypersexuality?
 Probe 1: (if yes) How so?
 Probe 2: Have you been successful?
96. Have you ever lied about or covered up your partner's hypersexuality?
 Probe 1: (if yes) How so?
 Probe 2: Have you been successful?
97. Have you ever tried to uncover facts about your partner's hypersexuality?
 Probe 1: (if yes) How so?
 Probe 2: What have you found?
98. Have you ever given in to your partner's hypersexuality to avoid any upset with them?
 Probe: Have you ever felt welcoming of the hypersexuality?
99. Have you ever tried to ignore or avoid your partner's hypersexuality?
 Probe: (if yes) How so?
100. How have you tried to cope with your partner's hypersexuality?
 Probe 1: Have you encountered difficulty in coping with the hypersexuality?
 Probe 2: What has been the difficulty?

Coping with the hypersexuality

101. Have you felt a sense of responsibility or feelings of guilt over your partner's hypersexuality?
 Probe: (if yes) Why?
102. Have you ever tried to understand the hypersexuality?
 Probe: Have you ever tried to take a step back and rationalise it?
103. Have you ever tried to forgive your partner for their hypersexuality?
 Probe 1: (if no) Why not?
 Probe 2: Do you think you will ever be able to forgive them for the hypersexuality?
104. Have you ever tried to convince yourself that your partner's hypersexuality should not bother you?
 Probe 1: (if yes) How?
 Probe 2: Were you successful?
 Probe 3: (if no) How did this make you feel?

Self-image

105. Has your partner's hypersexuality affected your self-confidence?
 Probe: How so?
106. Since your partner developed hypersexuality, have you felt objectified?
 Probe: (if yes) How so?
107. Since your partner developed hypersexuality, have you felt unloved?
 Probe: (if yes) How so?
108. Since your partner developed hypersexuality, have you felt used?
 Probe: (if yes) How so?

Stigma

109. Do you believe it is difficult to discuss your partner's hypersexuality with them?
 Probe: (if yes) Why?
110. Do you believe it is difficult to discuss your partner's hypersexuality with your family?
 Probe: (if yes) Why?
111. Do you believe it is difficult to discuss your partner's hypersexuality with your friends?
 Probe: (if yes) Why?
112. Do you believe it is difficult to discuss your partner's hypersexuality with health professionals?
 Probe: (if yes) Why?
113. Do you believe it is difficult for your partner to discuss their hypersexuality?
 Probe: (if yes) Why?
114. Has your partner's hypersexuality made you feel ashamed or embarrassed?
 Probe: (if yes) Why?
115. Have you tried to hide your partner's hypersexuality from your family?
 Probe 1: (if yes) How so?
 Probe 2: Why have you tried to hide it from your family?

116. Have you tried to hide your partner's hypersexuality from your friends?
 Probe 1: (if yes) How so?
 Probe 2: Why have you tried to hide it from your friends?
117. Have you tried to hide your partner's hypersexuality from health professionals?
 Probe 1: (if yes) How so?
 Probe 2: Why have you tried to hide it from health professionals?
118. Do you believe your partner has tried to hide their hypersexuality?
 Probe 1: (if yes) How so?
 Probe 2: Why do you believe your partner has tried to hide it?
119. Have you ever worried that others would find out about your partner's hypersexuality?
 Probe: What do you think will happen if others find out about it?

Professional help-seeking

120. Have you ever sought help for your partner's hypersexuality from health professionals?
 Probe 1: (if yes) What has been their reaction to your concerns?
 Probe 2: How has that made you feel?
121. Has your partner ever sought help for their hypersexuality from health professionals?
 Probe 1: (if yes) What has been their reaction to your partner's concerns?
 Probe 2: How has that make you partner feel?
122. How do you believe health professionals should treat the issue of hypersexuality?

Aspirations

123. Has anything positive come out of your experience with hypersexuality?
 Probe: (if yes) What is it?
124. Do you have any hopes moving forward with regards to your partner's hypersexuality?
 Probe: (if yes) What are they?

Conclusion *(to read aloud to the patient):*

We have reached the end of our interview. I would like to thank you for being so patient. However, do you believe there is anything we have missed out that you would like to add?

Do you have any other comments about what we have discussed, or about the research as a whole?

We will send you a summary of the research findings when it becomes available. Thank you so much for your participation.

3.7 Conclusions

To date, there is no research systematically assessing hypersexuality in neurological disorders. This study, therefore, aimed to assess prevalence, clinical phenomenology, and impact of hypersexuality in neurological disorders. It is important to note that the assessment tools used in the study included a semi-structured interview (qualitative), as well a range of quantitative questionnaires. A primary limitation of this study, therefore, is that these quantitative questionnaires are not hypersexuality-specific and thus may not provide comprehensive information about the hypersexuality. This is suggestive of a need for clinical researchers to develop valid and reliable hypersexuality in neurological disorder-specific questionnaires to better assess these patients. Also, the interview that was used was informed by the MSc thesis on hypersexuality in neurological disorders as well as the literature on sex addiction. A new, modified hypersexuality and neurological disorder-specific interview has been developed, based on the detailed findings of the qualitative analysis, that could potentially be used across all neurological disorders. Although several neurological disorder groups were approached for inclusion in the study, the researchers were successful in assessing patients with PD and their carers, as well as carers for patients with FTD. Results from the study showed that although a prevalence figure was determined for hypersexuality in PD (12.22%), it cannot be regarded as true prevalence. The reason for this may be the methodological challenges associated with the discussion about sex and sexuality that may have made the patients hesitant about disclosing sensitive information, thus influencing the outcome of the assessment of prevalence, as well as the recruitment of patients/carers into the study. The issues with the assessment of prevalence realised in this study mirrors those in literature, which consists of a lack or inconsistencies in reported prevalence figures. Further assessment of the PD patients showed that the profile of PD patients with hypersexuality includes compulsivity as a behavioural correlate, as well as impulsivity, addiction, risk-taking, and sensitivity to reward and punishment as dissociable factors, although further research still needs to be done into the relationship between these factors for definitive conclusions to be drawn. A key finding that emerged from the result analyses includes the issue of insight. Most of the PD patients did not have insight into their hypersexuality: (1) they did not regard their hypersexuality as a problem; and (2) did not express a true desire to overcome it. Despite this, the patients were evidently still able to indicate negative effects that the hypersexuality has had on other areas of living, such as their marital life. This finding suggests that although patients express a lack of insight into the hypersexuality, they may still retain insight into the ways in which those around them might be affected (reflective of empathy scale). Although these findings emerged from the PD group alone, they can still be examined in other neurological disorders in future research. Perhaps researchers could then be able to assess patterns between the expression of hypersexuality in different neurological disorders in order to draw definitive conclusions. Furthermore, the assessment of hypersexuality in PD and FTD implicated the neurological disorders themselves, as well as the pharmacological options used to manage the disorders in contributing to the development of hypersexuality. Implicated factors, however, are not necessarily causative of the hypersexuality as further research still needs to be done into the causes and neurobiology of hypersexuality in neurological disorders. Additionally, the manifestations of hypersexuality in PD and FTD can be categorised under the following larger headings: increased sexual urges/thoughts/fantasies/frequency of sexual acts, self-stimulating sexual behaviour/interests, compulsive sexual behaviour, verbally and physically inappropriate sexual behaviour (sexual disinhibition), new sexual interests/behaviours (paraphilias), and illegal sexual behaviour. Findings showed a modest distinction between hypersexuality in PD and FTD in that hypersexuality in PD is associated with sexual compulsivity while hypersexuality in dementia is associated with sexual disinhibition, although there is some cross-over between these manifestations. A clearer distinction might be drawn if there was a larger sample size of carers of FTD patients providing information. The study also found that hypersexuality may lead to substantial, detrimental difficulties in the daily lives of the patients with neurological disorders and their carers leading to significant distress. Findings show that the patients and carers are experiencing challenges in the alleviation of their distress due to the stigma associated with the discussion regarding sex, as well as the professional help-seeking barriers that impede conversations between these affected individuals and their

health professionals. Patients and carers suggest that their health professionals do not have full knowledge and understanding of the hypersexuality, which in turn leaves the patients and carers without anchor, further exacerbating their feelings of being disregarded. Health professionals, therefore, along with researchers, can aid in mitigating the stigma associated with sex. Consultants, psychologists, nurses, and GPs, must be educated about hypersexuality and the negative impact it has in order to then educate the patients and their carers/families, as is necessary. Perhaps in doing so, hypersexuality can be explained and normalised. This could help alleviate the patient and carer burden of living with hypersexuality and consequently facilitate better help-seeking behaviour.

3.8 References

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Chapter 4

Development of management pathways and a psychoeducation tool for patients and carers

4.1 Relevance to overall thesis

Professional help-seeking barriers, that were explored in the previous chapter, possibly stem from the stigma associated with sex and the difficulties associated with the discussion of such a sensitive topic for the patients and carers, as well as for the health professionals. One might argue that health professionals do not want to upset their patients or cause them discomfort, do not know how to broach the subject, and/or do not know what resources to provide if hypersexuality is presented as an issue. The findings showed that neither the patients nor carers are getting the adequate and necessary information and help for the newly-developed hypersexuality. It thus became apparent to the research team the importance of an easily accessible, psychoeducative tool to provide basic, necessary information about hypersexuality in neurological disorders to *both* patients and carers (that health professionals might benefit from also) informed by the previous chapter and the systematic review chapter, as well as the investigation/development of feasible psychological/behavioural management pathways that health professionals can consider when faced with this issue, informed by the systematic review chapter and the psychological literature.

Although this chapter does not involve piloting the psychological/behavioural management options on actual patients and carers and is therefore tentative in nature, it does show that the research team has thought about the clinical implications of this research.

4.2 Introduction

Management options for patients

Although there is currently no guide available for clinicians and researchers to consult to help manage hypersexuality and its effects on patients, there is merit in consulting the results of the systematic review carried out in Chapter 2 regarding the psychological/behavioural management options that have had ameliorating effects on the patients' hypersexuality *symptoms*. Table 30 summarizes and describes those options¹:

Table 30 – Management options for symptoms of hypersexuality

Management option	Description
Custodianship	Patient transferred to nursing home where the setting is more secure and adapted to demented patients similar to him ⁽¹⁾
Electrical aversion therapy	Therapy intended to suppress the hypersexual behaviour by associating the behaviour with a noxious stimulus in the form of electric shock ⁽²⁾
Using cues (spaced-retrieval method)	Patient presented with a written statement reading: “Ward Rule – No Touching Any Females on the Ward” and was provided an explanation. This written cue was then withdrawn and a series of spaced retrieval trials at gradually increasing intervals were presented.

¹ It is important to note that these options have been reported in case reports/series only. There have been no interventional studies in larger populations.

The patient was asked about the ward rule during each trial to ensure that he had learned and was able to retrieve the rule until it was fully adhered to⁽³⁾

Access to sex worker	Facilitating visits to sex workers with monitoring of frequency and safety of visits to wean patients off the hypersexual behaviour ⁽⁴⁾
Reprimands	Patients getting told off for their hypersexual behaviour (as a form of negative reinforcement) ⁽⁵⁾
Being given stuffed animal to fondle	Patient who tended to fondle and touch others inappropriately was given a stuffed animal to fondle for distraction ⁽⁶⁾
Extinction	Procedure in which (unintentional) reinforcement that is provided for hypersexual behaviour is discontinued using negative reinforcement in order to decrease the hypersexual behaviour ⁽⁷⁾
Functional communication	Procedure in which patients are able to express themselves without resorting to challenging hypersexual behaviour ⁽⁷⁾
Hourly feedback	Patients regularly informed by staff whether their interactions were appropriate or inappropriate using verbal and written feedback ⁽⁸⁾
Behavioural contracting	Patient earning a pre-established activity for demonstrating a low frequency of inappropriate touching throughout the week ⁽⁸⁾
Isolation from children	Because patients were involved in hypersexual behaviour towards children, removal of the patients from usual surroundings and placing them in child-free environment to try and extinguish behaviour ⁽⁹⁾
Being given opportunity to express sexual desires in private	Patient allowed to cross-dress in private (preferable to allowing him to steal female under garments from the other residents and neighbours' washing line) ⁽¹⁰⁾
Supervised environment	Patients supervised and monitored by professionals so that they are unable to engage in hypersexual behaviour ⁽⁹⁾

Furthermore, the systematic review showed only two studies reporting psychological interventions used to alleviate the *effects* of the hypersexuality on the lives of the patients, such as depression and anxiety. These studies are represented in Table 31 below:

Table 31 – Management options for effects of hypersexuality

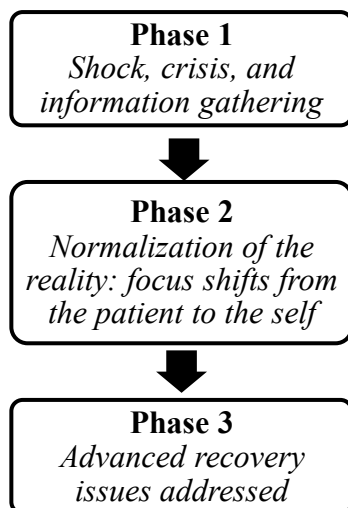
Management option	Description
Sex therapy	Therapy to help patient and partner cope with desire differences and sexual pain; redefining intimacy within the couple ⁽¹¹⁾
Psychoeducative intervention	Intervention for patients that provides information and support to better understand and cope with the hypersexuality ⁽¹²⁾

Management options for carers

There has also been no research into the effects of management options on the carers who are affected by their partners' hypersexuality, although they often provide more information about the hypersexuality than do patients⁽¹³⁾, as evident in the previous chapters. Carers should thus not be disregarded. Since this literature is lacking, the literature on sexual addiction was consulted. Tripodi (2006) presents an article regarding the long-term treatment of partners of sex addicts where she provides four reasons as to why carers may seek professional help that can be extrapolated to hypersexuality in neurological disorders: (1) Carers want to support the patient in their desire to stop the destructive sexual behaviours; (2) Carers are looking for validation and acknowledgement of the pain they are feeling; (3) Carers require information about the hypersexuality and a guide that they can consult to help them through this challenging time; (4)

Carers want reassurance that there is hope that their partners can overcome the hypersexuality and that their relationship can be repaired⁽¹⁴⁾. Tripodi presented a 3-phase approach for treatment⁽¹⁴⁾ summarized in Figure 23.

Figure 23 – Three-phase approach for long-term treatment for partners of sex addicts as presented by Tripodi et al. (2006)⁽¹⁴⁾



Psychoeducation

Results from the previous chapter have shown that patients and carers do not have proper understanding of hypersexuality, reasons why it develops, how it manifests, and how it can be managed. Reasons for this lack of knowledge include the highly sensitive nature of the topic and the stigma surrounding sexuality that may make it difficult and embarrassing for some to discuss affecting the relationship with health professionals. The hesitation to discuss hypersexuality, as well as the lack of knowledge and proper understanding of it, has evidently caused and perpetuated patients and carers' upset, distress, confusion, and feelings of being disregarded. For this reason, the first thing that must be considered is a method that can be reached by all that would provide the necessary information and potentially benefit this population. Psychoeducation can be defined as an educational method for patients and carers alike that offers information and support for better understanding and coping with a disorder^(15, 16). Bäuml et al. (2006) (p. S4) presented 10 goals of psychoeducation and are reproduced below⁽¹⁵⁾:

1. Ensuring patients' and their relatives' attainment of "basic competence"
2. Facilitating an informed and self-responsible handling of the illness
3. Deepening the patients' role as an "expert"
4. "Co-therapists" – strengthening the role of the relatives
5. Optimal combination of professional therapeutic methods and empowerment
6. Improving insight into illness and improvement of compliance
7. Promoting relapse prevention
8. Engaging in crisis management and suicide prevention
9. Supporting healthy components
10. Economizing information and educational activities

Benefits of psychoeducation

There are several potential benefits for individuals associated with psychoeducation and they include⁽¹⁷⁾:

1. Feeling more in control if due to a greater level of understanding
2. Higher likelihood to actively participate in self-management due to education of the issue
3. Feeling more positive leading to better self-efficacy

4. Normalizing the issue, which consequently leads to reducing stigma, promoting awareness, and preventing emergencies

4.3 Aims

The present chapter has two aims and is thus divided into two main parts:

Part A aims to develop feasible recommended pathways for management of patients and carers that professionals can consult when presented with hypersexual patients and their carers.

Part B aims to create a public-facing website that will provide patients and carers with succinct, proper information about hypersexuality in neurological disorders, based on the findings of this thesis. Part B then aims to ask for feedback about the website from clinicians, therapists, patients, and carers, and consequently modifying the website based on their suggestions.

4.4 Methods

Part A

Recommended patient and carer pathways for management, in the form of flowcharts, were developed based on the information collected in the previous chapters of this thesis, information from the literature regarding management options of symptoms and effects of hypersexuality, as well as information from the literature regarding psychological interventions in general. An anonymized case study, chosen from the patients who took part in the study detailed in the previous chapter, will then be presented. The vignette aims to illustrate an example of a case presented to a therapist. It addresses the main issues and how the therapist might choose to approach the issue using the appropriate pathway.

Part B

The development of the website entailed a multiphasic process:

Phase I: Surveying and scoping

This phase entailed surveying of the available literature regarding hypersexuality in neurological disorders and scoping of available websites. Surveying of the literature was completed in Chapters 1 and 2 of this thesis. Although there exist no educational websites regarding hypersexuality in neurological settings, other educational websites regarding neurological disorders were consulted in order to get a feel for what was required. Websites that were reviewed included: www.neurosymptoms.org providing information on functional and dissociative neurological symptoms and www.parkinsons.org.uk providing information on Parkinson's disease.

Phase II: Deciding on the purpose of the website

The purpose of the website was determined based on limitations found in the literature search and study results. The patients and carers reported a lack of information about hypersexuality that affected the patient/carer relationship with health professionals and their own quality of life. The purpose of the website was thus to develop a public-facing website that would provide patients and carers with the necessary information about hypersexuality in neurological disorders, as well as provide the appropriate contact information if any further information beyond the website is required. Before the content was written, Trevor Peacock, the Information Governance Lead at the UCL School of Life and Medical Sciences, was consulted who advised that since the aim was to build a patient engagement site, to refer to <https://understandingpatientdata.org.uk/>, a website that provides some useful information on explaining research to patients and how to handle sensitive information.

Phase III: Writing up the content of website

The research student wrote up the content of the website in Frequently Asked Questions format while

adhering as closely as possible to plain English. The content was based on the purpose of the website, the literature search, and the study results.

Phase IV: Revising content

Clinical/academic oversight was provided by the three supervisors of the study (JNP, CS, and JF) who reviewed the content. Suggestions made by them were used to modify the content in preparation for website launch.

Phase V: Preliminary testing

Since neither the research student nor the supervisors were proficient in website development, Mohamad Nasser, a website developer, was provided the content and was informed of the required simple, minimalist design of the website. The design consisted of five tabs/pages: Introduction, Hypersexuality in neurological disorders, More information for partners, References to consult, and a Contact page. Before launching, the developer checked site speed, optimization of content for Search Engine Optimization, mobile responsiveness, form for contact, links, formatting consistency, security, spelling errors, typos, and grammar mistakes to ensure functionality, accessibility, and ease of use.

Phase VI: Website launch

After all the necessary checks were carried out, the website was launched and is now retrievable on search engines. The URL of the website is: www.neurohypersexuality.co.uk.

A link to this website has also been provided on UCL's Brain Repair and Rehabilitation website at: <https://www.ucl.ac.uk/ion/departments/repair/themes/uroneurology>.

Phase VII: Testing – feedback from clinicians, therapists, patients, and carers

After the website was launched, four groups of testers, consisting of clinicians, therapists, patients, and carers, were approached by the student or supervisors by phone or email to review the design, content, and effectiveness of the website. The patients and carers, who had already taken part in the assessment part of the study detailed in Chapter 3, were provided a Website Feedback Form (Appendix 51) if required, for ease of evaluation, developed by the research student to complete and return.

Phase VIII: Editing of website

After the feedback was collated, the website was edited according to the suggestions.

4.5 Results

Part A

4.5.1 Recommended pathways for intervention

There have only been case reports and case series reporting successful psychological/behavioural management options for the *symptoms* of hypersexuality. There has been very limited research, however, into management options for *effects* of hypersexuality. The effects of hypersexuality on the patients and carers as witnessed in the previous chapter include depression, anxiety, anger, and suicidal ideation, all of which have been researched extensively in the psychological literature. Because these effects have not been specifically investigated for hypersexuality, one can extrapolate from the information in the psychological literature regarding usual intervention protocols employed to treat these effects.

The terms that are included in the flowcharts (Figures 24 and 25), found on the following 2 pages, are described in Table 32.

Table 32 – Flowchart terms for psychological interventions described

Term	Description
Acceptance and commitment therapy	Uses mindfulness techniques to overcome negative thoughts and accept difficulties ⁽¹⁸⁾
Cognitive therapy	Helps patients correct false self-beliefs and negative thoughts ⁽¹⁸⁾
Cognitive behavioural therapy	Includes a behavioural component in cognitive therapy, such as activity scheduling and homework ⁽¹⁸⁾
Interpersonal therapy	Focuses on relationships and how to address issues related to them ⁽¹⁸⁾
Psychodynamic therapy	Focuses on conscious and unconscious feelings and past experiences ⁽¹⁸⁾
Third-wave cognitive behavioural therapy	Targets thought processes to help persons with awareness and acceptance ⁽¹⁸⁾
Group therapy	Patients treated in a setting with others who have similar experiences/feelings ⁽¹⁹⁾
Individual therapy	One-on-one setting (patient and therapist) ⁽¹⁹⁾
Couple therapy	Helps patient and partner improve communication, better understand relationship and reflect on how to change and problems needing to be sorted out ⁽¹⁹⁾

The patient pathway that was developed is aimed for patients with insight. These patients acknowledge that the hypersexuality is a problem that needs to be resolved (insight into hypersexuality), as described in the previous chapter. It is important to note, however, that some of the patients who do not recognize their hypersexuality as a problem might still experience the effects reported above in response to their partners' upset caused by the hypersexuality (insight into their partners' reactions to hypersexuality). These patients may also benefit from the recommended interventions for effects of hypersexuality. The pathway, therefore, requires patients to have (1) insight into hypersexuality; and/or (2) insight into partners' reactions to hypersexuality. Patients who do not express either will likely not benefit from psychological intervention.

Figure 24 – Pathway 1: Patients with insight

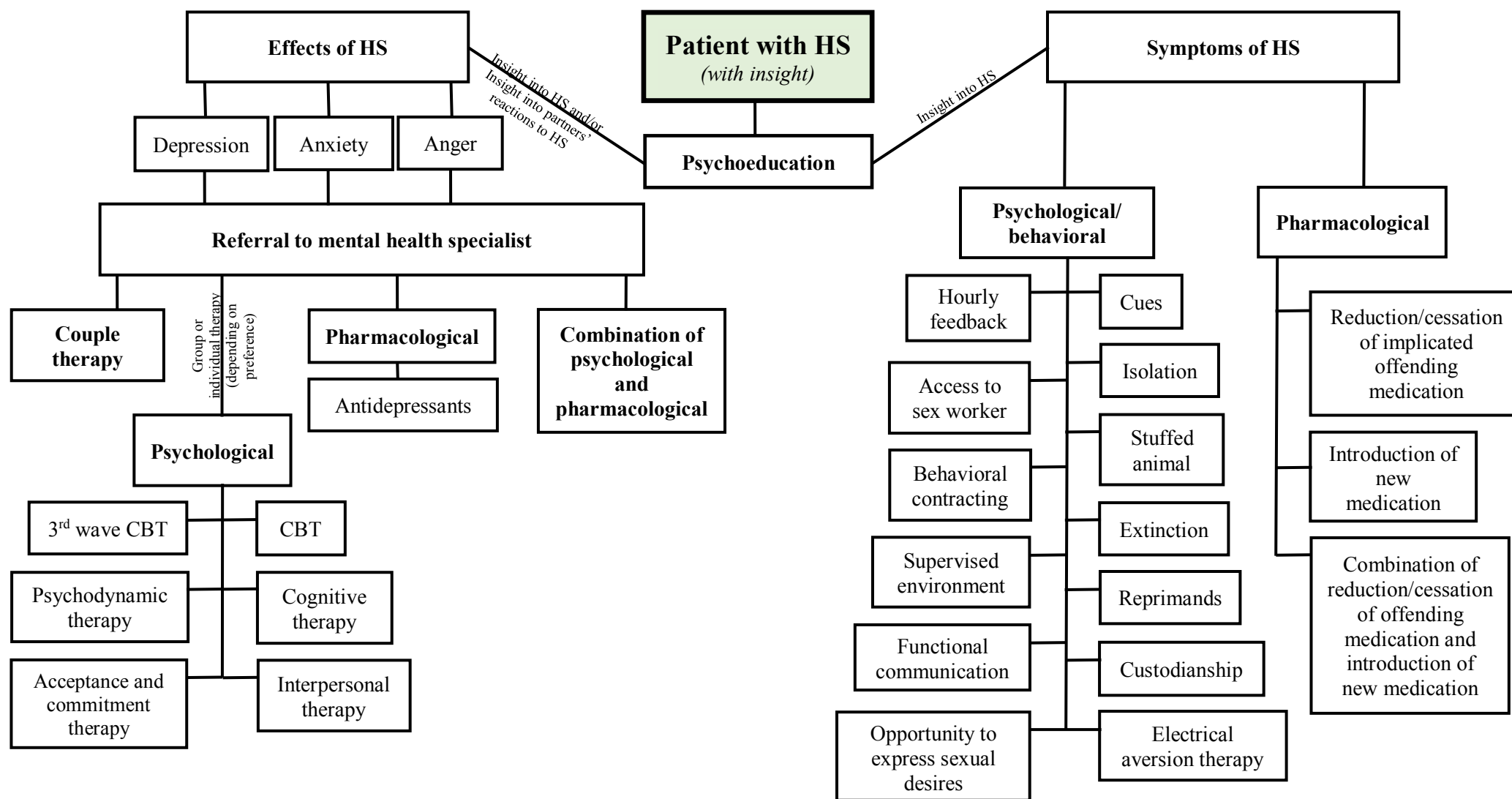
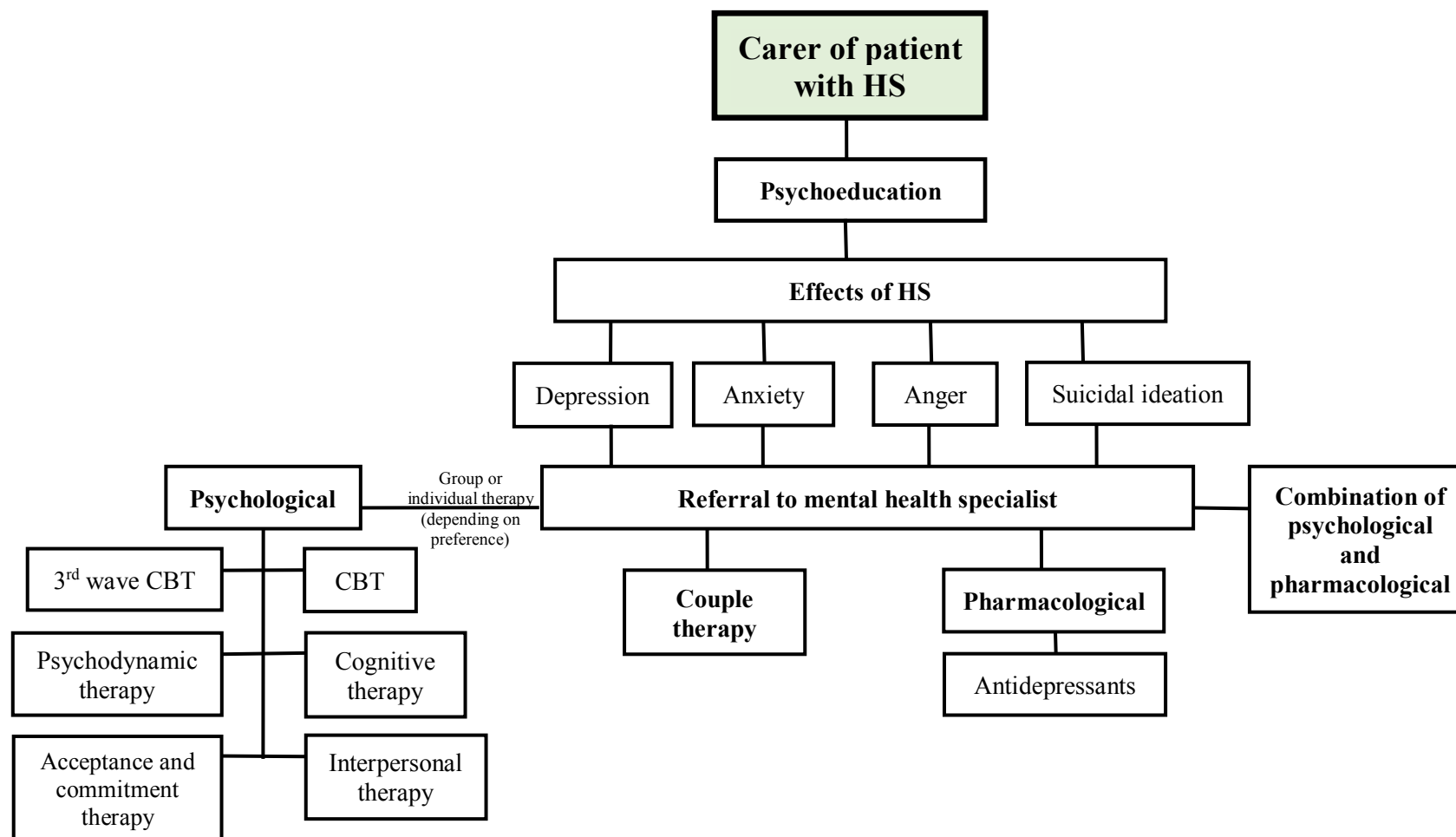


Figure 25 – Pathway 2: Carers



As presented in the pathways, the importance of psychoeducation is fundamental for both patients and carers, before any further interventions are considered.

4.5.2 Case study

Case presentation

Patient 1, a single 44-year-old male with PD, indicates hypersexuality as having been an issue for him. He has identified as a homosexual his entire life and associates it with having been sexually abused by his mother's brother at the age of 3. However, since taking ropinirole to help manage his PD, he noticed being in a "hyper" state with a newly-developed unusual interest in women and an increased desire for sex with men. He explains that he has always been highly interested in sex, especially since moving to a more liberal country than the one he was raised in, but not to the same intensity of the desire he has felt since developing hypersexuality aged 35. He explains that at the peak of his hypersexuality, he was feeling like "sex was [his] only escape" and was spending 6 hours a day in gay bath houses and saunas, sleeping with 14 to 15 strange men a day. He explains that the bath houses and saunas are filled with at least 200 men and that most of his days are spent there. This was unusual behaviour for him because, prior to becoming hypersexual, he had been in an eight-year monogamous relationship with a man. He reports that although he has discontinued the medication, he is still hypersexual though not as severe as before. Although he now prefers watching heterosexual porn and spends time and money on call girls, he still looks for sex on gay online applications such as Grindr and actively has sex with males and thus now identifies as bisexual. He describes the constant desire to look for sex as making him feel like he is "on the edge all the time". When he first noticed the changes in his sexual behaviour, he was unable to get an informative and clear explanation from the doctors as to the reasons why these changes were happening, which is why he felt "neglected", "denied", and "depressed" as he felt like he had not been believed.

The hypersexuality has negatively affected several areas of his life. He has paid less attention to his family, has been more absent and therefore has spent less time with them, and has been more irritable towards them. He no longer has as many friends as he once did as he has abandoned social activities and ignored his friends. He has noticed a decrease in efficiency and concentration at work due to thinking too much about sex. Although his finances have been mostly affected by gambling behaviour, they have also been affected by the hypersexuality as he was spending around 500 pounds on call girls. He recalls his health being affected by catching bad flues, "horrible" sore throat, and STDs. He had also lost a lot of weight drinking only milk and hot chocolate. He suffered from lack of sleep as he would return from the bath houses at 5 pm, sleep until 12 am and then go back out again. He claims the hypersexuality has also affected his self-confidence. He says he only feels self-confident and satisfied with sex in the moment it is happening, but claims that after sex, he feels very depressed and low in confidence. He believes the hypersexuality has affected his overall quality of life and has caused him to feel depressed and anxious. He does not believe his hypersexuality matches his personal values as it is "too much" for him to take. He also believes it limits his daily activities as he has been focusing only on it for 3-4 years, always wondering why he was doing it. He claims he has tried to decrease and stop his hypersexual behaviour to no avail, which has made him feel "desperate", "screaming and crying for help". He indicates feelings of sadness and depression as a result of loneliness (having no one to talk to) as triggers for his hypersexual behaviour.

He does feel that a lot of his time is spent on sexual behaviour that he would rather use on something else. Although he feels he is much better able to control his behaviour now, he would still like more information on how to control it. He wants to overcome his hypersexuality "most times" when he feels his desire is stronger than he is, but feels like it has now become a habit and a part of his personality.

I need to know... it would be good to know if I can control it more... what's the methods... is there any particular way out... I'll do anything just to have that...

He claims that he has never felt happy with this hypersexuality.

That's not happiness for me... horrible... my sex life... I'm dissatisfied... always I have the idea that I wish always that I been a boring straight man... has wife and kids... that's all I'm dreaming of... I wish I was just like any guy... beggar... street cleaner... I just want to be straight... have no... you know... I'm tired of it... it's getting... I wish I wish I wish I can find a simple man and find... what do you call it... I just give up... I found a way to give up...

Although not indicated during the interview, his clinical notes have reported a suicide attempt.

General cognitive ability testing showed that the patient does not suffer from cognitive impairment and still retains sound cognitive ability. Mood testing showed that the patient suffers from anxiety.

Possible treatment approach

The following steps outline the possible treatment approach that neurologists/therapists could employ when presented with such a case:

1. **Initial psychoeducation – delivered by neurology team**

Generally, when presented with hypersexual patients, neurologists should inform the patients of the implicated association between hypersexuality and dopaminergic medication and the possible symptoms and effects of hypersexuality, so that the patients remain aware and feel comfortable with discussing it.

2. **Pharmacological adjustment**

The neurologists could then choose to adjust the implicated medications and/or add new medication and monitor for sexual changes. If the hypersexuality subsides, the patient might not require further treatment; however, the possibility remains that despite amelioration of the symptoms of the hypersexuality, its consequences could remain potent. In the case of Patient 1 above, his medication was reduced to no effect so it could be worthwhile to refer him to neuropsychology for further psychoeducation and screening for therapy.

3. **Psychoeducation – delivered by (neuro)psychology/therapist teams**

The first step to alleviating his apparent distress might be to provide him the information he “desperately” requires by explaining that hypersexuality commonly occurs in patients with PD and by providing reassurance that, although his behaviour has not reduced with the cessation of the medication as was expected, all hope is not lost and that there are still psychological measures that can be taken to help him. This can be delivered by neurology and/or (neuro)psychology teams. This must be accompanied by assessing the behaviour carefully, writing a detailed record of the behaviour, and not shaming the patients⁽²⁰⁾.

4. **Emerging themes**

After the patient is referred to the appropriate therapist, the therapist might choose to review the patient's history of hypersexuality and identify possible themes that the patient and therapist might decide collaboratively to work on. It is necessary to have a comprehensive, thorough assessment because “it is unlikely that a client will change their behaviour without having explored and understood why it is a problem within their individual cultural and social environment”(21), indicating the importance of insight. The themes emerging from Patient 1's case include: negative emotional triggers for hypersexuality, low mood and quality of life, sexual compulsivity, and suicidal ideation.

5. **Exploring cognitions/negative automatic thoughts**

The therapist might then choose to explore what associations the patient has with the hypersexuality by first investigating the evident negative cognitions/thoughts that the patient has about sex and his sexuality. Patient 1's hypersexual behaviour seems to stem from the cognitive association of happiness and hypersexuality. The patient feels that he is only able to achieve/feel happiness after performing sexual acts. He is well aware, however, that his happiness is temporary but continues to foster these thoughts.

6. **Exploring emotions**

The therapist might also explore the emotions that the patient has regarding sex and his hypersexuality. Patient 1's account of his hypersexuality indicates negative emotions, such as sadness and low mood, that trigger his hypersexual behaviour. It appears that the patient's negative emotions trigger the negative thoughts that, in turn, trigger the hypersexual behaviour.

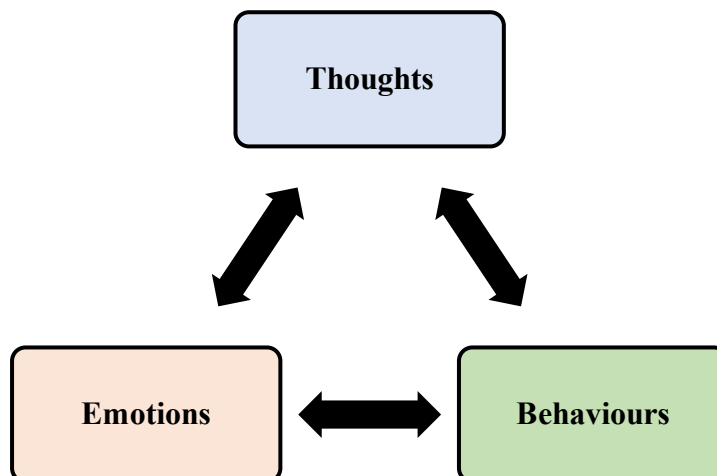
7. **Exploring situational effect**

The therapist might also explore the situations that might lead the patient to develop the emotions that lead to the thoughts and consequent hypersexual behaviour. Patient 1's account of his hypersexuality indicates loneliness triggers his negative emotions, triggering his automatic negative thoughts, and triggering the hypersexual behaviour.

8. **Explaining CBT to patient**

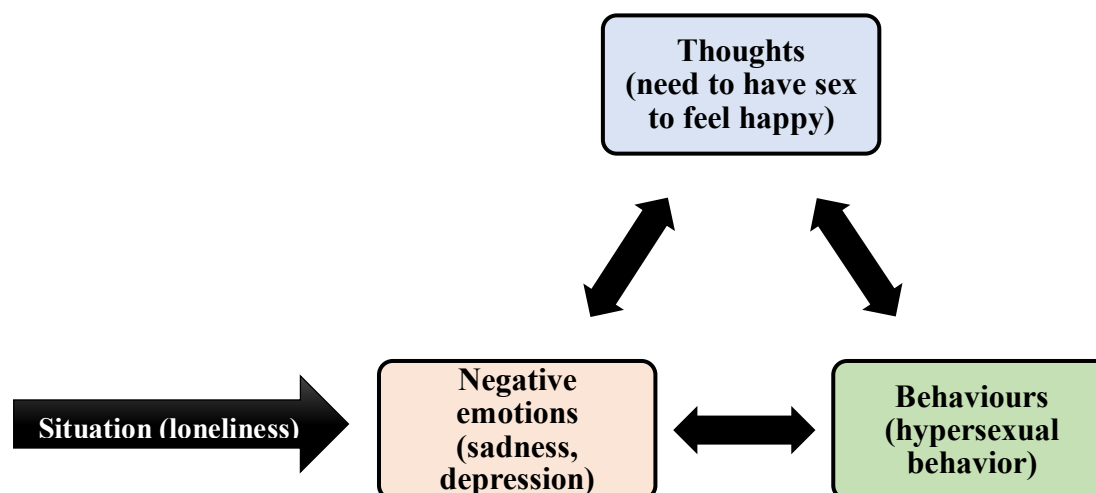
Because (1) the patient's behaviour is a product of emotions and thoughts; (2) the patient acknowledges the hypersexuality as a problem that needs to be resolved; and (3) the patient does not have cognitive impairment, CBT might be the appropriate intervention to consider. CBT is based on the interaction between how we feel, how we think, and how we act^(22, 23), making up the cognitive triangle. This cognitive triangle is represented in Figure 26.

Figure 26 – Cognitive triangle: basis of cognitive behavioural therapy



Patient 1's loneliness leads to negative emotions (low mood and sadness) making his desire for sex increase, eventually leading to the hypersexual behaviour that only temporarily elates him. His situational effect and cognitive triangle is presented in Figure 27.

Figure 27 – Cognitive triangle and situational effect for Patient 1



By using CBT, the therapist will teach the patient how to change his thoughts and the consequent behaviours even in the presence of the triggering negative emotions using the following tentative steps:

- a. The first step involves assessment of the patient where rapport is built between the patient and therapist. This step usually informs the nature of the treatment plan and the length of the treatment⁽²⁴⁾.
- b. The second step involves the understanding of the patients' thoughts and past events that make them think the way they do⁽²⁴⁾. The therapist and patient may choose to work on the emergent themes. In the case of Patient 1, the therapist and patient may choose to discuss and outline what causes the emotional triggers, reasons for his sexual preoccupation/compulsivity, low mood and quality of life, and suicidal ideation. Perhaps the patient might choose to discuss his past sexual experiences resulting from the increased impulse disorder that used to bring him joy. The hard-wiring of this connection, despite the reduction of his implicated medication, prompts him to search for the experiences that he knows for sure will bring him happiness when he is feeling down, despite knowing that this 'happiness' is fleeting. The therapist might choose to explain this to the patient and help the patient identify his distorted cognitions leading to the behaviour which bothers him. The patient could then learn the influence that cognition has on his feelings, and consequently "recognize, observe, and monitor"⁽²²⁾ his own thoughts.

Although the general consensus is that dopamine replacement therapy leads to hypersexuality, it might also be necessary for the therapist to consider the effect of Patient 1's past trauma on any behavioural change. Although it has not been discussed in the literature regarding neurological disorders, research on sex addiction in the general population hypothesizes that "sexual behaviour may become a way for trauma sufferers to numb feelings of hyperarousal and also alleviate feelings of dissociation, numbness, depression, and exhaustion experienced in hypoarousal. In short, it is thought that addictive behaviours can be become an effective technique to regulate the nervous system"⁽²¹⁾.

- c. The third step of involves finding new patterns of thinking that will be applied to the behaviour⁽²⁴⁾. These patterns are learned by the patient through completing

weekly homework, where the patient chronicles their emotions and thoughts as required by their therapist^(22, 23). This homework will challenge the patient's thoughts causing them to change. In the case of Patient 1, perhaps a discussion on other things that bring him joy, such as music, could be beneficial. The patient may then choose to listen to music or play his own music when experiencing negative emotions, steering him away from the hypersexual behaviour.

- d. The final step is the maintenance phase where the therapist and the patient ensure that the changes are permanent, so that there is no need for therapy again⁽²³⁾.

It is important to note that CBT does not consist of a rigid system with fixed rules; therefore, the above steps do not necessarily have to be carried out separately, as long as the therapy employs all the methods described⁽²⁴⁾. There are different types of CBT but the type to be used in therapy will ultimately be a matter of therapist preference.

9. **Ensuring patient willingness**

CBT therapy involves the patient to be active in the process⁽²³⁾; therefore, the patient needs to be as involved in the process as possible to ensure maximum effectiveness.

Part B

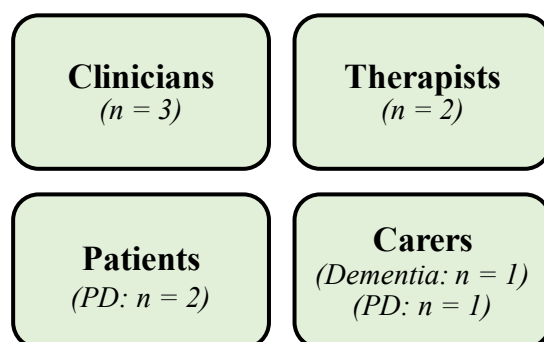
4.5.3 Website content

The website content that was developed by the research student, reviewed by the supervisors, and provided to the website developer is available in Appendix 52 and constitutes of five tabs:

1. *Introduction* – defines hypersexuality and presents the neurological disorders in which it is reported
2. *Hypersexuality in patients with neurological disorders* – consists of general information about the hypersexuality, and provides advice for patients on how to deal with it
3. *More information for partners* – consists of more information about the hypersexuality and ways to cope for carers of hypersexual patients with neurological disorders
4. *Contact us* – consists of contact details for two experts at UCL and a contact form that patients/carers can use to get in touch with two experts for more information
5. *References* – includes some references that patients/carers may choose to consult for more information about hypersexuality in specific neurological disorders

4.5.4 Feedback

Feedback for the website was obtained from the following four groups:



Their evaluation, including merits and suggestions for revision, of the website is summarized in following Table 33. Patients and carers have been grouped together in the table as they were provided the same feedback form.

Table 33 – Merits and suggestions for revision of website

Group	Merits	Suggestions for revision
<i>Clinicians</i>	Clear content “Nice” and “clean” layout/design (minimalist) FAQ style helping readability Contact us section useful	List of possible manifestations of hypersexuality presented in visual diagram rather than text* Title/introductory page with names and brief introduction* More illustration/pictures Increased size of font* Mention of hypersexuality in PD and relation to DA as it is the most commonly explored neurological disorder References* Removal of the word “professionals” found in rapid succession in an identified sentence* Unresponsive social media buttons*

<i>Therapists</i>	Clear content Ease of readability Contact us section useful Inclusion of carers	References* Increased font size*
<i>Patients/ carers</i>	Clear content Concise yet sufficient information Attractive layout/design No illustrations/photographs tending to be distracting Easy to use (clear tabs) Informative Helpful for patients with neurological disorders who have hypersexuality and their partners	Introductory page with clear statement of aim of website* Inclusion of 2-3 case studies References* Increased font size*

DA: dopamine agonists; FAQ: Frequently Asked Questions; PD: Parkinson's disease

*. These suggestions have been accepted and the website was modified accordingly.

Although most of the suggestions were accepted, three were not. The first is the suggestion for more illustration/pictures. This was not modified because the website is unable to host illustrations or pictures² as the platform does not allow it. The second is the suggestion to mention hypersexuality in PD and its relation to dopamine agonists as it is the most commonly explored neurological disorder. This was not modified as the aim of the website was to have information encompassing all neurological disorders, without the need to specify any one. The third is the suggestion to include 2-3 case studies, which was not considered for desire to keep the website as succinct as possible and to avoid any issues with confidentiality.

4.6 Discussion

4.6.1 Introduction

The aims of this chapter were to develop feasible recommended pathways of management for patients with insight and carers who are affected by hypersexuality, as well as to develop a website as an easily accessible psychoeducational tool that patients and carers can access to get proper information about hypersexuality. These aims are important as there is a lack in the literature regarding interventions used for symptoms and effects of hypersexuality, and no educational tool that can provide the information that the patients and carers do aspire to have in an easily accessible manner.

4.6.2 Management of symptoms and effects of hypersexuality

Reasons for the lack of interventional studies assessing psychological/behavioural management options for hypersexuality and its effects include the fact that patients with neurological disorders may suffer from cognitive impairment, which might make it more challenging for them to understand the changes in their sexuality and the effects these changes have on their lives and those around them. This consequently makes it difficult for them to benefit from any type of intervention. Another reason, as demonstrated in the previous chapter, is that patients with neurological disorders may suffer from lack of insight and may thus be unable to acknowledge the hypersexuality, provide sufficient information about their experience, or commit to required psychological help.

² One patient (Patient 6) appreciated the lack of pictures because he said it would distract him.

4.6.3 Website as a psychoeducational tool

The resistance and hesitation to discuss hypersexuality observed in the patients and carers highlighted the need for the website as an educational tool providing proper information that could be reached by everyone, without the need for them to go through the challenges of seeking information from individuals who do not have the appropriate knowledge and expertise. The website was thus created for patients and carers to consult as a starting point potentially encouraging conversations with health professionals and consequently expanding awareness.

4.6.4 Limitations

Because this website is the first to provide information on hypersexuality in neurological disorders as a psychoeducational tool, the following limitations should be addressed:

1. Lack of information regarding psychological intervention
The lack of information regarding psychological interventions for the effects of hypersexuality prompted a search of the literature on psychological interventions for depression, anxiety, anger, and suicidality in general. The pathways that were developed for patients and carers are, therefore, only recommendations/suggestions that health professionals can consider when presented with patients and/or carers affected by hypersexuality and its effects and are subject to improvement.
2. Patients with cognitive decline
The patient flowchart that was developed did not account for patients who are cognitively impaired. As mentioned in the previous chapter, patients with worse cognitive ability have potentially worse treatment outcomes⁽²⁵⁾.
3. Exacerbation of presented effects of hypersexuality
Health professionals must recognize that the unhappiness, or other reactions, may be exacerbated by external factors (e.g. if the family are very religious). It is thus beneficial for health professional to recognize potential factors that might play into the reactions towards hypersexuality to properly plan for interventions.
4. Case study
Although the case study and suggested intervention was presented using the information collected from the interview assessing the hypersexuality, there may be some information missing as a complete psychological evaluation was not conducted as it was not within the scope of the research. The case study is just intended as an example for health professionals considering possible intervention for hypersexuality and its effects.
5. More changes
There will always be room for improvement with both the pathways and the website regarding design and content, depending on feedback and new research. Content will be ever-changing as long as there is new research being carried out.
6. Feedback samples
The patients and carers approached to evaluate the website were the ones that took part in the study detailed in Chapter 3. This may have given rise to selection bias. Moreover, although feedback was obtained from patients with PD only, patients from other neurological disorders were not consulted. They may have provided different feedback, especially considering that hypersexuality in non-PD neurological conditions have not been researched as much. Also, the total number of individuals who gave feedback ($n = 9$) was small. The website could have benefited from a larger sample evaluating it. It was also difficult to get patients/carers to review

the website.

7. Experience with hypersexuality and feedback
Individuals who have not experienced or have not had a negative experience with hypersexuality might evaluate the website differently than those who have had been negatively affected by it. Due to the small number of patients/carers evaluating the website, this cannot be accounted for and, therefore, definitive conclusions about it cannot be drawn.
8. Online tool
Although the internet is the fastest way to reach groups of people and can be accessed from anywhere, there remain some individuals who are not tech-savvy and who will not be able to access the website.
9. Contact us
Although the website allows patients and carers to contact two experts by email or by using the “Contact us” form, responses may not be immediate as there is no option to chat with experts as available on some other informational websites.
10. Inability to provide illustration/pictures
As mentioned earlier, the platform used to develop the website did not allow illustrations and pictures, which may have provided more visual appeal to some readers, although one patient did claim that it was more easily read without illustrative material.
11. Overestimation of changed sexual behaviour
Some carers might misinterpret their partners’ sexual change to be hypersexuality when in reality it could just be the patient just trying to make up for erectile dysfunction or the development of sexual desire differences within a couple, as was reported by Bronner et al. (2011; 2012)^(11, 26).
12. Unnecessary suspicion
Some carers might come across this website while researching symptoms of neurological disorders, which may unnecessarily worry them that their partners will develop hypersexuality.
13. Advice
The researcher emailed more than 20 sexual and relationship therapists based in the UK to ask for their professional opinions on how best to tackle couples suffering from hypersexuality. There was no substantial response.

4.6.5 Implications

Although the pathways were developed based on the literature on psychological interventions in general, health professionals can still consult them when presented with patients and/or carers who acknowledge the issue and want to manage it. Also, health professionals might consult the pathways when asked by patients and/or carers about possible management options. The recommended pathways should be regarded as starting points; therefore, it is important for health professionals and clinical researchers consulting these pathways to note that effects and potential interventions for hypersexuality include but are not limited to the effects and interventions presented in the pathways. Further research into hypersexuality will allow for the improvement of these pathways. Health professionals must also recognize that in some cases the patient is content with the hypersexuality while the spouse and/or other family members might not be, as witnessed in the previous chapter. If the patient does not acknowledge the issue, it would still be worthwhile to ask carers if there is anything noteworthy and how they are potentially feeling about it. Carers might benefit from being told that the hypersexuality is not a reflection of the relationship.

Further, although the website is aimed primarily towards patients and carers, clinicians and researchers can also read it for succinct, thorough information about hypersexuality in neurological disorders that may eventually help facilitate discussion with patients/carers. This could aid in the process of alleviating the stigma around sex. If patients and carers see that others are contributing to the field and putting effort into the creation of a forum where patients/carers can learn and reach out to experts, it would yield better satisfaction with health professionals and researchers, minimize the professional help-seeking barriers, and consequently ease the discussion about sex. Moreover, it is important that health professionals as well as patients/carers themselves inform others (especially those who are not tech-savvy) about the website so that it can reach as many individuals/couples as possible.

4.6.6 Recommendations for future research

Recommendations for future research and enhancement of the recommended pathways and website include:

1. Conducting interventional studies for symptoms and effects of hypersexuality that will provide hypersexuality-specific results that will improve the pathways.
2. Conducting studies testing the recommended pathways for improvement.
3. After carrying out interventional studies and studies testing the pathways, a full guide can be developed for professionals and researchers to use.
4. Carrying out further research into hypersexuality in neurological disorders that will benefit the website as it will provide more information that can be accessed by patients and carers.
5. Obtaining larger samples of health professionals, patients, and carers for evaluation of website.
6. Obtaining feedback from more groups of people, such as nurses and patients of different neurological disorders, who encounter patients with hypersexuality and their carers, just as much as do consultants/psychologists.
7. Creating a forum on the website, similar to the design of a chat room, for patients/carers who have experienced hypersexuality to chat anonymously with each other. Research shows that individuals who share similar experiences help with coping methods, as evident in group therapy settings (e.g. Alcoholics Anonymous).
8. Creating an option allowing patients/carers to chat with experts on the website for immediate help and/or conversation.

4.7 Conclusions

When hypersexuality occurs, it contributes considerable tensions for patient and family that are already dealing with the negative consequences of the neurological disorder. There is still very limited research on psychological modalities used to manage the consequences of the hypersexuality on patients and their families. Due to the lack of research into psychological management options for hypersexuality, professionals and researchers can consult the recommended pathways for management of symptoms and effects of hypersexuality that have been developed. No such pathways exist in the available literature on hypersexuality in neurological disorders. Further research testing these pathways and providing additional information about the experience of patients and carers with hypersexuality can be edited into the pathways, until a full guide can be developed. Furthermore, results from the previous chapter showed that

patients and carers find challenges in obtaining information about the hypersexuality from their health professionals that have, consequently, caused the patients and carers upset and feelings of disregard. This signified the need for an educative tool providing information in an easily accessible manner. For this reason, a website with contact details was developed that patients and carers can access in the privacy of their own homes that will, hopefully, help facilitate the discussion about hypersexuality.

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Chapter 5

Thesis conclusions

5.1 Introduction

Although each chapter has been discussed and presented with its own conclusion, this chapter aims to remind the reader of the following:

- Aims of the thesis
- Main findings of the thesis
- Limitations of the thesis
- Implications of the findings
- Recommendations for future research
- Contributions this thesis has made to research

5.2 Aims of the thesis

This research was intended to systematically examine prevalence, clinical phenomenology, impact, and potential feasible psychological interventions for hypersexuality in patients with neurological disorders and their carers.

The thesis was divided into three main studies and chapters:

1. *Study I* (Chapter 2) comprised of a systematic review of the Embase, Medline, and PsycINFO databases assessing the following primary outcomes: (1) *prevalence* of hypersexuality in specific neurological disorders; (2) *clinical phenomenology* of hypersexuality in specific neurological disorders; and (3) *options* that have been explored to ameliorate or manage hypersexuality in these neurological disorders, as well as the following secondary outcomes: (1) *implicated factors* contributing to the development of hypersexuality; and (2) *tools* used to assess hypersexuality in specific neurological disorders.
2. *Study II* (Chapter 3) comprised of two parts. Part A aimed to assess the *prevalence* of hypersexuality in neurological disorders. Part B aimed to (1) examine the clinical *phenomenology* of hypersexuality in neurological disorders and its possible clinical, pharmacological, behavioural, psychological, and cognitive factors; and (2) assess its *impact* on both patients and carers, using qualitative and quantitative tools.
3. *Study III* (Chapter 4) comprised of two parts. Part A aimed to develop feasible *recommended pathways of management* for patients (with insight) and carers that health professionals can consult when presented with hypersexual patients and/or their carers. Part B aimed to (1) develop a public-facing *psychoeducational website* that will provide patients and carers with succinct, proper information about hypersexuality in neurological disorders, based on the findings of previous research and the findings of this thesis; and (2) request feedback about the website from clinicians, therapists, patients, and carers, and consequently modify the website based on their suggestions.

5.3 Main findings of the thesis

In general, findings from the studies show that research into hypersexuality in neurological disorders is still in its infancy and more research is required before definitive conclusions can be drawn.

5.3.1 Prevalence of hypersexuality in neurological disorders

Prevalence figures of hypersexuality in neurological disorders are inconsistent, as is presented in Study I. It is important here to note that the studies reporting prevalence included in the systematic review do not explicitly outline reasons for the difficulties in assessing prevalence. Nevertheless, reasons could include the myriad of assessment tools used to assess it, lack of insight, as well as the inherent challenges associated with discussing matters relating to sex and/or sexuality and the stigma associated with it, which might cause some patients to feel embarrassed or shameful, prompting them not to disclose any information, especially if there have been any unlawful acts. This suggests that prevalence of hypersexuality is underreported, making it difficult to determine true prevalence figures.

One might thus argue the purpose of venturing to assess prevalence as part of Study II. Although the research team was aware of the possible difficulties, they thought it interesting/important to attempt it first-hand and see what challenges might arise in the process. These challenges initially became apparent during the process of setting up the study. Both the PD and dementia teams voiced their concerns about assessing the patients and carers and, for the most part, did not agree to it. They did not want to make the patients and carers uncomfortable and did not want them to feel challenged in any capacity. The second challenge became apparent when the study team were informed of the hesitation of patients in completing the QUIP questionnaire at the ECH, which is evident in the low return rate of the questionnaires; only 33 out of 251 questionnaires were completed and returned. These findings are consistent with a study by Baumann-Vogel et al. (2012) showing that ICDs, including hypersexuality, are much more frequent than reported⁽⁹⁾. Despite these challenges, however, the prevalence figure for hypersexuality in PD from the ECH sample in Study II was determined at 12.22%.

Furthermore, the results from the QUIP from the ECH sample challenge the literature in showing that hypersexuality is the most prevalent in patients with PD whereas other studies such as the DOMINION⁽⁹⁾ showed compulsive gambling behaviour as the most prevalent, and hypersexuality, typically, coming second. Reasons for these inconsistencies may involve different samples, sample sizes and gender differences, lack of insight, different assessment tools used, as well as the difficulties in discussing sex.

It appears, therefore, that there are challenges in determining prevalence figures for hypersexuality in neurological disorders, which remain unresolved. This raises questions as to whether prevalence of hypersexuality in neurological disorders can ever be measured accurately.

Despite these inconsistencies and challenges, results from the systematic review preliminarily indicate that:

1. Patients with PD, dementia, TBI, epilepsy, RLS, and stroke have lower propensity in developing hypersexuality than patients with KLS¹.
2. Prevalence of hypersexuality is higher in FTD^(3,5) than in AD^(5,8), and higher in TLE than in grand mal epilepsy⁽⁹⁾, most likely due to temporal lobe involvement.
3. Prevalence of hypersexuality in PD^(10,12) and RLS^(11,13) appears to be higher in patients who are taking dopamine agonists, suggestive of an association between hypersexuality and dopamine agonists,

¹ There are too many references to list here as this was determined from many articles. For more details regarding this, please refer to pages 62-67.

although definitive causality cannot be determined.

4. Prevalence of hypersexuality in PD is higher in younger patients⁽¹⁴⁾. A reason for this may be that younger patients may be more likely to report hypersexuality as there is a stigma surrounding sex in older populations, which may prompt them not to disclose the changes in their sexuality⁽¹⁵⁾. Also, younger patients are more likely to be treated with dopamine agonists, which are frequently implicated in developing hypersexuality^(16,17).
5. Prevalence of hypersexuality in PD is higher in patients post-DBS, suggesting that surgery may help manage hypersexuality^(18,19), and suggesting a possible link between surgery and ICDs.

5.3.2 Implicated factors contributing to the development of hypersexuality

Study I shows that most commonly implicated in the contribution to the development of hypersexuality are the neurological disorders themselves, as well as the modalities used to manage them (i.e. either pharmacological or surgical). This finding is consistent with those from Study II. All PD patients who participated in the study implicated dopaminergic medications used to manage PD as the primary cause of their hypersexuality. A review of the pharmacological history of the PD patients from clinical notes showed that dopamine agonists, especially ropinirole ($n = 6$), are most likely contributing to the development of hypersexuality. This is consistent with the literature that reports dopamine agonists, as possibly causing more cases of hypersexuality than other dopamine replacement therapy options^(16,17) and reflects the higher prevalence figures reported in patients taking dopamine agonists presented in Study I. It is common clinical practice to either reduce or discontinue the implicated hypersexuality-inducing medication⁽²⁰⁾. At time of assessment, six patients indicated either reducing or stopping the implicated medication. This proved successful for only one patient (Patient 5) in the study (as determined by clinical notes), whose hypersexuality resolved completely, and partially successful for another patient (Patient 1) whose hypersexuality was slightly reduced after discontinuing the medication, although the effects of the hypersexuality are still potent in his life. The remaining patients did not indicate decrease/cessation of hypersexuality. One participant (Patient 7) claims: “*I am off the dopamine... but it is not off me*”. The lack of consistency in success rates can possibly be explained by four reasons. First, not all the cases of hypersexuality are necessarily attributable to dopamine therapy. This is consistent with a study by Young et al. (2016) suggesting that not all ICD behaviour, including hypersexuality, are attributable to dopamine therapy⁽²¹⁾. Their study describes hypersexual patients with PD who were unresponsive to reduction in dopamine therapy⁽²¹⁾. Although this suggests that dopamine therapy might not be attributable to the hypersexuality, one might also argue that failure to extinguish a newly-acquired habitual response following reduction of dopamine agonists may reflect the hard-wiring of the behaviour by repeated excessive dopaminergic stimulation. Many patients continue to demonstrate (perhaps a sub-clinical level of) ICDs, including hypersexuality, even after the reduction of dopamine agonists. Third, the patients might implicate the wrong medication. It is thus the clinician’s duty to meticulously investigate the medications the patient is taking and their potential effects. Gupta et al. (2015) show that while ICD expression may be an effect of dopaminergic medication, it does not appear to demonstrate “dose-related or medication-specific effects” and may be influenced by polypharmacy⁽²²⁾. It is thus important to consider non-PD-specific medication such as antipsychotics and antidepressants, which have been reported to possibly cause hypersexuality⁽²³⁾. Fourth, Codling et al. (2015) posit that treatment has more than just a pharmacological component⁽¹⁷⁾, suggesting the multidisciplinary nature of hypersexuality in neurological disorders.

Moreover, findings indicate varying accounts of the effect of DBS on hypersexuality. Although there are no cases where DBS is implicated in contributing to the development of hypersexuality, DBS is implicated in either exacerbating or reducing the symptoms of hypersexuality. This inconsistency is mirrored in the literature. A study by Kasemsuk et al. (2017) shows that there is still no consensus on the effect of DBS as

some studies show improvement of ICDs following DBS while others show worsening of ICDs following DBS⁽²⁴⁾. Specifically, Gee et al. (2015) report reduced hypersexuality following DBS⁽²⁵⁾, while Demetriades et al. (2011) report cases of worsening hypersexuality following DBS⁽²⁶⁾. It is important to note, however, that DBS is often associated with worsening of impulsivity shortly after surgery, which likely reflects the oedema[‡] on the frontal lobes⁽²⁷⁾, leading to disinhibition and the unmasking of the impulsivity. This might explain why the hypersexuality immediately worsened for Patient 2 (e.g. demanding blowjobs in hospital room after surgery), but then levelled off[§]. It is thus important to follow up the patients to see whether the hypersexuality resolves over time in order to make definitive conclusions regarding this. DBS might also allow for the patients to refrain taking the offending drug which also may result reduction of hypersexuality, as suggested by Bronner et al. (2017)⁽²⁸⁾.

Moreover, all carers of FTD patients who took part in Study II implicate the dementia as having contributed to the development of hypersexuality. This is consistent with the literature reporting that hypersexuality likely develops in FTD due to frontal lobe damage and temporolimbic involvement⁽⁹⁾.

Although these factors are implicated in contributing to the development of hypersexuality, no causality can be determined as research still needs to be conducted into the actual causes and neurobiology of hypersexuality.

It is important to note that because sexual dysfunction is common in neurological disorders, health professionals might overlook other potential ‘causes’ of hypersexuality (apart from the neurological disorder and/or its management). Some of these implicated factors, which are highlighted in Study I, include expression of unmet sexual desire⁽²⁹⁾, trying to make up for erectile dysfunction⁽³⁰⁾, and a gap in sexual desire between members of a couple⁽³⁰⁾. This suggests that although sexual dysfunction is common in patients with neurological disorders, one should not be quick in diagnosing hypersexuality as a product of neurological disease and consequent management, as it is multidisciplinary in nature.

5.3.3 Clinical phenomenology of hypersexuality

The studies included in Study I, especially the case reports and case series, show the many ways in which hypersexuality manifests. In cross sectional, cohort, and case control studies, little clinical phenomenology associated with hypersexuality is described, especially in the PD population, probably because of very few hypersexuality-specific studies, which is echoed in Codling et al. (2015)’s systematic review⁽¹⁷⁾. Similarly, the findings from Study II show that hypersexuality does not manifest in the same way amongst all patients but does appear to overlap across different neurological disorders. Sexual changes were observed in patients’ sexual cognitions and behaviours. These changes include but are not limited to the preoccupation with sex, change in sexual orientation, commenting about other women’s underwear, pretending to be wife on dating sites, and transvestic fetishism.

The categories under which the hypersexual manifestations, reported in both Studies I and II, can be sorted to include but not limited to those presented in Figure 9, reproduced from Chapter 2.

‡ Oedema: buildup of fluid which causes affected tissue to become swollen.

§ Patient 2 (worsening of hypersexuality after DBS) because more recently underwent DBS than Patient 6 (reduced hypersexuality symptoms).

Figure 9 – Summary of categories for clinical phenomenology of hypersexuality in neurological disorders

Increased sexual urges/thoughts/fantasies	Self-stimulating sexual behaviour/interests	Compulsive/impulsive sexual behaviour
Verbally and physically inappropriate sexual behaviour (sexual disinhibition)	Excessive reactions when sex refused	Unsolicited sexual acts
New sexual interests/behaviours (e.g. paraphilias; change in sexual orientation)	Illegal sexual behaviour	Increased frequency of sexual acts

Increased urges/desires are the common denominator among all the patients, even for the partners of the carers in the study.

Some of the more serious reported hypersexual behaviours include paedophilic tendencies, penile strangulation, voyeurism, performing sexual acts in front of children, and sexual encounters with animals. It is, therefore, important for health professionals not to underestimate the hypersexuality if being discussed by the patients and/or their carers as it may involve serious offences potentially causing serious harm to the patients and those around them.

Furthermore, Study II shows a distinction between the nature of the hypersexuality in PD and dementia, consistent with the results of the systematic review in Study I (sexual compulsivity/impulsivity⁽⁷⁾ and sexual disinhibition/inappropriateness, respectively⁽⁸⁾). Sexual compulsivity is characteristic of the PD patients in Study II (e.g.: having sex with up to 15 different men in one day; increased requests for sex) and sexual disinhibition, although indicated by the carers and not the patients themselves, is characteristic of FTD patients (e.g.: commenting on the length of wife's sister's skirt; wearing women's underwear to masturbate; commenting to wife about seeing other women's underwear; taking "expired" meat over to a woman he did not know). The FTD carers specifically used the term "disinhibited" to describe their partners' behaviour. Similarly, Study I outlines this distinction, although there are no studies directly comparing between hypersexuality in the two neurological disorders. Of the 51 included studies that report on clinical phenomenology of hypersexuality in PD, 41 (80.4%) indicate sexual impulsivity/compulsivity. Despite a small amount of cases reporting it (10 of 51 studies; 19.6%), sexual inappropriateness alone does not appear to be a primary feature of hypersexuality in PD, although there are some cases where both sexual impulsivity/compulsivity and disinhibition may be present (15 of 51 studies; 29.4%). Dementia, on the other hand, appears to be more closely associated with sexually inappropriate behaviour usually consisting of unsolicited, public displays. Of the 55 included studies that reported on clinical phenomenology of hypersexuality in dementia, 50 (90.9%) indicate sexual inhibition, even though there

are some studies (5 of 55 studies; 9.1%) reporting sexual impulsivity/compulsivity alone. As in PD, there are some studies where both sexual impulsivity/ compulsivity and disinhibition are present (14 of 55 studies; 25.5%), which suggests that clinical phenomenology can overlap and that it is possible for behaviours to cross over between neurological disorders. The exact reasons for the possible differences in clinical phenomenology between disorders is unclear and a reason could be the lack of a standardized tool or the use of many different assessment tools, making it challenging to compare.

It is important to note that even patients with erectile dysfunction and low sexual functioning can evidently still develop hypersexuality and vice versa, as four of the patients who took part in Study II demonstrate this³².

5.3.4 Insight

To determine whether the PD patients have insight, they must first acknowledge the presence of the problem, understand that their hypersexuality is unnatural, have awareness with regards to what contributed to its development, and have a true desire to overcome the problem. Study findings show that, although all the patients acknowledge the presence of hypersexuality and are aware that the PD and the medication may have contributed to its development, only three (Patients 1, 6, and 7) of the patients who took part in Study II appear to have accurate and intuitive understanding of the problem and who are consequently determined as having insight, while the remaining six are not.

Although there are no studies assessing insight and its constituents regarding hypersexuality or other impulse control behaviours in PD or neurological disorders, the findings from Study II helped to formulate a profile for patients with insight. Generally, a patient who presents with the following may be determined to have insight into their hypersexuality:

1. *Acknowledgement of the presence of hypersexuality*
2. *Recognition that hypersexuality is unnatural*
3. *Presence of negative emotional formulations around hypersexuality*
4. *Indication of loss of control over hypersexuality*
5. *Awareness regarding the factors contributing to the development of hypersexuality*
6. *Presence of true desire to overcome hypersexuality*
7. *Indication of negative impact of hypersexuality on quality of life/ daily living*
8. *Hypersexuality triggered by negative emotions*

One might ask: what determines insight? In the research student's unpublished MSc thesis³³, it is suggested that patients who reduce the implicated dopaminergic medication were able to develop insight. This finding is not consistent with the current study's. The three patients who had insight included two patients whose implicated medications were discontinued and one who had no changes in medication regimen (as he had not disclosed his hypersexuality to his consultant or GP). It is difficult to assess, however, whether they developed insight before stopping medications because they were only assessed after stopping them. Further, the remaining six patients include four who had their medication reduced/stopped. This reduction/cessation in medication did not allow them to develop insight. The discrepancy in the findings can be explained by two reasons. First, the patients might implicate the wrong medication. Second, insight into hypersexuality may not relate to medication. For instance, "presentation of hypersexuality may be gender-dependent. Male patients may consider the increased libido as a sign of well-being"³⁴.

Moreover, triangulation results from the four couples who took part in the study together show that the carers provided more information about the hypersexuality than did the patients. This may be due, in large

part, to the patients' lack of insight. This is supported by the fact that the one patient (Patient 7) with insight who came with their carer (Carer 3) show the highest level of accordance between the two accounts about hypersexuality. This finding is consistent with the finding in Study I reporting a high prevalence (>50%) in a cohort of PD patients with information from caregivers⁽³⁴⁾. The importance of including carers in such studies for a better understanding of the phenomenon can thus be argued. A study by Rana and Gangat (2011) shows that when asked about ICDs directly, patients denied while carers provided affirmation and details of the ICDs, which were later confirmed by the patients⁽³⁵⁾.

It is important to note, however, that another reason for the discrepancy in carer and patient accounts could be social desirability, which refers to instances where participants respond to questions on questionnaires and/or interviews in a manner that make themselves or the situation they are in appear better than it really is in order to reflect a more 'desirable' self⁽³⁶⁾.

5.3.5 Impact of hypersexuality

The impact of hypersexuality on patients and their carers is only addressed in Study II.

Patients

Study II findings show that hypersexuality negatively impacts almost all the areas of patients' daily living, including marital life, family life, social life, health, finances, self-confidence, mood, and quality of life. This is consistent with Mendez and Shapira (2013) who posit that the hypersexuality causes substantial "personal distress or impairment in social occupational or other important areas of functioning"⁽³⁾. Interestingly, the patients who do not have insight into the hypersexuality (i.e. do not acknowledge the hypersexuality as a problem that needs to be resolved) are still aware of the negative impact on at least one area of their daily living. Specifically, some of the patients acknowledge that the hypersexuality has a negative effect on the spousal relationship and distresses their partners. This indicates that the patients, although possibly lacking insight into the hypersexuality, may not lack insight into what is happening around them. This can be explained using the results regarding the patients' social cognition. The PD patients in the study were not significantly different than healthier individuals in their social cognition and, therefore, retain their empathy, social sensitivity, and emotional perception.

On average, the PD patients in the study are in the normal range for depression but in the abnormal range for anxiety. This is consistent with other research that shows that a high rate of comorbidity between anxiety and hypersexuality is observed⁽³⁷⁾, although the exact relationship has not been examined. It is difficult, however, to determine the relationship between anxiety and hypersexuality due to the presence of PD. Research shows that disturbances in anxiety are common in PD⁽³⁷⁾, occurring in up to 20-50% of patients^(37,38). For this reason, it would be challenging to distinguish the effect of the hypersexuality from the effect of the neurological disorder itself on aspects of mood. This challenge is further exacerbated by the possibility that some hypersexual PD patients may not have insight and may thus attribute their anxiety to the PD when it might actually be due to the hypersexuality. More research needs to be done regarding the relationship between mood and hypersexuality before any definitive conclusions can be drawn. The patients were assessed only once and the lack of follow-up may have made the distinction unclear. For this reason, this research issue could greatly benefit from a hypersexuality-specific questionnaire.

Furthermore, the PD patients in the study have a similar quality of life to PD controls. One must consider, however, that the scale used aims to assess quality of life of patients living with PD and might thus not be sensitive enough to capture the effects of other changes in the patients' lives, such as hypersexuality. For this reason, it would be challenging to determine the effect of hypersexuality on the quality of life of PD patients. More research needs to be done regarding the relationship between quality of life and

³ Could be due to small sample size.

hypersexuality before any definitive conclusions can be drawn. Perhaps it would be beneficial to develop a quality of life assessment tool that is hypersexuality-specific.

Carers

All the carers who took part in Study II, except one, indicate being negatively affected by their spouses' hypersexuality, suggesting that the struggles relating to hypersexuality does not affect just the patients but rather the carers as well. This is termed "caregiver burden"^(39,40). Research shows that hypersexuality can have a substantial effect on the carers' lives⁽⁴¹⁾, as evident in the study, showing that some carers, due to their frustration and despair from dealing with their partners and the hypersexuality, have reached a point where they have desires, though fleeting, to react aggressively towards their partners. Moreover, some carers express feelings of responsibility and guilt while other carers express a desire not to exist. These difficulties with coping further support the claim that the carers might suffer as much as the patients themselves, if not more because there is no question of insight for the carers as in the case of the patients. These findings are consistent with the literature. A study by Kaizik et al. (2016) shows an association between hypersexual behaviour and carer distress⁽⁴²⁾. Themes of "grief and loss"⁽⁴²⁾ and "changed role"⁽⁴²⁾ emerged from the carers' accounts and are evident in Study II. Other research shows that hypersexuality is a "source of suffering and hardship to patient's entourage"⁽⁴³⁾ and affects spouses' well-being and physical health⁽⁴⁴⁾. The findings of the study are also consistent with the literature on sex addiction. One may thus draw comparisons with the literature on sex addiction, which also leaves the carers "overlooked"⁽⁴⁵⁾. Prayer (2011) states that "many people married to sex addicts are left traumatized [and] devastated"⁽⁴⁶⁾. Furthermore, Wadleigh (2017) concludes that the experience may leave the carers feeling "alone and ashamed... trust is severely damaged, which cripples emotional intimacy and creates distance and a breakdown in communications"⁽⁴⁵⁾, evident in the study.

Results also show that the carers are in the borderline abnormal range for anxiety⁽⁴⁷⁾ and have mid-range quality of life⁽⁴⁸⁾, respectively. Research shows that carers of individuals with neurological disorders can experience anxiety and a reduction in quality of life; therefore, it would be difficult to distinguish between how much of the effect on the carers' mood and quality of life was due to living with an individual with neurological disorders and how much, if any, it was exacerbated by the hypersexuality. Also, the carers were expected to spend around two hours in assessment; however, the carers tended to spend more time discussing the hypersexuality, with one carer spending almost three hours and a half. This may suggest that the carers' distress is undermined and that, in actuality, they need time just to express the way they feel and talk about their experiences.

Although this study focuses primarily on spousal carers, this burden may also be experienced by other members of the family who are affected by the hypersexuality. Also, the impact and burden on the carers may be exacerbated due to the presence of a neurological disorder with the hypersexuality that they are also expected to come to terms with. This sentiment is echoed by Carer 2 who said in her interview: "*Had it been just the hypersexuality, it might've been easier than the hypersexuality and PD together*".

It is important to note that there is no significant distinction between the burden experienced by the PD and FTD carers and no correlation between quality of life and depression scores of carers. This may be due to small sample size and some patients being deceased. It might be worthwhile to consider sex-specific QoL scales.

5.3.6 Stigma

The stigma associated with hypersexuality is only addressed in Study II.

Sex has long been regarded as a taboo subject with roots in religion and culture which appear to influence the nature and frequency of sex and its practices. Religion and historical literature portray women having

sex out of wedlock as impure, and sexual practices were thus limited to acts occurring only between married people. Further, sexual practices beyond the straightforward, missionary, ‘penis-in-vagina’ paradigm were frowned upon and only heterosexual relationships were accepted. Historically, sexual relationships outside the heterosexual norm were punished, condemned, and ridiculed⁽⁹⁾. There was no room socially, culturally, religiously, or biologically for bisexual or homosexual relationships. These values have instilled in people, even years later, a fear of sexual expression and exploration, which has yielded sexual stigma and thus shame. Although cultures and societies have since evolved and become more tolerant⁽⁹⁾, the taboos are deep-rooted enough in that their effects can still be observed in present day and are observed in the patients and carers who took part in the study. During the interviews, most of the patients and carers expressed stigma regarding their hypersexuality. Some refer to being older as a reason for their embarrassment about the hypersexuality. This is consistent with the literature on stigma and sexuality in old age. A study by Dominguez and Barbagallo (2016) shows that sexuality in old age is “still conditioned by biases, prejudices”, and borne from “stereotyped vision” which considers older people as “asexual” although older people do have “sexual potential to express”⁽⁹⁾. This might explain the higher prevalence of hypersexuality in younger patients expressed in Study I⁽¹⁴⁾. Moreover, patients and carers also appear to laugh or apologize when describing sexually explicit details of the patients’ experience with hypersexuality. Apologizing and nervous laughter may be methods used to try and balance anxiety or embarrassment and mask discomfort⁽⁹⁾. Some patients and carers explicitly express shame due to the sexual behaviour. One patient said that “*hypersexuality has not crossed the threshold where people can talk about it... it’s really embarrassing to discuss...*”.

One might raise the question about how stigma could drive behaviour. Results show that sexual stigma might drive patients and carers to attempt to hide the patients’ hypersexuality and causes them to worry about others finding out about it. This is not only evident in the interviews but rather in the process of assessing prevalence. The research team was informed that the patients were hesitant in completing the screening questionnaires, although anonymous, and the reason likely driving their resistance is fear of being stigmatised. Similarly, patients and carers who declined participation in the study indicate embarrassment as their reason for choosing not to partake, which may also be directly related to fear of being stigmatised. It is also possible that the patients and carers who did not attend their scheduled appointments and did not schedule appointments after indicating interest may have done so out of fear and embarrassment of discussing this issue. This is also evident in the refusal of some patients and carers to having their interviews recorded, despite ensured deletion and confidentiality.

This sexual stigma seems to impede patients/carers’ ability to access bodies of help for the hypersexuality, perpetuating their suffering. Therefore, any further research/work done into hypersexuality needs to try and mitigate the stigma so that the patients and carers get the help that they so desperately require.

5.3.7 Professional help-seeking barriers

The professional help-seeking barriers associated with hypersexuality are only addressed in Study II.

Although the patients and carers in Study II were not directly asked about their professional help-seeking behaviour or the barriers associated with professional help-seeking, it is a salient theme. The participants expressed their discontent with the services, or lack thereof, that were provided to them. Professional help-seeking barriers may stem from the stigma⁽⁹⁾ associated with sex and the difficulties associated with the discussion of such a sensitive topic for the patients and carers as well as the health professionals. One might argue that health professionals do not want to upset their patients or cause them discomfort, do not know how to broach the subject, and/or do not know what resources to provide if hypersexuality is presented as an issue. The findings show that neither the patients nor carers are getting the adequate and necessary information and help for the newly-developed hypersexuality. Specifically, one patient said: “*Feels like no one cares enough... you just don’t feel listened to... carers see everything... I gave up... the*

overwhelming feeling is of not being believed... by the professionals... the GPs and... it is quite awful... they don't know... I'm part of our patient liaison committee at the local surgery and I said that I was interested in [hypersexuality]... because of what happened... and there was almost a sort of 'Would you please lead a group?' and I said 'No I can't' but they were aware... completely aware... as almost undoubtedly a lot of people are... but even neurologists... even psychoneurologists... don't know enough about it...". Evidently, the professional help-seeking barriers impeding the patients and carers' ability to express their concerns about hypersexuality include the lack of communication, lack of understanding, lack of education, neglect by the health professionals, and difficulties discussing sex. Although there is no research to date specifically examining the professional help-seeking barriers for sex-related issues, the findings are consistent with a study by Hinchcliff et al. (2005) exploring the perspectives of general practitioners on the challenges associated with the discussion of sexual health issues⁽⁵³⁾. Some of the challenges that were established include practitioners' unawareness of the sexual lifestyles and practices, and "concerns about the appropriate language to use" when discussing sex⁽⁵³⁾. One GP says: "I daresay I might find it embarrassing"⁽⁵³⁾. Although their study focuses primarily on homosexuality, one might be able to draw comparisons with hypersexuality, as both notions are regarded as being 'outside the sexual norm'. The findings from Study II show that these professional help-seeking barriers cause further distress to the patients and carers and have caused them to suffer longer in silence about the issue.

5.3.8 Management options for hypersexuality

Because of the lack of knowledge regarding the exact causes of hypersexuality, studies report many different options that have been successful in the management of hypersexuality. Most commonly, PD patients' implicated medication is reduced or stopped. In some cases, despite the reduction/cessation of the medication, the patient still expresses the hypersexual behaviour as is evident in Study II. One might thus argue that failure to extinguish a newly-acquired habitual response following reduction of dopamine agonists may reflect the hard-wiring of the behaviour by repeated excessive dopaminergic stimulation. Patients continue to demonstrate (perhaps a sub-clinical level of) ICDs, including hypersexuality, even after the reduction of dopamine agonists. Pharmacologically, hypersexuality in neurological disorders other than PD can be treated by the addition of certain medications as is evident in Study I.

Other successful management options for hypersexuality in neurological disorders include behavioural/psychological and surgical options. It is important to note, however, that studies reporting psychological/behavioural options used to manage hypersexuality are more frequently case reports and case series⁵⁴ as evident in Study I. Because case reports and case series are regarded as having low level of evidence, one must be cautious in drawing conclusions about the effectiveness of these options. This has demonstrated the need for well-designed, adequately-sampled, and powered interventional studies for any definitive conclusions to be drawn.

Possible reasons for the lack of interventional studies assessing psychological/behavioural management options for hypersexuality and its effects include the fact that patients with neurological disorders may suffer from cognitive impairment, which might make it more challenging for them to understand the changes in their sexuality and the effects these changes have on their lives and those around them. This consequently makes it difficult for them to benefit from any type of intervention. Another reason, as observed in Study II, is that patients with neurological disorders may suffer from lack of insight into the hypersexuality and may thus be unable to acknowledge the hypersexuality, provide sufficient information about their experience, or commit to required psychological help. A third possible reason might be the fact that, because patients and carers experience/cope with the hypersexuality differently, interventions are subjective and may vary from one patient/carer to another, which may be expensive, time-consuming for therapists/psychologists. A fourth reason could be the lack of knowledge about hypersexuality.

⁵⁴ Managing symptoms of hypersexuality rather than consequences.

Because currently there is no available guide for health professionals and researchers to consult to help manage hypersexuality and its effects on patients and carers, recommended pathways for management of the symptoms and effects of hypersexuality were developed and presented in Chapter 4. This was based on: (1) the results from the systematic review, albeit limited; and (2) the information in the psychological literature regarding usual intervention protocols employed to treat depression, anxiety, anger, and suicidal ideation (the effects of the hypersexuality), all of which have been extensively researched. The recommended pathways should only be regarded as a tentative starting point; therefore, it is important for health professionals and clinical researchers consulting these pathways to note that effects and potential interventions for hypersexuality include but are not limited to the effects and interventions presented in the pathways. Further research into hypersexuality will allow for the improvement of these pathways. Health professionals must also recognize that in some cases the patient is content with the hypersexuality while the spouse and/or other family members might not be, as demonstrated in Study II. If the patient does not acknowledge the issue, it would still be worthwhile to ask carers if there is anything noteworthy and how they are potentially feeling about it.

The pathways stress the importance of psychoeducation as being fundamental for both patients and carers, before any further interventions are considered. This relates back to the sexual stigma and the psychological help-seeking barriers discussed earlier. The resistance and hesitation to discuss hypersexuality expressed by the patients and carers highlights the need for an educational tool providing proper information that could be reached by everyone, without the need for them to go through the challenges of seeking information from individuals who do not have the appropriate knowledge and expertise. A website (www.neurohypersexuality.co.uk) was thus created by the research team for patients and carers to consult as a starting point potentially encouraging conversations with health professionals and consequently expanding awareness.

5.3.9 Evaluation of hypersexuality

Results from Study I show more than 20 different tools used to evaluate prevalence and clinical phenomenology of hypersexuality in neurological disorders, signifying the lack of a single standardized tool and set of diagnostic criteria that are hypersexuality-specific and the lack of consensus about the type of assessment for hypersexuality among clinicians and researchers. This prompts health professionals and researchers to use questionnaires and criteria suiting their research aims and not necessarily geared towards hypersexuality in a neurological disorder setting, which automatically yields inaccuracies and challenges. This challenge was realised in choosing tools for Study II (e.g.: because there were no hypersexuality-specific tools^o, interview schedules were custom-developed according to available research). The heterogeneity in assessment tools makes it potentially challenging to compare between neurological disorders. Moreover, as aforementioned, there are inconsistencies in prevalence figures, probably owing to the many different tools used and the possibility that the tools were not sensitive enough to capture prevalence, as well as full extent of the patients' hypersexuality, particularly if the patients are not insightful and are feeling embarrassed and/or shameful. It is important to note that an appropriate standardized tool for assessment of hypersexuality in neurological disorders would also be necessary in determining options for management, once the extent and nature of the hypersexuality is appropriately and thoroughly examined and assessed.

Specifically in PD, the QUIP and the PD-SAST are commonly used as screening tools; however, a full diagnostic tool is still required; "screening instruments should not be used as definitive 'diagnostic instruments'. When the gold standard for diagnosis (e.g. a detailed diagnostic interview) is too complex to apply, then the tool can act as a substitute"⁽⁵⁴⁾. Apart from these two screening tools, and as discussed in Chapter 1 (p. 3), the Voon proposed operational diagnostic criteria for pathologic hypersexuality are also

^o Further signifies the 'holes' in the research area.

commonly used to diagnose hypersexuality⁶⁵ as determined by the results in Study I. Following the findings from Study II, the researcher proposes some possible modifications and additions to these criteria, which are italicized and underlined below:

- A. The sexual thoughts or behaviours are excessive or an atypical change from baseline marked by one or more of the following:
1. Maladaptive preoccupation with sexual thoughts
 2. Inappropriately or excessively requesting sex from spouse or partner
 3. Habitual promiscuity
 4. Compulsive masturbation *OR increased desire in pleasing oneself sexually*
 5. Telephone sex lines or pornography
 6. Paraphilias
 7. *Compulsive sexual acts*
 8. *Sexual inappropriateness or disinhibition*
 9. *Development of new sexual interests*
 10. *Change in sexual orientation*
 11. *Increased use of medication used to treat erectile dysfunction*
- B. The behaviour must have persisted for at least one month; *should not necessarily be a criterion as patients might divulge about their sexual changes when they first begin*
- C. The behaviour causes at least one or more of the following:
1. Marked distress
 2. Attempts to control thoughts or behaviour unsuccessfully or result in marked anxiety and distress
 3. Are time-consuming
 4. Interfere significantly with social or occupational functioning, *as well as mood, finances, self-confidence, etc.*
- D. The behaviour does not occur exclusively during periods of hypomania or mania
- E. If all the criteria except C are fulfilled, the disorder is subsyndromal; *not in complete agreement with this because the issue of insight could impede the patients from realising the impact of hypersexuality on different areas of their lives and this does not mean that the condition is 'subsyndromal'*

As more keeps being learned in this research area, these criteria will be open to modification and change.

5.3.10 Past experiences and hypersexuality

Although all the carers attribute the onset of their partners' hypersexuality to the neurological diseases, some carers believe the nature in which the hypersexuality develops is related to some of the patients' past experiences. There are four examples of this emergent from Study II. The first carer indicates that her hypersexual husband had a homosexual experience at the age of fifteen with a school friend. She claims that her husband "*might have been a repressed homosexual and the hypersexuality had overridden his control of that and was forcing him... allowing him... stimulating him to pursue the homosexuality as he had never done*" before. The second carer indicates that her hypersexual husband had an ex-girlfriend during his twenties who was of Indian descent and who tragically died in a car accident. She claims that both prostitutes he was involved with, and one of whom he fell in love with, were dark-skinned. The third carer's hypersexual husband put on women's makeup and clothing as a teenager and used to masturbate while wearing his mother's underwear at eleven years of age. She believes that this behaviour had "*come back*" from his early years and claims that he had consequently "*reverted to factory settings*". The fourth carer indicates that, after developing hypersexuality, some of her husband's old behaviours that he seemed

happy not to do had “rekindled” such as swallowing and anal and oral sex. There has been no research exploring this possible link in either the hypersexuality in neurological diseases literature or the sex addiction literature; however, one might argue that there may be two potential reasons for this. The first involves the patient’s lack of disclosure. Two of the above carers claim that the behaviour their partners once experienced seemed to come back after long years of absence; however, it is a possibility that these behaviours had never gone but rather their partners had been successful in suppressing them. It is conceivable that because of the neurological disorders, their inhibitions might have been affected which allows these behaviours to manifest. The second possible reason involves molecular and biological underpinnings of the medications used to manage the neurological disorders, namely PD. Although this has not been investigated and is beyond the scope of this research, it is conceivable that latent tendencies become manifest due to chemical changes following the use of certain medications.

5.3.11 Methodological challenges

There were several challenges associated with engaging of the patients and carers in the area of hypersexuality for both the quantitative and qualitative components of Study II.

The main challenge relates to the issue of sex research in general. Hypersexuality is likely underreported and understudied due to patient and/or carer stress and shame which complicates the identification and assessment of the behaviour⁽⁵⁶⁾. Patients and carers tend to be too ashamed to divulge information about the patients’ sexual behaviour and pursuits⁽⁵⁷⁾, especially in older populations⁽⁵⁸⁾. Research into sex warrants its own set of challenges including but not limited to fearful and hesitant participants⁽⁵⁹⁾. Sexuality is considered a sensitive and private topic, which is fed into by social, cultural, moral, and legal norms and restraints⁽⁶⁰⁾, and may involve stigmatised and/or illegal behaviour⁽⁶⁰⁾. This limits the number of individuals willing to speak of their sexuality with health professionals, which may explain the modest number of patients who completed the QUIP at ECH. Consequently, it is seemingly very difficult to ensure the size and boundaries of a study population which, in turn, makes it difficult to get a representative sample⁽⁶⁰⁾. Concerns also arise with regards to privacy and confidentiality and are often “difficult to resolve”⁽⁶⁰⁾. Another challenge is having unbiased and precise measures of sexuality as errors may arise due to “participation bias, recall and comprehension, problems, and respondents’ willingness to report sensitive and sometimes socially censured attitudes or behaviours”⁽⁵⁹⁾. Conclusively, as with research on any sensitive and private matter, there are no guarantees with regards to participants or what information they should and are willing to divulge.

There are also challenges associated with assessing individuals with neurological conditions in general. Patients with PD and dementia may have cognitive deficits possibly impacting their understanding of the questions. They may also suffer from memory problems which could affect their recall of certain events and experiences. In the study, some of the patients with PD required multiple breaks in order to get their tremors under control and in order to take their medications at specified times. One of the PD patients (Patient 7) had to stop the interview because she had had a “PD attack”, a term she uses to describe a flare-up of her symptoms, requiring her to stop. Also, one of the patients suffers from slurring of his speech as a result of his PD which made it a bit difficult to understand him.

Ensuring limited power differentials between researcher and participants by granting them control when necessary and withdrawing control was necessary, as outlined in the study’s reflexive process. In brief, the participants may have felt intimidated not only by the topic being discussed, but also by the researcher’s position in deciding the questions, doing the questioning, determining the course of the interviews, and analysing the data.

Apart from the interview, the patients had to complete seventeen questionnaires. Although most were relatively short in length (on average 5-15 minutes per questionnaire/test), the primary challenge

associated with a long battery of questionnaires is patient fatigue and boredom which might have affected their answers. Furthermore, the questionnaires had been given in the same order to all the patients, so there is a possibility that due to the boredom and fatigue the patients may have inadvertently scored worse on the tests that were completed towards the end potentially showing greater deficits than they actually have. For purposes of the study, however, these tests were necessary to complete on the same day because there were no guarantees of having the patients come in on two or more separate days to complete the questionnaires.

The data generated for the participants relied heavily on self-reporting. The main challenge associated with self-reporting is that the information collected cannot be verified. The only way the participants could interact with the researcher was through the use of language, which could be a challenge in itself. Carla Willig (2008) claims that since language is the only determinant of participants' realities, the real essence of the experience may get "lost in translation" between participants and researcher⁽⁶¹⁾. Other challenges include selective memory, telescoping, and exaggeration⁽⁶²⁾. Selective memory refers to a participant "remembering and not remembering" past experiences or events⁽⁶³⁾. Telescoping refers to a participant "recalling events that occurred at one time as if they occurred at another"⁽⁶²⁾. Exaggeration refers to participants "embellishing" events and experiences⁽⁶²⁾. Moreover, some participants' answers may have been skewed also due to social desirability, which is especially evident when some of the carers of the patients who took part in the study informed the researcher that their partners had not been as forthcoming and honest in their answers as they could have been. This, however, could also relate back to the stigma and challenges associated with the discussion of sex. Additionally, although patients and carers who came together were advised to complete their assessments separately, one PD patient (Patient 2) requested his wife be present, which may have affected his responses. After his assessment, his wife indicated that much of what her husband had said about his hypersexuality was down-played to possibly appease her discontentment with it. Self-reporting could also be influenced by possible external factors on day of assessment (e.g. mood; severity of PD).

Because of the researcher's background in psychology and her training in emotional intelligence, she knows how to read non-verbal cues and understands shifts in body language. In this regard, the researcher was able during data collection to internally acknowledge such changes and consequently alter the course of the interviews as deemed necessary in that moment. This may have resulted in variable interview quality across the dataset, although this was anticipated considering the nature of the research and the types of questions asked (e.g. frequency of masturbation). This variable quality of data was more evident in the patient group rather than the carer group. A possible reason for this could be that the patients are the ones actually experiencing the hypersexuality, so the potential feelings of shame, guilt, and embarrassment may have caused them discomfort enough during the interview for the researcher to decide to modify or cut the question short and/or move to a different one. This, however, is solely based on researcher judgment and may thus have generated some research bias, although it was necessary in order to keep the research process running smoothly, without causing any upset. Another reason for this variable quality may be due to the issue of insight that emerged from the qualitative findings. The data shows that the majority of the patients do not have insight and thus do not have much to contribute during the interviews, unlike the carers who are more insightful and thus offered more information on the issue of hypersexuality.

Furthermore, the participants, as part of their familiarization with the research, learned that the study is connected with the Urology department where some of the patients were receiving treatment for their neurological disorders (as part of their routine clinical practice). The researcher tried to assure the participants of the independence of the study from the hospital department; however, it may be possible that some participants were influenced or intimidated by this affiliation. For this reason, the researcher tried to establish rapport and trust with the participants, as well as provide a welcome environment in order to get them to better open up about their experiences and feel secure and comfortable in doing so.

Some of the participants of the study did not consent to having their interviews be audio-recorded using a Dictaphone although absolute confidentiality was ensured and they were informed that the recordings would be deleted immediately at the end of transcription. The researcher was thus required to ensure thorough, accurate, and complete note-taking during the interviews to guarantee all important information was collected. Although this was done to a high degree of diligence, there are obviously limitations to not having actual transcripts of the interviews such as the lack of verbatim quotations. Also, there is always a possibility that something might have been left out or overlooked.

5.4 Limitations

Due to the preliminary nature of this research, there are several general limitations, although limitations have been extensively discussed in each chapter.

1. Lack of prior research on hypersexuality

A major limitation of the study is the lack of available prior research on hypersexuality in neurological disorders. More research has been done into sexual dysfunction (outside of hypersexuality) in neurological disorders such as erectile dysfunction and hyposexuality. In PD research, most mention of hypersexuality has been in conjunction with the other impulse control disorders and has therefore not been examined in depth on its own. Although in recent years hypersexuality has become more recognized as an issue in research, there is still very limited information regarding its manifestation, impact, and correlates. Health professionals and researchers do not or choose not to recognise hypersexuality as an issue and have therefore not ventured to examining/exploring it. This limited research primarily limits the comparison of findings from this data to other similar data to see how different patients fare. Further, there has been no research directly comparing hypersexuality in PD to hypersexuality in dementia.

2. Mixed methods research design

There are several challenges with using both qualitative and quantitative methodology in research. First, the research design can be very complex⁽⁶³⁾. Second, it is more time-consuming⁽⁶³⁾. Third, it may require more resources to implement⁽⁶⁴⁾. Fourth, it may be difficult to resolve discrepancies between the two methods because they are operationally different⁽⁶⁴⁾. Fifth, it may be difficult for “quantitative” researchers to cross over and see the merit and validity of qualitative research⁽⁶⁵⁾.

3. Sample size

Quantitatively the limitations include the effect the small sample has on statistical power. Statistical power refers to the ability of a statistical test to discover effects that truly exist in the population⁽⁶⁶⁾. Lower sample sizes typically suggest lower statistical power⁽⁶⁶⁾. Moreover, the small sample size may affect correlational analyses and may thus produce overestimations in the magnitude of the relationship in the data⁽⁶⁷⁾. There is also a possibility that if the sample size had been larger, more correlations between the questionnaires and the constructs could have been established. Furthermore, the small sample size did not allow the exploration of gender differences. However, because no other systematic investigations of hypersexuality in neurological disorders exist, the limitation of small sample size is not significant enough to minimize and undermine the results and value of the study as it provides a basis for future research. A study by Maxwell (2004) actually suggests that there is persistence of underpowered studies in research⁽⁶⁸⁾. A reason for this may be that the current state of academia supports novel studies that provide new insights and angles.

Qualitatively, on the other hand, saturation is a highly debated subject in qualitative research. Saturation cannot be measured and is a subjective decision⁽⁶⁹⁾. It can be therefore argued that there

was enough data from the interviews to ensure that the research questions were answered[†].

4. Tools used to assess hypersexuality

There are no tools specifically assessing hypersexuality in neurological disorders. Because of this and because this is the first study to systematically investigate hypersexuality in neurological disorders, the researcher had to ensure that the battery of tests used assessed a wide range of constructs from sex addiction to executive functioning to ensure breadth and depth of the analysis of hypersexuality and its possible correlates, which could in the future facilitate the creation of hypersexuality-specific questionnaires.

5. Neurological disorders

Although the systematic review reviewed hypersexuality in all neurological disorder that have reported it, Study II included only two neurological disorders: PD and dementia. This may have limited the scope of the study by not allowing researchers to compare between the neurological disorders. Other neurological disorder groups, however, such as epilepsy were approached to no avail possibly due to the challenges associated with discussing sex, which this study hopes to help minimize.

6. Lack of control groups

There were no age-matched, disease-matched control/comparison groups included in the study to compare the quantitative data to, which could have made the results of the study more significant. The results, however, were compared to similar data found in the literature. Because this study is exploratory rather than explanatory, the lack of control groups for comparison does not undermine the significance of this research.

7. Recruitment

The MDC had initially decided that the QUIP would become part of routine assessment in clinic and that it would be given to every patient attending; however, the consultants and nurses later decided that the QUIP was too intrusive and was making the patients uncomfortable. The research team was thus no longer able to assess prevalence of hypersexuality using the QUIP at the MDC. Also, there was a plan of an ICD-clinic being set up that did not solidify. The recruitment methods, therefore, that were used in Study II were limited to leaflets and blurbs of the study distributed with the QUIP at ECH, at one seminar, included in a dementia newsletter, and circulated online by Parkinson's UK and having consultants, psychologists, and nurses inform patients presenting with hypersexuality and/or their carers about the study which ultimately may have contributed to the small sample size.

8. No interventional studies

There were no interventional studies aimed at systematically assessing possible management options for hypersexuality in neurological disorders. All data reported (excluding case reports and case series), as presented in Study I, appeared to mention management options as a by-product of the studies. More information is thus required for health professionals and clinical researchers to develop management strategies.

9. Lack of information regarding psychological/behavioural interventions

The lack of information regarding psychological interventions for the effects of hypersexuality prompted a search of the literature on psychological interventions for depression, anxiety, anger, and suicidality in general. The pathways that were developed for patients and carers are, therefore,

[†] Not saturate enough for comparison between PD and FTD, however.

only recommendations/suggestions that health professionals can consider when presented with patients and/or carers affected by hypersexuality and its effects and are subject to improvement.

10. No follow-up

The patients and carers were not followed up after their assessment. The only updates that the research team received were from the patients' clinical notes. The lack of follow-up does not allow the researchers to detect changes in hypersexuality over time, especially in the case of some PD patients who had their implicated medications withdrawn.

5.5 Implications

The main implications that this research has is for health professionals and service providers.

Health professionals are in position to help mitigate the stigma around sex. Health professionals, including consultants, psychologists, nurses, and GPs, must be educated enough about hypersexuality and the negative impact it has in order to then educate the patients and their carers/families. Perhaps in doing so, they can attempt to *normalize* hypersexuality, explain it, and provide reassurance, if nothing else. This would help alleviate the patient and carer burden of living with hypersexuality and consequently facilitate better help-seeking behaviour, that the patients and carers really seem to need.

Ways in which health professionals can ensure this include:

1. Ensuring that a thorough, clinical assessment is performed⁽⁶⁾. Hypersexuality cases “demand careful and comprehensive assessment of the behaviour, settings, location, time, frequency, and people involved. Predisposing factors, as well as physical, psychiatric and social needs, concerning patients and their partners should also be evaluated. A full understanding of both the behaviour and the contexts in which they occur is essential to created unbiased and reasonable plan of intervention, agreed with staff and other interested partners such as residents’ family”⁽⁷⁾.
2. Informing patients and their carers of the possibility of developing hypersexuality and its relationship to the neurological disease. Lack of information might have negative consequences on the patients’ lives and the lives of those around them.
3. Routinely asking patients and their carers about such sexual changes to allow them to keep a close eye on its development and progression.
4. Paying closer attention to carers’ emotional and physical health⁽⁷⁾ and thus considering the need to include carers in the discussion of hypersexuality, especially since some patients may choose not to disclose information about the changes in their sexuality because of the sensitive nature of the issue.
5. Consulting the management pathways when presented with patients and/or carers who acknowledge the issue and want to manage it, even if they were developed based on the literature on psychological interventions in general. They might choose to consult the pathways when asked by patients and/or carers about possible management options. Health professionals must recognize that in some cases the patient is content with the hypersexuality while the spouse and/or other family members might not be. If the patient does not acknowledge the issue, it would still be worthwhile to ask carers if there is anything noteworthy and how they are potentially feeling about it.

6. Realizing that intervention is not ‘one-size-fits-all’ as assumed in the Okai et al. (2013) study⁽⁷²⁾, especially since hypersexuality impacts different patients and carers differently.
7. Informing patients and carers (especially those who are not tech-savvy) about the website so that it can reach as many individuals/couples as possible.
8. Health professionals who do not feel equipped or comfortable enough to tackle this issue on their own or are too busy to, should consider identifying one individual from their multidisciplinary team who *is* willing evaluate and treat this complicated and sensitive issue, and who patients/carers can be referred to⁽²⁰⁾.

Other implications might be for carers of patients with hypersexuality. These can include understanding the hypersexuality and understanding that it is beyond the patients’ control. This does not mean that carers must accept however the hypersexuality manifests, but rather to know that they are able to access bodies of help that can provide support and advice if needed. Carers and patients could also choose to inform others in need of information about hypersexuality about the website.

Implications on researchers might include the duty to disseminate information about hypersexuality and possibly having ‘training packages’ for health professionals, aiming to provide information about the hypersexuality and ways to deal with it. Also, the term hypersexuality needs to be coined to describe these sexual changes, rather than having many different variances in terms potentially causing confusion to those affected who want to research and learn more.

Further implications may require society to take a step back and reevaluate stigmatised beliefs. Although this is difficult considering the deep-rooted stigmas associated with sex, it is not impossible. Sexual issues “thrive in secrecy and shame, and until we as a society can start talking about it openly and non-judgmentally, the problem is going to continue to grow”⁽⁷³⁾.

5.6 Recommendations for future research

There were many suggestions outlined for future research included in each of the chapters. The following suggestions are the most important:

1. Conducting studies to examine, at a neurobiological, molecular, and chemical level, why the PD medications, and mainly the dopamine agonists, contribute to the development of hypersexuality and other impulse control disorders. This would allow a more holistic picture of the phenomenon to emerge.
2. Developing sensitive, standardized hypersexuality-specific tools to be used across all neurological disorders that would make it easier to assess prevalence and phenomenology and may consequently make it simpler to compare between neurological disorders to create a more holistic view of hypersexuality. For instance, the URICA used in the study could inspire researchers to create a sexual readiness for change scale, the BIS-11 and UPPS-P could inspire researchers to create sexual impulsivity scales, and the AC-QoL could inspire researchers to create a quality of life scale for carers about dealing with the hypersexuality.
3. Developing a guide for the management of hypersexuality. This may prove challenging as there are several things that may need to be established before this can be developed including a standardized assessment tool to assess and an understanding of the causes of hypersexuality in the different neurological disorders.

4. Conducting interventional studies to test the effect of management options on the hypersexuality, separate from other ICDs.
5. Conducting studies to test recommended pathways for improvement.
6. Conducting studies to compare the manifestation and impact of hypersexuality within neurological disorders, such as in dementia between FTD and AD, and between neurological disorders, such as PD, dementia, and epilepsy. These studies could be beneficial as they could uncover patterns that have yet to be uncovered. This may prove challenging as it would take a long time to recruit these patients.
7. Conducting studies with large sample size to compare patients with neurological disorders who have hypersexuality to people with no neurological disorders who have sex addiction. This would allow researchers to investigate the differences between these two groups and perhaps specifically assess the association of hypersexuality with impulsivity, compulsivity, addiction, and risk-taking.
8. Exploring other recruitment methods that could guarantee a higher sample size such as the use of the radio and social media to inform people of the study, as was suggested by one of the participants, or providing study leaflets to every patient and carer attending the clinic. Home visits could also be of benefit.
9. Considering multi-centre studies to further ensure substantial sample size, potentially benefiting prevalence studies.
10. Not to disregard the carer in any assessment of hypersexuality as they can often provide more information than the patients, as was evident in the study and the literature. It is important for health professionals, however, to be careful in their assessment as the carers might overestimate their partners' hypersexual behaviour.
11. Conducting studies investigating the professional help-seeking barriers and possibly involving GPs and consultants and considering reasons why they do not broach the subject.
12. Using the newly-developed patient and carer semi-structured interview schedules in Chapter 3 to assess past and current hypersexuality in neurological disorders.
13. Creating a forum on the website, similar to the design of a chat room, for patients/carers who have experienced hypersexuality to chat anonymously with each other. Research shows that individuals who share similar experiences help with coping methods, as evident in group therapy settings (e.g. Alcoholics Anonymous).
14. Creating an option allowing patients/carers to chat with experts on the website for immediate help and/or conversation. This may take long as it requires assembly of a group of experts on the topic.

5.7 Contributions of thesis

In addition to the provision of some directions for future research, this study has made ten major contributions to the literature on hypersexuality in neurological disorders, since research into this area is relatively new and the related literature is still limited:

1. Systematic review
There are no other systematic reviews to date examining prevalence, clinical phenomenology, and ameliorating management options of hypersexuality in neurological disorders. The systematic

review completed as part of this research provides all information about hypersexuality in neurological disorders in one place and even includes case reports and case series.

2. **Systematic investigation of phenomenology and impact**
There are no other studies systematically investigating or providing detailed accounts of the phenomenology and impact of hypersexuality in patients with neurological disorders and their carers using both qualitative and quantitative research methods. This research area is usually glossed over and no in-depth work has been done to try to unravel the phenomenon. For this reason, the small sample size is not enough to undermine the value of the research.
3. **Profile of insight**
There are no other studies investigating the association between insight and hypersexuality, and presenting a potential profile of patients who do have insight.
4. **Including carers**
A very limited number of studies take carers' accounts into consideration; however, none have systematically investigated the effects of the hypersexuality in the way this research has done.
5. **Triangulation of patient and carer accounts**
Following from the previous points, there are no other studies 'triangulating' the themes/accounts regarding hypersexuality of individuals in a couple. This signifies the importance of including carers as insight might affect patients' accounts of the hypersexuality and one might argue that this enhances the overall reliability of the research.
6. **New interview schedules**
Since there are none, new interview schedules, one for patients and one for carers, informed by the research into hypersexuality and sex addiction as well as the findings from Studies I and II, were developed and presented in Chapter 3. Although they are lengthy, they are necessary to acquire comprehensive information about hypersexuality across all neurological disorders, potentially facilitating future research.
7. **Website as a psychoeducational tool**
The importance of psychoeducation about hypersexuality was established in the study. Because there appears to be a discord between patients/carers and health professionals, there appears a need for an educational tool that can be easily accessed by any information-seeking individual at any time. For this reason, a website was developed, serving as a psychoeducational tool which also provides contact details of two experts in the field who can provide more information if need be. No other such website exists.
8. **Recommended pathways for management**
No treatment protocols exist for the management of hypersexuality in neurological disorders, signifying a need for feasible suggestions that health professionals and clinical researchers can consult when presented with patients and carers suffering the effects of hypersexuality. These pathways, although tentative, provide the foundation for management options of symptoms and effects of hypersexuality.
9. **Hesitancy to discuss sex and sexual disorders in neurology**
There are no studies explicitly addressing the challenges associated with the discussion of sex in the neurological disorder setting. This is an important part of this research as this hesitation limits

research and understanding of the full implications of routine clinical practice

10. Link between background psychology and psychological side-effects of medications

The research illustrates a link between early formative experiences and later manifestations (both in nature of the hypersexuality and the response to hypersexuality). These repetitive patterns of thinking (about sex, sex objects, and effects of hypersexuality) may be further exacerbated by reduced inhibitory abilities. This suggests that the hypersexuality is triggered by the medication, but shaped by early experience, similar to findings in Foley et al. (2017)⁽⁷⁴⁾.

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**QUALITY ASSESSMENT TOOL FOR
QUANTITATIVE STUDIES**



COMPONENT RATINGS

A) SELECTION BIAS

(Q1) Are the individuals selected to participate in the study likely to be representative of the target population?

- 1 Very likely
- 2 Somewhat likely
- 3 Not likely
- 4 Can't tell

(Q2) What percentage of selected individuals agreed to participate?

- 1 80 - 100% agreement
- 2 60–79% agreement
- 3 less than 60% agreement
- 4 Not applicable
- 5 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

B) STUDY DESIGN

Indicate the study design

- 1 Randomized controlled trial
- 2 Controlled clinical trial
- 3 Cohort analytic (two group pre + post)
- 4 Case-control
- 5 Cohort (one group pre + post (before and after))
- 6 Interrupted timeseries
- 7 Other specify _____
- 8 Can't tell

Was the study described as randomized? If NO, go to Component C.

- No
- Yes

If Yes, was the method of randomization described? (See dictionary)

- No
- Yes

If Yes, was the method appropriate? (See dictionary)

- No
- Yes

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

C) **CONFOUNDERS**(Q1) **Were there important differences between groups prior to the intervention?**

- 1 Yes
- 2 No
- 3 Can't tell

The following are examples of confounders:

- 1 Race
- 2 Sex
- 3 Marital status/family
- 4 Age
- 5 SES (income or class)
- 6 Education
- 7 Health status
- 8 Pre-intervention score on outcome measure

(Q2) **If yes, indicate the percentage of relevant confounders that were controlled (either in the design (e.g. stratification, matching) or analysis)?**

- 1 80 – 100% (most)
- 2 60 – 79% (some)
- 3 Less than 60% (few or none)
- 4 Can't Tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

D) **BLINDING**(Q1) **Was (were) the outcome assessor(s) aware of the intervention or exposure status of participants?**

- 1 Yes
- 2 No
- 3 Can't tell

(Q2) **Were the study participants aware of the research question?**

- 1 Yes
- 2 No
- 3 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

E) **DATA COLLECTION METHODS**(Q1) **Were data collection tools shown to be valid?**

- 1 Yes
- 2 No
- 3 Can't tell

(Q2) **Were data collection tools shown to be reliable?**

- 1 Yes
- 2 No
- 3 Can't tell

RATE THIS SECTION	STRONG	MODERATE	WEAK
See dictionary	1	2	3

F) WITHDRAWALS AND DROP-OUTS

(Q1) Werewithdrawalsand drop-outs reported in terms of numbers and/or reasons per group?

- 1 Yes
- 2 No
- 3 Can't tell
- 4 Not Applicable (i.e. one time surveys or interviews)

(Q2) Indicate the percentage of participants completing the study. (If the percentage differs by groups, record the lowest).

- 1 80 -100%
- 2 60 - 79%
- 3 less than 60%
- 4 Can't tell
- 5 Not Applicable (i.e. Retrospective case-control)

RATE THIS SECTION	STRONG	MODERATE	WEAK	
See dictionary	1	2	3	Not Applicable

G) INTERVENTION INTEGRITY

(Q1) What percentage of participants received the allocated intervention or exposure of interest?

- 1 80 -100%
- 2 60 - 79%
- 3 less than 60%
- 4 Can't tell

(Q2) Was the consistency of the intervention measured?

- 1 Yes
- 2 No
- 3 Can't tell

(Q3) Is it likely that subjects received an unintended intervention (contamination or co-intervention) that may influence the results?

- 4 Yes
- 5 No
- 6 Can't tell

H) ANALYSES

(Q1) Indicate the unit of allocation (circle one)

community organization/institution practice/office individual

(Q2) Indicate the unit of analysis (circle one)

community organization/institution practice/office individual

(Q3) Are the statistical methods appropriate for the study design?

- 1 Yes
- 2 No
- 3 Can't tell

(Q4) Is the analysis performed by intervention allocation status (i.e. intention to treat) rather than the actual intervention received?

- 1 Yes
- 2 No
- 3 Can't tell

GLOBAL RATING

COMPONENT RATINGS

Please transcribe the information from the gray boxes on pages 1-4 onto this page. See dictionary on how to rate this section.

A	SELECTION BIAS	STRONG	MODERATE	WEAK
		1	2	3
B	STUDY DESIGN	STRONG	MODERATE	WEAK
		1	2	3
C	CONFOUNDERS	STRONG	MODERATE	WEAK
		1	2	3
D	BLINDING	STRONG	MODERATE	WEAK
		1	2	3
E	DATA COLLECTION METHOD	STRONG	MODERATE	WEAK
		1	2	3
F	WITHDRAWALS AND DROPOUTS	STRONG	MODERATE	WEAK
		1	2	3
				Not Applicable

GLOBAL RATING FOR THIS PAPER (circle one):

- | | | |
|---|----------|----------------------------|
| 1 | STRONG | (no WEAK ratings) |
| 2 | MODERATE | (one WEAK rating) |
| 3 | WEAK | (two or more WEAK ratings) |

With both reviewers discussing the ratings:

Is there a discrepancy between the two reviewers with respect to the component (A-F) ratings?

No Yes

If yes, indicate the reason for the discrepancy

- | | |
|---|---|
| 1 | Oversight |
| 2 | Differences in interpretation of criteria |
| 3 | Differences in interpretation of study |

Final decision of both reviewers (circle one):

- | | |
|---|-----------------|
| 1 | STRONG |
| 2 | MODERATE |
| 3 | WEAK |

**Questionnaire for Impulsive-Compulsive Disorders in Parkinson's Disease
(QUIP-Anytime During PD-Full)**

Reported by: _____ Patient _____ Informant* _____ Patient and Informant

Patient name: _____

Date: _____

*If information reported by an informant, answer questions based on your understanding of the patient.

**Answer ALL QUESTIONS based on BEHAVIORS ANYTIME DURING PD
LASTING AT LEAST 4 WEEKS**

A. IMPULSE CONTROL DISORDERS

1. Do [Did] you or others think that you have [had] an issue with too much gambling, sex, buying, or eating behaviors? Answer for all four behaviors listed below.

Gambling (such as casinos, internet gambling, lotteries, scratch tickets, betting, or slot or poker machines) _____ **Yes** _____ **No**

Sex (such as making sexual demands on others, promiscuity, prostitution, change in sexual orientation, masturbation, internet or telephone sexual activities, or pornography) _____ **Yes** _____ **No**

Buying (such as too much of the same thing or things that you don't need or use) _____ **Yes** _____ **No**

Eating (such as eating larger amounts or different types of food than in the past, more rapidly than normal, until feeling uncomfortably full, or when not hungry) _____ **Yes** _____ **No**

2. Do [Did] you think too much about the behaviors below (such as having trouble keeping thoughts out of your mind or feeling guilty)?

Gambling _____ **Yes** _____ **No**

Sex _____ **Yes** _____ **No**

Buying _____ **Yes** _____ **No**

Eating _____ **Yes** _____ **No**

3. Do [Did] you have urges or desires for the behaviors below that you feel are [felt were] excessive or cause [caused] you distress (including becoming restless or irritable when unable to participate in the behavior)?

Gambling _____ **Yes** _____ **No**

Sex _____ **Yes** _____ **No**

Buying _____ **Yes** _____ **No**

Eating _____ **Yes** _____ **No**

4. Do [Did] you have difficulty controlling the behaviors below (such as increasing them over time, or having trouble cutting down or stopping them)?

Gambling _____ **Yes** _____ **No**

Sex _____ **Yes** _____ **No**

Buying _____ **Yes** _____ **No**

Eating _____ **Yes** _____ **No**

**Questionnaire for Impulsive-Compulsive Disorders in Parkinson's Disease
(QUIP-Anytime During PD-Full)**

5. Do [Did] you engage in activities specifically to continue the behaviors below (such as hiding what you are [were] doing, lying, hoarding things, borrowing from others, accumulating debt, stealing, or being involved in illegal acts)?

Gambling	___ Yes	___ No
Sex	___ Yes	___ No
Buying	___ Yes	___ No
Eating	___ Yes	___ No

B. OTHER BEHAVIORS

1. Do [Did] you or others think that you spend [spent] too much time....

A. On specific tasks, hobbies or other organized activities (such as writing, painting, gardening, repairing or dismantling things, collecting, computer use, working on projects, etc.)? ___ **Yes** ___ **No**

B. Repeating certain simple motor activities (such as cleaning, tidying, handling, examining, sorting, ordering, or arranging objects, etc.)? ___ **Yes** ___ **No**

C. Walking or driving with no intended goal or specific purpose? ___ **Yes** ___ **No**

2. Do [Did] you or others think you have [had] difficulty controlling the amount of time spent on these activities? ___ **Yes** ___ **No**

3. Do [Did] these activities interfere with daily functioning, or cause relationship or work difficulties? ___ **Yes** ___ **No**

C. MEDICATION USE

1. Do [Did] you or others (including your physicians) think that you consistently take [took] too much of your Parkinson's medications? ___ **Yes** ___ **No**

2. Have [Had] you over time increased on your own, without medical advice, your overall intake of Parkinson's medications for psychological reasons, such as improved mood or motivation? ___ **Yes** ___ **No**

3. Have [Had] you over time increased on your own, without medical advice, your overall intake of Parkinson's medications because you only feel fully "on" when you are dyskinetic? ___ **Yes** ___ **No**

4. Do [Did] you have difficulty controlling your use of Parkinson's medications (such as experiencing a strong desire for more medication, or having worse mood or feeling unmotivated at a lower dosage)? ___ **Yes** ___ **No**

5. Do [Did] you hoard or hide your Parkinson's medications to increase the overall dosage? ___ **Yes** ___ **No**

If you would like to discuss the hypersexuality (i.e. increased sexual behavior) issue in further detail at a later time, please inform the individual who will collect this from you or leave your contact number/email below and an individual from the research team will contact you.

Your participation would be of great help.

Carer Hypersexuality Screening**Questionnaire**

Chief Investigator: Dr Jalesh Panicker

Participant Identification Number:

Date:

NHS Foundation Trust

The National Hospital for Neurology and Neurosurgery

Queen Square, London

WC1N 3BG

Carer Hypersexuality Screening Questionnaire

Neurological disorders can sometimes be associated with changes in the desire for sex. In some disorders, the desire for sex can increase, but in others, desire for sex can decrease. This can cause significant problems for some patients and their partners/carers. However, because this is such a sensitive topic, such problems are often underreported. This study seeks to further our understanding of this important issue, and hopefully lead to improved treatment.

Please circle the answer that best applies to you.

1. Have you felt embarrassment or hurt because of your partner's sexual conduct?

YES	NO
-----	----

2. Have you feared your partner would leave you if you confront them about their behavior?

YES	NO
-----	----

3. Have you felt a sense of responsibility or feelings of guilt over your partner's sexual behavior?

YES	NO
-----	----

4. Have you ever lied to cover up your partner's sexual behavior?

YES	NO
-----	----

5. Have you tried to uncover secrets about your partner's sexual behavior?

YES	NO
-----	----

6. Have you had feelings of betrayal or abandonment as a result of your partner's sexual behavior?

YES	NO
-----	----

7. Have you used sex in your relationship with your partner as a means of maintaining peace?

YES	NO
-----	----

8. Have you tried to control your partner's sexual behavior in an attempt to keep your partner from having sex with other people?

Carer Hypersexuality Screening**Questionnaire**

Chief Investigator: Dr Jalesh Panicker

Participant Identification Number:

Date:

NHS Foundation Trust

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WC1N 3BG

Examples include dressing suggestively, being sexual with him/her, or throwing out pornography.

YES NO

9. Have you tried to convince yourself that your partner's sexual behavior and thoughts should not bother you?

YES NO

10. Have you felt that sex was/is an all-consuming part of your relationship with your partner?

YES NO

11. Have you felt this has affected your self-confidence?

YES NO

12. Has your partner's hypersexuality caused you to feel stupid or angry when you discovered it?

YES NO

13. Has your partner insisted on sexual behavior with you that you found uncomfortable or unwanted?

YES NO

14. Have your relationships with your children, family, friends, or co-workers deteriorated as a result of your partner's hypersexuality?

YES NO

15. Have you felt your partner has lost interest in you sexually?

YES NO

16. Have you felt your partner has lost interest in sexual things more generally?

YES NO

17. Was/is your partner less affectionate in other non-sexual ways?

University College London Hospitals

Carer Hypersexuality Screening

Questionnaire

Chief Investigator: Dr Jalesh Panicker

Participant Identification Number:

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YES NO

18. Have the physical aspects of your relationship changed substantially?

YES NO

19. Have you felt there is less intimacy between you and your partner when you have sex?

YES NO

20. Has your partner developed a heightened interest in sex with you?

YES NO

21. Has your partner developed a heightened interest in sex more generally?

YES NO

22. Has your partner developed new sexual interests or preferences that were not there before the illness?

YES NO

23. Have you ever felt too ashamed or alone to ask for help?

YES NO

If you would like to discuss the hypersexuality (i.e. increased sexual behavior) issue in further detail at a later time, please inform the individual who will collect this from you or leave your contact number/email below and an individual from the research team will contact you.

Your participation would be of great help.

Leaflet
PD patients

Neurological disorders can sometimes be associated with changes in the desire for sex. In some disorders, the desire for sex can increase, but in others, desire for sex can decrease. This can cause significant problems for some patients and their partners/carers. However, because this is such a sensitive topic, such problems are often underreported.

A study that has been set up at National Hospital for Neurology and Neurosurgery, UCL at Queen Square seeks to further our understanding of this important issue, and hopefully lead to improved treatment. This will be done by investigating (1) the prevalence of any changes in sexual desire in neurological disorders; (2) the physical, psychological and cognitive factors associated with such changes; and (3) the impact of these on the patient and their carer.

This study aims to understand the changes in sexual behavior that may occur in Parkinson's disease and the impact this has on you. It would first require the completion of the Parkinson's Disease Impulsive-Compulsive Disorders Questionnaire (QUIP), which is used to screen for any impulse control issues. This will then be followed up using a semi-structured interview and questionnaires.

Participants will be asked some general questions about their health (including their Parkinson's disease) and their sexual behavior. Participants will then be asked about how their changed sexual behavior has impacted them.

We hope that the information we gain from this study will help us improve our care for people with neurological disorders and their carers. It is hoped that this research will inform (1) our understanding of the predisposing, precipitating, and prolonging factors involved in the development of hypersexuality, to reveal predictors of the disorder; and (2) the development of a feasible psychological intervention for people affected by hypersexuality, to reduce distress and promote wellbeing.

If you are interested to learn more about the study, please contact the researcher, Miss Natalie Tayim, at 07455002488 or email at skgttay@ucl.ac.uk

Leaflet
AD/FTD carers

Neurological disorders can sometimes be associated with changes in the desire for sex. In some disorders, the desire for sex can increase, but in others, desire for sex can decrease. This can cause significant problems for some patients and their partners/carers. However, because this is such a sensitive topic, such problems are often underreported.

A study that has been set up at Queen Square in collaboration between the DRC and Department of Uroneurology seeks to further our understanding of this important issue, and hopefully lead to improved treatment. This will be done by investigating (1) the prevalence of any changes in sexual desire in neurological disorders; (2) the physical, psychological and cognitive factors associated with such changes; and (3) the impact of these on the patient and their carer.

This study aims to understand the changes in sexual behavior that may occur in dementia and the impact this has on you. This will be done using a semi-structured interview and questionnaires.

Participants will be asked some general questions about the patient's health (including their dementia) and their sexual behavior. Participants will then be asked about how the patient's changed sexual behavior has impacted them.

We hope that the information we gain from this study will help us improve our care for people with neurological disorders and their carers. It is hoped that this research will inform (1) our understanding of the predisposing, precipitating, and prolonging factors involved in the development of hypersexuality, to reveal predictors of the disorder; and (2) the development of a feasible psychological intervention for people affected by hypersexuality, to reduce distress and promote wellbeing.

If you are interested to learn more about the study, please contact the researcher, Miss Natalie Tayim, at 07455002488 or email at skgttay@ucl.ac.uk

Patient Assessment Interview
Chief Investigator: Dr Jalesh Panicker
Participant Identification Number:
Date:

The National Hospital for Neurology and Neurosurgery
Queen Square, London
WC1N 3BG

Patient Assessment Interview

Semi-structured interview schedule

Interview length: 35-60 minutes

About the interviewee (to be extracted from patient notes)

Age:

Marital Status:

Neurological disorder:

Age of onset of neurological disorder:

Date:

Time:

INTRODUCTION

Thank you for agreeing to take part in an interview for this project.

This interview will be audio recorded. The main reason for this is to have an accurate set of data on this topic. This will help researchers analyze the data as the project develops. Rest assured that you would remain completely anonymous. All data collected is confidential. No records of the interview will be kept with your name or the name of the patient on it.

The following sections include questions about increased sexual behavior that has happened since getting (insert name of neurological disorder name). This is called hypersexuality. Please remember that sexual acts involving physical harm to others or child abuse is against the law. For this reason, please do not answer any questions that show that the patient's sexual behavior has been a threat to others or that the patient has had sexual relationships with minors.

I understand how sensitive this topic is. If any questions make you uncomfortable, you are completely free not to answer. Answer what you want. Also, if any questions are not understandable, please ask and they will be explained.

Patient Assessment Interview
Chief Investigator: Dr Jalesh Panicker
Participant Identification Number:
Date:

The National Hospital for Neurology and Neurosurgery
Queen Square, London
WC1N 3BG

GENERAL

1. **Question:** Since your (insert name of neurological condition) started, have you felt that there is something unusual about your sexual behavior?
Probe 1: Can you tell me what is unusual?
Probe 2: Is this still the case?
Probe 3: How does this make you feel?

2. **Question:** Do you notice that there has been an increase in your sexual behavior and thoughts since getting (insert name of neurological condition)?
Probe 1: Is this still the case?
Probe 2: How does this make you feel?

3. **Question:** How old were you when the hypersexuality started?

4. **Question:** Do you think the PD caused your hypersexuality?
Probe: Why do you think so?

5. (if patient has Parkinson's disease)
Question: What medications were you taking when the hypersexuality started?
Probe 1: Do you think the medication has caused your hypersexuality?
Probe 2: (if so) Which medication?

6. **Question:** Did/do you have any other impulse control disorders such as increased gambling behavior or thought, increased eating behavior or thought, or increased buying?
Probe 1: Which ones?
Probe 2: When did they start?
Probe 3: How severe do you think these behaviors or thoughts were/are?

Patient Assessment Interview
Chief Investigator: Dr Jalesh Panicker
Participant Identification Number:
Date:

The National Hospital for Neurology and Neurosurgery
Queen Square, London
WC1N 3BG

7. **Question:** Did/do you notice any other changes in your behavior apart from the hypersexuality?
Probe 1: What are they?
Probe 2: When did these changes happen?

8. **Question:** Did you have any behavioral or cognitive disorders before the PD?
Example of behavioral disorder is obsessive-compulsive disorder.
Example of a cognitive disorder is perception and memory disorders.
Probe: Can you tell me what they are?

9. **Question:** Do you have any previous addictions, such as drugs or alcohol?
Probe: What addictions?

10. **Question:** Do you think there has been a change in the frequency of sexual intercourse with your partner or otherwise?
Probe: Can you provide more details?

SPECIFIC

11. **Question:** Did/do you choose to please yourself sexually?
Probe 1: How often?
Probe 2: Did/does this leave you feeling satisfied?

12. **Question:** Did/do you feel you are promiscuous?
Probe: What made/makes you think so?

13. **Question:** Did/do you feel sexually excited by anything unusual?
Probe 1: Can you provide examples?
Probe 2: When did you start noticing this?

Patient Assessment Interview

Chief Investigator: Dr Jalesh Panicker

Participant Identification Number:

Date:

The National Hospital for Neurology and Neurosurgery

Queen Square, London

WC1N 3BG

14. **Question:** Which of the following have you tried since experiencing hypersexuality? I will list them and you are required to just say yes or no to each.

Internet porn?

Pornographic novels ?

Uncontrollable masturbation?

Prostitution?

Voyeurism: getting sexual satisfaction from spying on sexual objects or acts?

Exhibitionism: the act of showing your genitals to strangers?

Affairs?

Anonymous sexual encounters?

One-night stands?

Bath houses: communal bath places?

Massage parlors?

Strip clubs?

Sexual encounters with a gender not typically interested in?

Sexual misconduct in the workplace?

Being aggressive with sexual partner?

Asking for sexual partner to be aggressive?

Bestiality: sexual encounters with animals?

Any others that I haven't listed?

15. **Question:** Do you think your hypersexuality has negatively affected your life?

Probe: Has it affected your

Marital life? How so?

Family life? How so?

Social life? How so?

Work? How so?

Finances? How so?

Health? How so?

Mood? How so?

Sleep? How so?

Patient Assessment Interview

Chief Investigator: Dr Jalesh Panicker

Participant Identification Number:

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WC1N 3BG

Self-confidence? How so?

Quality of life? How so?

16. **Question:** Did/does your hypersexuality match your personal beliefs and values?
Probe 1: In what way?
Probe 2: Do you believe this limited/limits your daily activities?

17. **Question:** Did/do you try to decrease your hypersexuality or stop it altogether?
Probe 1: Were you successful?
Probe 2: How does this make you feel?

18. **Question:** Did/do you feel more hypersexual when you had/have certain feelings such as happiness, stress, anger, or sadness?
Probe 1: Which of these feelings?
Probe 2: Are there any other feelings besides these?

19. **Question:** Did/do you try to hide your hypersexuality?
Probe: How?

20. **Question:** Did/do you worry that others will find out about it?

21. **Question:** Did/do you think you are only able to feel satisfied when sex is involved?

22. **Question:** Did/do you believe you needed/need more and more risk in order to reach the same level of excitement?

23. **Question:** Did/do you feel a lot of time was/is spent on sexual behavior or thought that you would have rather used on something else?
Probe: How much time do you think was/is spent?

Patient Assessment Interview

Chief Investigator: Dr Jalesh Panicker

Participant Identification Number:

Date:

The National Hospital for Neurology and Neurosurgery

Queen Square, London

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24. **Question:** Did/do you find it hard to concentrate on other areas of your life because of thoughts and feelings about your hypersexual behavior?
Probe: What areas?
25. **Question:** Did/do you feel that you had/have no control over your hypersexuality?
26. **Question:** What do you think will happen if the public learns about your hypersexuality?
27. **Question:** How did/does your partner feel about your hypersexuality?
Probe 1: Have they talked about it with you?
Probe 2: Did/does the way your partner feels affect you?
Probe 3: How?
28. **Question:** Did/do you ever feel your partner is to blame for your hypersexuality?
29. **Question:** Have you ever felt happy with your hypersexuality?
30. **Question:** Did/do you want to overcome your hypersexuality?
Probe: Have you made this clear to your partner?

CLOSURE

We have reached the end of our interview. I would like to thank you for being so patient. However, do you believe there is anything we have missed out that you would like to add?

Do you have any other comments about what we have discussed, or about the research as a whole?

We will send you a summary of the research findings when it becomes available.

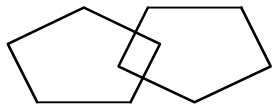
Thank you so much for your participation.

Mini-Mental State Examination (MMSE)

Patient's Name: _____

Date: _____

Instructions: Score one point for each correct response within each question or activity.

Maximum Score	Patient's Score	Questions
5		"What is the year? Season? Date? Day? Month?"
5		"Where are we now? State? County? Town/city? Hospital? Floor?"
3		The examiner names three unrelated objects clearly and slowly, then the instructor asks the patient to name all three of them. The patient's response is used for scoring. The examiner repeats them until patient learns all of them, if possible.
5		"I would like you to count backward from 100 by sevens." (93, 86, 79, 72, 65, ...) Alternative: "Spell WORLD backwards." (D-L-R-O-W)
3		"Earlier I told you the names of three things. Can you tell me what those were?"
2		Show the patient two simple objects, such as a wristwatch and a pencil, and ask the patient to name them.
1		"Repeat the phrase: 'No ifs, ands, or buts.'"
3		"Take the paper in your right hand, fold it in half, and put it on the floor." (The examiner gives the patient a piece of blank paper.)
1		"Please read this and do what it says." (Written instruction is "Close your eyes.")
1		"Make up and write a sentence about anything." (This sentence must contain a noun and a verb.)
1		"Please copy this picture." (The examiner gives the patient a blank piece of paper and asks him/her to draw the symbol below. All 10 angles must be present and two must intersect.) <div style="text-align: center;">  </div>
30		TOTAL

SEXUAL ADDICTION SCREENING TEST-Revised (SAST-R)

The Sexual Addiction Screening Test (SAST) is designed to assist in the assessment of sexually compulsive or "addictive" behavior. Developed in cooperation with hospitals, treatment programs, private therapists and community groups, the SAST provides a profile of responses which help to discriminate between addictive and non-addictive behavior. To complete the test, answer each question by placing a check in the appropriate yes/no column.

- | | | |
|-----|----|---|
| YES | NO | 1. Were you sexually abused as a child or adolescent? |
| YES | NO | 2. Did your parents have trouble with sexual behavior? |
| YES | NO | 3. Do you often find yourself preoccupied with sexual thoughts? |
| YES | NO | 4. Do you feel that your sexual behavior is not normal? |
| YES | NO | 5. Do you ever feel bad about your sexual behavior? |
| YES | NO | 6. Has your sexual behavior ever created problems for you and your family? |
| YES | NO | 7. Have you ever sought help for sexual behavior you did not like? |
| YES | NO | 8. Has anyone been hurt emotionally because of your sexual behavior? |
| YES | NO | 9. Are any of your sexual activities against the law? |
| YES | NO | 10. Have you made efforts to quit a type of sexual activity and failed? |
| YES | NO | 11. Do you hide some of your sexual behaviors from others? |
| YES | NO | 12. Have you attempted to stop some parts of your sexual activity? |
| YES | NO | 13. Have you felt degraded by your sexual behaviors? |
| YES | NO | 14. When you have sex, do you feel depressed afterwards? |
| YES | NO | 15. Do you feel controlled by your sexual desire? |
| YES | NO | 16. Have important parts of your life (such as job, family, friends, leisure activities) been neglected because you were spending too much time on sex? |
| YES | NO | 17. Do you ever think your sexual desire is stronger than you are? |
| YES | NO | 18. Is sex almost all you think about? |
| YES | NO | 19. Has sex (or romantic fantasies) been a way for you to escape your problems? |
| YES | NO | 20. Has sex become the most important thing in your life? |
| YES | NO | 21. Are you in crisis over sexual matters? |
| YES | NO | 22. The internet has created sexual problems for me. |
| YES | NO | 23. I spend too much time online for sexual purposes. |

- YES NO 24. I have purchased services online for erotic purposes (sites for dating, pornography, fantasy and friend finder).
- YES NO 25. I have used the internet to make romantic or erotic connections with people online.
- YES NO 26. People in my life have been upset about my sexual activities online.
- YES NO 27. I have attempted to stop my online sexual behaviors.
- YES NO 28. I have subscribed to or regularly purchased or rented sexually explicit materials (magazines, videos, books or online pornography).
- YES NO 29. I have been sexual with minors.
- YES NO 30. I have spent considerable time and money on strip clubs, adult bookstores and movie houses.
- YES NO 31. I have engaged prostitutes and escorts to satisfy my sexual needs.
- YES NO 32. I have spent considerable time surfing pornography online.
- YES NO 33. I have used magazines, videos or online pornography even when there was considerable risk of being caught by family members who would be upset by my behavior.
- YES NO 34. I have regularly purchased romantic novels or sexually explicit magazines.
- YES NO 35. I have stayed in romantic relationships after they became emotionally or abusive.
- YES NO 36. I have traded sex for money or gifts.
- YES NO 37. I have maintained multiple romantic or sexual relationships at the same time.
- YES NO 38. After sexually acting out, I sometimes refrain from all sex for a significant period.
- YES NO 39. I have regularly engaged in sadomasochistic behavior.
- YES NO 40. I visit sexual bath-houses, sex clubs or video/bookstores as part of my regular sexual activity.
- YES NO 41. I have engaged in unsafe or "risky" sex even though I knew it could cause me harm.
- YES NO 42. I have cruised public restrooms, rest areas or parks looking for sex with strangers.
- YES NO 43. I believe casual or anonymous sex has kept me from having more long-term intimate relationships.
- YES NO 44. My sexual behavior has put me at risk for arrest for lewd conduct or public indecency.
- YES NO 45. I have been paid for sex.

URICA: University of Rhode Island Change Assessment

Please indicate the extent to which you tend to agree or disagree with each statement. In each case, make your choice in terms of how you feel right now, not what you have felt in the past or would like to feel. For all the statements, answer in terms of what you write on the "Habit/Study Problem" line below. There are FIVE possible responses to each of the items in the questionnaire:

Habit/Study Problem: _____

1 = Strongly Disagree 2 = Disagree 3 = Undecided 4 = Agree 5 = Strongly Agree

1.	As far as I'm concerned, I don't have any habits that need changing.	
2.	I think I might be ready for some self-improvement.	
3.	I am doing something about the problems/habits that had been bothering me.	
4.	It might be worthwhile to work on my problem.	
5.	I don't have a problem with organizing my time or studying. It doesn't make much sense for me to be here.	
6.	It worries me that I might slip back on a problem I have already changed, so I am here to seek help.	
7.	I am finally doing some work on my problem.	
8.	I've been thinking that I might want to change something about myself.	
9.	I have been successful in working on changing but I'm not sure I can keep up the effort on my own.	
10.	At times my problem is difficult, but I'm working on it.	
11.	Being here is pretty much a waste of time for me because the problem doesn't have to do with me.	
12.	I'm hoping talking about changing my study skills will help me to better understand myself.	
13.	I guess I have faults, but there's nothing that I really need to change.	
14.	I am really working hard to change.	
15.	I have a problem and I really think I should work at it.	
16.	I'm not following through with what I had already changed as well as I had hoped, and I'm here to prevent a relapse of the problem.	
17.	Even though I'm not always successful in changing, I am at least working on my problem.	
18.	I thought once I had resolved my problem I would be free of it, but sometimes I still find myself struggling with it.	
19.	I wish I had more ideas on how to solve the problem.	
20.	I have started working on my problems but I would like help.	
21.	Seeing a learning specialist may be a help to me.	
22.	I may need a boost right now to help me maintain the changes I've already made.	
23.	I may be part of the problem, but I don't really think I am.	
24.	I hope that someone here will have some good advice for me.	
25.	Anyone can talk about changing; I'm actually doing something about it.	
26.	All this talk about learning styles and how to study in medical school is boring.	
27.	I'm here to prevent myself from having a relapse of my problem.	
28.	It is frustrating, but I feel I might be having a recurrence of a problem I thought I had resolved.	
29.	I have worries/bad habits but so does the next guy. Why spend time thinking about them?	
30.	I am actively working on my problem.	
31.	I would rather keep doing what I am doing than try to change them.	
32.	After all I had done to try to change my problem, every now and again it comes back to haunt me.	
Precontemplation items		1, 5, 11, 13, 23, 26, 29, 31
Contemplation items		2, 4, 8, 12, 15, 19, 21, 24
Action items		3, 7, 10, 14, 17, 20, 25, 30
Maintenance items		6, 9, 16, 18, 22, 27, 28, 32

Summary scoring: University of Rhode Island Change Assessment

Subscale	Number of Items	Items	Minimum score	Maximum score	Scoring
PC	7	1, 5, 11, 13, 23, 26, 29	1	4	Strongly disagree = 1 Disagree = 2 Undecided = 3
C	7	2, 8, 12, 15, 19, 21, 24	1	4	Agree = 4 Strongly agree = 5
A	7	3, 7, 10, 14, 17, 25, 30	1	4	Readiness for Change score = (mean C + mean A + mean M) – mean PC
M	7	6, 16, 18, 22, 27, 28, 32	1	4	

Readiness for Change score	Stage
8 or lower	PC
8 – 11	C
11 – 14	A
14 or more	M

A: action; C: contemplation; M: maintenance; PC: precontemplation

INTERNATIONAL INDEX OF ERECTILE FUNCTION

Patient Questionnaire

HOSPITAL NUMBER (IF KNOWN)

NAME

.....

DATE OF BIRTH

AGE

ADDRESS

.....
.....
.....

TELEPHONE

.....

These questions ask about the effects that your erection problems have had on your sex life over the last four weeks. Please try to answer the questions as honestly and as clearly as you are able. Your answers will help your doctor to choose the most effective treatment suited to your condition. In answering the questions, the following definitions apply:

- **sexual activity** includes intercourse, caressing, foreplay & masturbation
- **sexual intercourse** is defined as sexual penetration of your partner
- **sexual stimulation** includes situation such as foreplay, erotic pictures etc.
- **ejaculation** is the ejection of semen from the penis (or the feeling of this)
- **orgasm** is the fulfilment or climax following sexual stimulation or intercourse

**OVER THE PAST 4 WEEKS
CHECK ONE BOX ONLY**

<input type="checkbox"/> Q1	How often were you able to get an erection during sexual activity?	0 No sexual activity 1 Almost never or never 2 A few times (less than half the time) 3 Sometimes (about half the time) 4 Most times (more than half the time) 5 Almost always or always
<input type="checkbox"/> Q2	When you had erections with sexual stimulation, how often were your erections hard enough for penetration?	0 No sexual activity 1 Almost never or never 2 A few times (less than half the time) 3 Sometimes (about half the time) 4 Most times (more than half the time) 5 Almost always or always
<input type="checkbox"/> Q3	When you attempted intercourse, how often were you able to penetrate (enter) your partner?	0 Did not attempt intercourse 1 Almost never or never 2 A few times (less than half the time) 3 Sometimes (about half the time) 4 Most times (more than half the time) 5 Almost always or always
<input type="checkbox"/> Q4	During sexual intercourse, <u>how often</u> were you able to maintain your erection after you had penetrated (entered) your partner?	0 Did not attempt intercourse 1 Almost never or never 2 A few times (less than half the time) 3 Sometimes (about half the time) 4 Most times (more than half the time) 5 Almost always or always
<input type="checkbox"/> Q5	During sexual intercourse, <u>how difficult</u> was it to maintain your erection to completion of intercourse?	0 Did not attempt intercourse 1 Extremely difficult 2 Very difficult 3 Difficult 4 Slightly difficult 5 Not difficult

<input type="checkbox"/> Q6	How many times have you attempted sexual intercourse?	0 No attempts 1 One to two attempts 2 Three to four attempts 3 Five to six attempts 4 Seven to ten attempts 5 Eleven or more attempts
<input type="checkbox"/> Q7	When you attempted sexual intercourse, how often was it satisfactory for you?	0 Did not attempt intercourse 1 Almost never or never 2 A few times (less than half the time) 3 Sometimes (about half the time) 4 Most times (more than half the time) 5 Almost always or always
<input type="checkbox"/> Q8	How much have you enjoyed sexual intercourse?	0 No intercourse 1 No enjoyment at all 2 Not very enjoyable 3 Fairly enjoyable 4 Highly enjoyable 5 Very highly enjoyable
<input type="checkbox"/> Q9	When you had sexual stimulation <u>or</u> intercourse, how often did you ejaculate?	0 No sexual stimulation or intercourse 1 Almost never or never 2 A few times (less than half the time) 3 Sometimes (about half the time) 4 Most times (more than half the time) 5 Almost always or always
<input type="checkbox"/> Q10	When you had sexual stimulation <u>or</u> intercourse, how often did you have the feeling of orgasm or climax?	1 Almost never or never 2 A few times (less than half the time) 3 Sometimes (about half the time) 4 Most times (more than half the time) 5 Almost always or always
<input type="checkbox"/> Q11	How often have you felt sexual desire?	1 Almost never or never 2 A few times (less than half the time) 3 Sometimes (about half the time) 4 Most times (more than half the time) 5 Almost always or always
<input type="checkbox"/> Q12	How would you rate your level of sexual desire?	1 Very low or none at all 2 Low 3 Moderate 4 High 5 Very high
<input type="checkbox"/> Q13	How satisfied have you been with your <u>overall sex life</u>?	1 Very dissatisfied 2 Moderately dissatisfied 3 Equally satisfied & dissatisfied 4 Moderately satisfied 5 Very satisfied
<input type="checkbox"/> Q14	How satisfied have you been with your <u>sexual relationship</u> with your partner?	1 Very dissatisfied 2 Moderately dissatisfied 3 Equally satisfied & dissatisfied 4 Moderately satisfied 5 Very satisfied
<input type="checkbox"/> Q15	How do you rate your <u>confidence</u> that you could get and keep an erection?	1 Very low 2 Low 3 Moderate 4 High 5 Very high

Summary scoring: International Index of Erectile Function

Function Domain	Number of Items	Items	Score Range	Minimum Score	Maximum Score	Scoring
Erectile function*	6	1, 2, 3, 4, 5, 15	0 (or 1) – 5	1	30	1-10: Severe erectile dysfunction 11-16: Moderate dysfunction 17-21: Mild to moderate dysfunction 22-25: Mild dysfunction 26-30: No dysfunction Patients with low scores in this domain (<14 out of 30) may be considered for trial courses of therapy with erectile function improvement drugs ⁽¹⁶⁾
Orgasmic function	2	9, 10	0 – 5	0	10	
Sexual desire	2	11, 12	1 – 5	2	10	Higher score = Less dysfunction
Intercourse satisfaction	3	6, 7, 8	0 – 5	0	15	
Overall satisfaction	2	13, 14	1 – 5	2	10	
*. Of interest in this study.						

Female Sexual Function Index (FSFI) ©

Subject Identifier _____

Date _____

INSTRUCTIONS: These questions ask about your sexual feelings and responses during the past 4 weeks. Please answer the following questions as honestly and clearly as possible. Your responses will be kept completely confidential. In answering these questions the following definitions apply:

Sexual activity can include caressing, foreplay, masturbation and vaginal intercourse.

Sexual intercourse is defined as penile penetration (entry) of the vagina.

Sexual stimulation includes situations like foreplay with a partner, self-stimulation (masturbation), or sexual fantasy.

CHECK ONLY ONE BOX PER QUESTION.

Sexual desire or interest is a feeling that includes wanting to have a sexual experience, feeling receptive to a partner's sexual initiation, and thinking or fantasizing about having sex.

1. Over the past 4 weeks, how **often** did you feel sexual desire or interest?

- Almost always or always
- Most times (more than half the time)
- Sometimes (about half the time)
- A few times (less than half the time)
- Almost never or never

2. Over the past 4 weeks, how would you rate your **level** (degree) of sexual desire or interest?

- Very high
- High
- Moderate
- Low
- Very low or none at all

Sexual arousal is a feeling that includes both physical and mental aspects of sexual excitement. It may include feelings of warmth or tingling in the genitals, lubrication (wetness), or muscle contractions.

3. Over the past 4 weeks, how **often** did you feel sexually aroused ("turned on") during sexual activity or intercourse?

- No sexual activity
- Almost always or always
- Most times (more than half the time)
- Sometimes (about half the time)
- A few times (less than half the time)
- Almost never or never

4. Over the past 4 weeks, how would you rate your **level** of sexual arousal ("turn on") during sexual activity or intercourse?

- No sexual activity
- Very high
- High
- Moderate
- Low
- Very low or none at all

5. Over the past 4 weeks, how **confident** were you about becoming sexually aroused during sexual activity or intercourse?

- No sexual activity
- Very high confidence
- High confidence
- Moderate confidence
- Low confidence
- Very low or no confidence

6. Over the past 4 weeks, how **often** have you been satisfied with your arousal (excitement) during sexual activity or intercourse?

- No sexual activity
- Almost always or always
- Most times (more than half the time)
- Sometimes (about half the time)
- A few times (less than half the time)
- Almost never or never

7. Over the past 4 weeks, how **often** did you become lubricated ("wet") during sexual activity or intercourse?

- No sexual activity
- Almost always or always
- Most times (more than half the time)
- Sometimes (about half the time)
- A few times (less than half the time)
- Almost never or never

8. Over the past 4 weeks, how **difficult** was it to become lubricated ("wet") during sexual activity or intercourse?

- No sexual activity
- Extremely difficult or impossible
- Very difficult
- Difficult
- Slightly difficult
- Not difficult

9. Over the past 4 weeks, how often did you **maintain** your lubrication ("wetness") until completion of sexual activity or intercourse?

- No sexual activity
- Almost always or always
- Most times (more than half the time)
- Sometimes (about half the time)
- A few times (less than half the time)
- Almost never or never

10. Over the past 4 weeks, how **difficult** was it to maintain your lubrication ("wetness") until completion of sexual activity or intercourse?

- No sexual activity
- Extremely difficult or impossible
- Very difficult
- Difficult
- Slightly difficult
- Not difficult

11. Over the past 4 weeks, when you had sexual stimulation or intercourse, how **often** did you reach orgasm (climax)?

- No sexual activity
- Almost always or always
- Most times (more than half the time)
- Sometimes (about half the time)
- A few times (less than half the time)
- Almost never or never

12. Over the past 4 weeks, when you had sexual stimulation or intercourse, how **difficult** was it for you to reach orgasm (climax)?

- No sexual activity
- Extremely difficult or impossible
- Very difficult
- Difficult
- Slightly difficult
- Not difficult

13. Over the past 4 weeks, how **satisfied** were you with your ability to reach orgasm (climax) during sexual activity or intercourse?

- No sexual activity
- Very satisfied
- Moderately satisfied
- About equally satisfied and dissatisfied
- Moderately dissatisfied
- Very dissatisfied

14. Over the past 4 weeks, how **satisfied** have you been with the amount of emotional closeness during sexual activity between you and your partner?

- No sexual activity
- Very satisfied
- Moderately satisfied
- About equally satisfied and dissatisfied
- Moderately dissatisfied
- Very dissatisfied

15. Over the past 4 weeks, how **satisfied** have you been with your sexual relationship with your partner?

- Very satisfied
- Moderately satisfied
- About equally satisfied and dissatisfied
- Moderately dissatisfied
- Very dissatisfied

16. Over the past 4 weeks, how **satisfied** have you been with your overall sexual life?

- Very satisfied
- Moderately satisfied
- About equally satisfied and dissatisfied
- Moderately dissatisfied
- Very dissatisfied

17. Over the past 4 weeks, how **often** did you experience discomfort or pain during vaginal penetration?

- Did not attempt intercourse
- Almost always or always
- Most times (more than half the time)
- Sometimes (about half the time)
- A few times (less than half the time)
- Almost never or never

18. Over the past 4 weeks, how **often** did you experience discomfort or pain following vaginal penetration?

- Did not attempt intercourse
- Almost always or always
- Most times (more than half the time)
- Sometimes (about half the time)
- A few times (less than half the time)
- Almost never or never

19. Over the past 4 weeks, how would you rate your **level** (degree) of discomfort or pain during or following vaginal penetration?

- Did not attempt intercourse
- Very high
- High
- Moderate
- Low
- Very low or none at all

Thank you for completing this questionnaire

Summary scoring: Female Sexual Function Index

Domain	Number of Items	Items	Score Range	Factor	Minimum score	Maximum score
Desire	2	1, 2	1 – 5	0.6	1.2	6.0
Arousal	4	3, 4, 5, 6	0 – 5	0.3	0	6.0
Lubrication	4	7, 8, 9, 10	0 – 5	0.3	0	6.0
Orgasm	3	11, 12, 13	0 – 5	0.4	0	6.0
Satisfaction	3	14, 15, 16	0 (or 1) – 5	0.4	0.8	6.0
Pain	3	17, 18, 19	0 – 5	0.4	0	6.0
<i>Full Scale Score Range*</i>					2.0	36.0
*. Of interest in this study.						

Barratt Impulsiveness Scale (BIS-11)

DIRECTIONS: People differ in the ways they act and think in different situations. This is a test to measure some of the ways in which you act and think. Read each statement and put an X on the appropriate circle on the right side of this page. Do not spend too much time on any statement. Answer quickly and honestly.						
1	2	3	4			
Rarely/Never	Occasionally	Often	Almost	Always/Always		
1	I plan tasks carefully.		1	2	3	4
2	I do things without thinking.		1	2	3	4
3	I make-up my mind quickly.		1	2	3	4
4	I am happy-go-lucky.		1	2	3	4
5	I don't "pay attention."		1	2	3	4
6	I have "racing" thoughts.		1	2	3	4
7	I plan trips well ahead of time.		1	2	3	4
8	I am self controlled.		1	2	3	4
9	I concentrate easily.		1	2	3	4
10	I save regularly.		1	2	3	4
11	I "squirm" at plays or lectures.		1	2	3	4
12	I am a careful thinker.		1	2	3	4
13	I plan for job security.		1	2	3	4
14	I say things without thinking.		1	2	3	4
15	I like to think about complex problems.		1	2	3	4
16	I change jobs.		1	2	3	4
17	I act "on impulse."		1	2	3	4
18	I get easily bored when solving thought problems.		1	2	3	4
19	I act on the spur of the moment.		1	2	3	4
20	I am a steady thinker.		1	2	3	4
21	I change residences.		1	2	3	4
22	I buy things on impulse.		1	2	3	4
23	I can only think about one thing at a time.		1	2	3	4
24	I change hobbies.		1	2	3	4
25	I spend or charge more than I earn.		1	2	3	4
26	I often have extraneous thoughts when thinking.		1	2	3	4
27	I am more interested in the present than the future.		1	2	3	4
28	I am restless at the theater or lectures.		1	2	3	4
29	I like puzzles.		1	2	3	4
30	I am future oriented.		1	2	3	4

UPPS-P

Below are a number of statements that describe ways in which people act and think. For each statement, please indicate how much you agree or disagree with the statement. If you **Agree Strongly** circle **1**, if you **Agree Somewhat** circle **2**, if you **Disagree somewhat** circle **3**, and if you **Disagree Strongly** circle **4**. Be sure to indicate your agreement or disagreement for every statement below. Also, there are questions on the following pages.

	Agree Strongly	Agree Some	Disagree Some	Disagree Strongly
1. I have a reserved and cautious attitude toward life.	1	2	3	4
2. I have trouble controlling my impulses.	1	2	3	4
3. I generally seek new and exciting experiences and sensations.	1	2	3	4
4. I generally like to see things through to the end.	1	2	3	4
5. When I am very happy, I can't seem to stop myself from doing things that can have bad consequences.	1	2	3	4
6. My thinking is usually careful and purposeful.	1	2	3	4
7. I have trouble resisting my cravings (for food, cigarettes, etc.).	1	2	3	4
8. I'll try anything once.	1	2	3	4
9. I tend to give up easily.	1	2	3	4
10. When I am in great mood, I tend to get into situations that could cause me problems.	1	2	3	4
11. I am not one of those people who blurt out things without thinking.	1	2	3	4
12. I often get involved in things I later wish I could get out of.	1	2	3	4
13. I like sports and games in which you have to choose your next move very quickly.	1	2	3	4
14. Unfinished tasks really bother me.	1	2	3	4
15. When I am very happy, I tend to do things that may cause problems in my life.	1	2	3	4
16. I like to stop and think things over before I do them.	1	2	3	4
17. When I feel bad, I will often do things I later regret in order to make myself feel better now.	1	2	3	4
18. I would enjoy water skiing.	1	2	3	4
19. Once I get going on something I hate to stop.	1	2	3	4
20. I tend to lose control when I am in a great mood.	1	2	3	4
21. I don't like to start a project until I know exactly how to proceed.	1	2	3	4

Appendix 16

	Agree Strongly	Agree Some	Disagree Some	Disagree Strongly
22. Sometimes when I feel bad, I can't seem to stop what I am doing even though it is making me feel worse.	1	2	3	4
23. I quite enjoy taking risks.	1	2	3	4
24. I concentrate easily.	1	2	3	4
25. When I am really ecstatic, I tend to get out of control.	1	2	3	4
26. I would enjoy parachute jumping.	1	2	3	4
27. I finish what I start.	1	2	3	4
28. I tend to value and follow a rational, "sensible" approach to things.	1	2	3	4
29. When I am upset I often act without thinking.	1	2	3	4
30. Others would say I make bad choices when I am extremely happy about something.	1	2	3	4
31. I welcome new and exciting experiences and sensations, even if they are a little frightening and unconventional.	1	2	3	4
32. I am able to pace myself so as to get things done on time.	1	2	3	4
33. I usually make up my mind through careful reasoning.	1	2	3	4
34. When I feel rejected, I will often say things that I later regret.	1	2	3	4
35. Others are shocked or worried about the things I do when I am feeling very excited.	1	2	3	4
36. I would like to learn to fly an airplane.	1	2	3	4
37. I am a person who always gets the job done.	1	2	3	4
38. I am a cautious person.	1	2	3	4
39. It is hard for me to resist acting on my feelings.	1	2	3	4
40. When I get really happy about something, I tend to do things that can have bad consequences.	1	2	3	4
41. I sometimes like doing things that are a bit frightening.	1	2	3	4
42. I almost always finish projects that I start.	1	2	3	4
43. Before I get into a new situation I like to find out what to expect from it.	1	2	3	4
44. I often make matters worse because I act without thinking when I am upset.	1	2	3	4
45. When overjoyed, I feel like I can't stop myself from going overboard.	1	2	3	4

Appendix 16

	Agree Strongly	Agree Some	Disagree Some	Disagree Strongly
46. I would enjoy the sensation of skiing very fast down a high mountain slope.	1	2	3	4
47. Sometimes there are so many little things to be done that I just ignore them all.	1	2	3	4
48. I usually think carefully before doing anything.	1	2	3	4
49. When I am really excited, I tend not to think of the consequences of my actions.	1	2	3	4
50. In the heat of an argument, I will often say things that I later regret.	1	2	3	4
51. I would like to go scuba diving.	1	2	3	4
52. I tend to act without thinking when I am really excited.	1	2	3	4
53. I always keep my feelings under control.	1	2	3	4
54. When I am really happy, I often find myself in situations that I normally wouldn't be comfortable with.	1	2	3	4
55. Before making up my mind, I consider all the advantages and disadvantages.	1	2	3	4
56. I would enjoy fast driving.	1	2	3	4
57. When I am very happy, I feel like it is ok to give in to cravings or overindulge.	1	2	3	4
58. Sometimes I do impulsive things that I later regret.	1	2	3	4
59. I am surprised at the things I do while in a great mood.	1	2	3	4

Summary scoring: UPPS-P Impulsive Behaviour Scale

Subscale	Number of Items	Items	Minimum score	Maximum score	Scoring
(negative) Urgency	12	2*, 7*, 12*, 17*, 22*, 29*, 34*, 39*, 44*, 50*, 53, 58*	12	48	Agree strongly = 1 Agree some = 2 Disagree some = 3
(lack of) Premeditation	11	1, 6, 11, 16, 21, 28, 33, 38, 43, 48, 55	11	44	Disagree strongly = 4
(lack of) Perseverance	10	4, 9*, 14, 19, 24, 27, 32, 37, 42, 47*	10	40	Items denoted with (*) are reverse scored:
Sensation-Seeking	12	3*, 8*, 13*, 18*, 23*, 26*, 31*, 36*, 41*, 46*, 51*, 56*	12	48	Agree strongly = 4 Agree some = 3 Disagree some = 2
Positive Urgency	14	5*, 10*, 15*, 20*, 25*, 30*, 35*, 40*, 45*, 49*, 52*, 54*, 57*, 59*	14	56	Disagree strongly = 1 Higher scores = higher impulsiveness
<i>Total score</i>			59	236	
+. Of interest in this study.					

Behavioral Inhibition System and Behavioral Activation System (BIS/BAS) Scale

Each item of this questionnaire is a statement that a person may either agree with or disagree with. For each item, indicate how much you agree or disagree with what the item says. Please respond to all the items; do not leave any blank. Choose only one response to each statement. Please be as accurate and honest as you can be. Respond to each item as if it were the only item. That is, don't worry about being "consistent" in your responses.

1. A person's family is the most important thing in life.
 - 1 Strongly disagree
 - 2 Disagree
 - 3 Agree
 - 4 Strongly agree

2. Even if something bad is about to happen to me, I rarely experience fear or nervousness.
 - 1 Strongly disagree
 - 2 Disagree
 - 3 Agree
 - 4 Strongly agree

3. I go out of my way to get things I want.
 - 1 Strongly disagree
 - 2 Disagree
 - 3 Agree
 - 4 Strongly agree

4. When I'm doing well at something I love to keep at it.
 - 1 Strongly disagree
 - 2 Disagree
 - 3 Agree
 - 4 Strongly agree

5. I'm always willing to try something new if I think it will be fun.
 - 1 Strongly disagree
 - 2 Disagree
 - 3 Agree
 - 4 Strongly agree

6. How I dress is important to me.
 - 1 Strongly disagree
 - 2 Disagree
 - 3 Agree
 - 4 Strongly agree

7. When I get something I want, I feel excited and energized.
 - 1 Strongly disagree
 - 2 Disagree
 - 3 Agree
 - 4 Strongly agree

8. Criticism or scolding hurts me quite a bit.
 - 1 Strongly disagree

- 2 Disagree
 - 3 Agree
 - 4 Strongly agree
9. When I want something I usually go all-out to get it.
- 1 Strongly disagree
 - 2 Disagree
 - 3 Agree
 - 4 Strongly agree
10. I will often do things for no other reason than that they might be fun.
- 1 Strongly disagree
 - 2 Disagree
 - 3 Agree
 - 4 Strongly agree
11. It's hard for me to find the time to do things such as get a haircut.
- 1 Strongly disagree
 - 2 Disagree
 - 3 Agree
 - 4 Strongly agree
12. If I see a chance to get something I want I move on it right away.
- 1 Strongly disagree
 - 2 Disagree
 - 3 Agree
 - 4 Strongly agree
13. I feel pretty worried or upset when I think or know somebody is angry at me.
- 1 Strongly disagree
 - 2 Disagree
 - 3 Agree
 - 4 Strongly agree
14. When I see an opportunity for something I like I get excited right away.
- 1 Strongly disagree
 - 2 Disagree
 - 3 Agree
 - 4 Strongly agree
15. I often act on the spur of the moment.
- 1 Strongly disagree
 - 2 Disagree
 - 3 Agree
 - 4 Strongly agree
16. If I think something unpleasant is going to happen I usually get pretty "worked up".
- 1 Strongly disagree
 - 2 Disagree
 - 3 Agree
 - 4 Strongly agree
17. I often wonder why people act the way they do.

- 1 Strongly disagree
 - 2 Disagree
 - 3 Agree
 - 4 Strongly agree
18. When good things happen to me, it affects me strongly.
- 1 Strongly disagree
 - 2 Disagree
 - 3 Agree
 - 4 Strongly agree
19. I feel worried when I think I have done poorly at something important.
- 1 Strongly disagree
 - 2 Disagree
 - 3 Agree
 - 4 Strongly agree
20. I crave excitement and new sensations.
- 1 Strongly disagree
 - 2 Disagree
 - 3 Agree
 - 4 Strongly agree
21. When I go after something I use a “no hold barred” approach.
- 1 Strongly disagree
 - 2 Disagree
 - 3 Agree
 - 4 Strongly agree
22. I have very few fears compared to my friends.
- 1 Strongly disagree
 - 2 Disagree
 - 3 Agree
 - 4 Strongly agree
23. It would excite me to win a contest.
- 1 Strongly disagree
 - 2 Disagree
 - 3 Agree
 - 4 Strongly agree
24. I worry about making mistakes.
- 1 Strongly disagree
 - 2 Disagree
 - 3 Agree
 - 4 Strongly agree

Summary scoring: Behavioural Inhibition System and Behavioural Activation System

Scale	Number of Items	Items	Minimum score	Maximum score	Scoring
<i>BIS</i> ⁺	7	2*, 8, 13, 16, 19, 22*, 24	7	28	Strongly disagree = 1 Disagree = 2
<i>BAS</i> ⁺			13	52	Agree = 3 Strongly agree = 4
BAS-DR	4	3, 9, 12, 21	4	16	
BAS-FS	4	5, 10, 15, 20	4	16	
BAS-RR	5	4, 7, 13, 18, 23	5	20	All items other than those denoted with (*) are reverse scored: Strongly disagree = 4 Disagree = 3 Agree = 2 Strongly agree = 1

Higher scores = higher sensitivity

BAS: Behavioural Activation System; BAS-DR: drive; BAS-FS: fun seeking; BAS-RR: reward responsiveness; BIS: Behavioural Inhibition System
+. Of interest in this study.

INTERPERSONAL REACTIVITY INDEX (IRI)

The following statements inquire about your thoughts and feelings in a variety of situations. For each item, indicate how well it describes you by choosing the appropriate letter on the scale at the top of the page: A, B, C, D, or E. When you have decided on your answer, fill in the letter next to the item number. **READ EACH ITEM CAREFULLY BEFORE RESPONDING.** Answer as honestly as you can. Thank you.

ANSWER SCALE:

A	B	C	D	E
DOES NOT DESCRIBE ME ME WELL				DESCRIBES VERY WELL

1. I daydream and fantasize, with some regularity, about things that might happen to me.
2. I often have tender, concerned feelings for people less fortunate than me.
3. I sometimes find it difficult to see things from the "other guy's" point of view.
4. Sometimes I don't feel very sorry for other people when they are having problems.
5. I really get involved with the feelings of the characters in a novel.
6. In emergency situations, I feel apprehensive and ill-at-ease.
7. I am usually objective when I watch a movie or play, and I don't often get completely caught up in it.
8. I try to look at everybody's side of a disagreement before I make a decision.
9. When I see someone being taken advantage of, I feel kind of protective towards them.
10. I sometimes feel helpless when I am in the middle of a very emotional situation.
11. I sometimes try to understand my friends better by imagining how things look from their perspective. |
12. Becoming extremely involved in a good book or movie is somewhat rare for me.
13. When I see someone get hurt, I tend to remain calm.

14. Other people's misfortunes do not usually disturb me a great deal.
15. If I'm sure I'm right about something, I don't waste much time listening to other people's arguments.
16. After seeing a play or movie, I have felt as though I were one of the characters.
17. Being in a tense emotional situation scares me.
18. When I see someone being treated unfairly, I sometimes don't feel very much pity for them.
19. I am usually pretty effective in dealing with emergencies.
20. I am often quite touched by things that I see happen.
21. I believe that there are two sides to every question and try to look at them both.
22. I would describe myself as a pretty soft-hearted person.
23. When I watch a good movie, I can very easily put myself in the place of a leading character.
24. I tend to lose control during emergencies.
25. When I'm upset at someone, I usually try to "put myself in his shoes" for a while.
26. When I am reading an interesting story or novel, I imagine how I would feel if the events in the story were happening to me.
27. When I see someone who badly needs help in an emergency, I go to pieces.
28. Before criticizing somebody, I try to imagine how I would feel if I were in their place.

Summary scoring: Interpersonal Reactivity Index

Subscale	Number of Items	Items	Minimum score	Maximum score	Scoring
PT	7	3*, 8, 11, 15*, 21, 25, 28	0	28	A = 0 B = 1 C = 2 D = 3 E = 4
FS	7	1, 5, 7*, 12*, 16, 23, 26	0	28	Items denoted with (*) are reverse scored: A = 4 B = 3 C = 2 D = 1 E = 0
EC	7	2, 4*, 9, 14*, 18*, 20, 22	0	28	Higher scores = better empathic functioning
PD	7	6, 10, 13*, 17, 19*, 24, 27	0	28	

EC: empathic concern; FS: fantasy; PD: personal distress; PT: perspective taking



PDQ-39 QUESTIONNAIRE

Please complete the following

Please tick one box for each question

Due to having Parkinson's disease, how often during the last month

<i>have you....</i>	Never	Occasionally	Sometimes	Often	Always or cannot do at all
1 Had difficulty doing the leisure activities which you would like to do?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2 Had difficulty looking after your home, e.g. DIY, housework, cooking?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3 Had difficulty carrying bags of shopping?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4 Had problems walking half a mile?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5 Had problems walking 100 yards?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6 Had problems getting around the house as easily as you would like?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7 Had difficulty getting around in public?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8 Needed someone else to accompany you when you went out?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9 Felt frightened or worried about falling over in public?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10 Been confined to the house more than you would like?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11 Had difficulty washing yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12 Had difficulty dressing yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13 Had problems doing up your shoe laces?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



PDQ-39 QUESTIONNAIRE

Due to having Parkinson's disease,
how often during the last month

Please tick one box for each question

have you....	Never	Occasionally	Sometimes	Often	Always or cannot do at all
14 Had problems writing clearly?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15 Had difficulty cutting up your food?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16 Had difficulty holding a drink without spilling it?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17 Felt depressed?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18 Felt isolated and lonely?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19 Felt weepy or tearful?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20 Felt angry or bitter?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21 Felt anxious?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22 Felt worried about your future?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23 Felt you had to conceal your Parkinson's from people?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24 Avoided situations which involve eating or drinking in public?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25 Felt embarrassed in public due to having Parkinson's disease?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26 Felt worried by other people's reaction to you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27 Had problems with your close personal relationships?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28 Lacked support in the ways you need from your spouse or partner?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<i>If you do not have a spouse or partner tick here</i>		<input type="checkbox"/>			
29 Lacked support in the ways you need from your family or close friends?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>



PDQ-39 QUESTIONNAIRE

***Due to having Parkinson's disease,
how often during the last month***

Please tick one box for each question

<i>have you....</i>	Never	Occasionally	Sometimes	Often	Always
30 Unexpectedly fallen asleep during the day?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31 Had problems with your concentration, e.g. when reading or watching TV?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
32 Felt your memory was bad?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
33 Had distressing dreams or hallucinations?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
34 Had difficulty with your speech?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35 Felt unable to communicate with people properly?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
36 Felt ignored by people?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37 Had painful muscle cramps or spasms?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38 Had aches and pains in your joints or body?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39 Felt unpleasantly hot or cold?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Thank you for completing the PDQ 39 questionnaire

Summary scoring: Parkinson's Disease Questionnaire-39

Dimensions	Number of Items	Items	Minimum score	Maximum score	Scoring
Mobility	10	1-10	0	100	Never = 0 Occasionally = 1
Activities of daily living	6	11-16	0	100	Sometimes = 2 Often = 3
Emotional well-being	6	17-22	0	100	Always (or cannot do at all, if applicable) = 4
Stigma	4	23-26	0	100	Each dimension is calculated as a scale from 0 to 100 0 = no problem at all; 100 = maximum level of problem
Social support	3	27-29	0	100	
Cognitive impairment	4	30-33	0	100	PDQ-39 SI: sum of scores from dimensions divided by 8
Communication	3	34-36	0	100	
Bodily discomfort	3	37-39	0	100	Lower scores = better quality of life
		<i>PDQ-39 SI*</i>	0	100	

*. Of interest in this study.

National Adult Reading Test (NART)

CHORD	SUPERFLUOUS
ACHE	SIMILE
DEPOT	BANAL
AISLE	QUADRUPED
BOUQUET	CELLIST
PSALM	FACADE
CAPON	ZEALOT
DENY	DRACHM
NAUSEA	AEON
DEBT	PLACEBO
COURTEOUS	ABSTEMIOUS
RAREFY	DETENTE
EQUIVOCAL	IDYLL
NAIVE	PUERPERAL
CATACOMB	AVER
GAOLED	GAUCHE
THYME	TOPIARY
HEIR	LEVIATHAN
RADIX	BEATIFY
ASSIGNATE	PRELATE
HIATUS	SIDEREAL
SUBTLE	DEMESNE
PROCREATE	SYNCOPE
GIST	LABILE
GOUGE	CAMPANILE

Summary scoring: Hayling Sentence Completion Task

- 1) The total response time (in seconds), labeled raw score, is recorded for each Hayling 1 and Hayling 2. The obtained raw score for Hayling 1 is converted to a **Scaled score A**, which ranges from 1 (Impaired) to 7 (High average). The following table is used for the conversion and classification:

Raw score (total time)	Scaled score A	Classification
0	7	High average
1-9	6	Average
10-18	5	Moderate average
19-22	4	Low average
23-50	3	Poor
51-60	2	Abnormal
>60	1	Impaired

- 2) Using the same method, the raw score for Hayling 2 is converted to a **Scaled score B**, which ranges from 1 (Impaired) to eight (Good). The following table is used for the conversion and classification:

Raw score (total time)	Scaled score B	Classification
0	8	Good
1-2	7	High average
3-50	6	Average
51-60	5	Moderate average
61-100	4	Low average
101-120	3	Poor
121-130	2	Abnormal
>130	1	Impaired

- 3) Each response for the Hayling 2 is also classified as being either unconnected, somewhat connected (Category B error), or directly connected (Category A error). The total number of Category A errors is then converted to an **A score** using the following table:

Category A error	A score
1	3
2	6
3	10
4	14
5	18
6	24
7	30
8	36
9	42
10	48
11	54
12	60
13	66

Summary scoring: Hayling Sentence Completion Task

14	72
15	78

- 4) Using the same method, the total number of Category B errors is converted to a **B score** using the following table:

Category B error	B score
1	1
2	2
3	3
4	4
5	9
6	14
7	19
8	24
9	29
10	34
>10	50

- 5) The converted score is then calculated by adding the obtained A score and B score after which it is converted into a **Converted scaled score** ranging from 1 (Impaired) to 8 (Good) using the following table:

Converted score	Converted scaled score	Classification
0	8	Good
1-3	7	High average
4-9	6	Average
10-12	5	Moderate average
13-14	4	Low average
15-17	3	Poor
18-29	2	Abnormal
≥30	1	Impaired

- 6) Next, the **Total scaled score** for each patient is calculated by summing Scaled score A (found for Hayling 1) and Scaled score B (found for Hayling 2) and the Converted scaled score (found for Hayling 2 error): **Total scaled score = Scaled score A + Scaled score B**.

Converted score	Converted scaled score	Classification
0	8	Good
1-3	7	High average
4-9	6	Average
10-12	5	Moderate average
13-14	4	Low average
15-17	3	Poor
18-29	2	Abnormal
≥30	1	Impaired

Summary scoring: Hayling Sentence Completion Task

- 7) Finally, the obtained Total scaled score is then converted to a **Hayling overall scaled score**, after which performance of each patients, ranging from 1 (Impaired) to 10 (Very superior), can be classified accordingly using the following table:

Total scaled scores	Hayling overall scaled score	Classification
23	10	Very superior
22	9	Superior
21	8	Good
20	7	High average
17-19	6	Average
15-16	5	Moderate average
13-14	4	Low average
11-12	3	Poor
10	2	Abnormal
<10	1	Impaired

Hospital Anxiety and Depression Scale (HADS)

Tick the box beside the reply that is closest to how you have been feeling in the past week.

Don't take too long over you replies: your immediate is best.

D	A		D	A	
		I feel tense or 'wound up':			I feel as if I am slowed down:
	3	Most of the time	3		Nearly all the time
	2	A lot of the time	2		Very often
	1	From time to time, occasionally	1		Sometimes
	0	Not at all	0		Not at all
		I still enjoy the things I used to enjoy:			I get a sort of frightened feeling like 'butterflies' in the stomach:
0		Definitely as much		0	Not at all
1		Not quite so much		1	Occasionally
2		Only a little		2	Quite Often
3		Hardly at all		3	Very Often
		I get a sort of frightened feeling as if something awful is about to happen:			I have lost interest in my appearance:
	3	Very definitely and quite badly	3		Definitely
	2	Yes, but not too badly	2		I don't take as much care as I should
	1	A little, but it doesn't worry me	1		I may not take quite as much care
	0	Not at all	0		I take just as much care as ever
		I can laugh and see the funny side of things:			I feel restless as I have to be on the move:
0		As much as I always could		3	Very much indeed
1		Not quite so much now		2	Quite a lot
2		Definitely not so much now		1	Not very much
3		Not at all		0	Not at all
		Worrying thoughts go through my mind:			I look forward with enjoyment to things:
	3	A great deal of the time	0		As much as I ever did
	2	A lot of the time	1		Rather less than I used to
	1	From time to time, but not too often	2		Definitely less than I used to
	0	Only occasionally	3		Hardly at all
		I feel cheerful:			I get sudden feelings of panic:
3		Not at all		3	Very often indeed
2		Not often		2	Quite often
1		Sometimes		1	Not very often
0		Most of the time		0	Not at all
		I can sit at ease and feel relaxed:			I can enjoy a good book or radio or TV program:
0		Definitely	0		Often
1		Usually	1		Sometimes
2		Not Often	2		Not often
3		Not at all	3		Very seldom

Please check you have answered all the questions

Scoring:

Total score: Depression (D) _____ Anxiety (A) _____

Summary scoring: Hospital Anxiety and Depression Scale

Dimension	Number of Items	Minimum score	Maximum score	Scoring	
Anxiety	7	0	21		
Depression	7	0	21		

Total score	Severity
0-7	Normal
8-10	Borderline abnormal
11 – 21	Abnormal

Carer Assessment Interview
 Chief Investigator: Dr Jalesh Panicker
 Participant Identification Number:
 Date:

The National Hospital for Neurology and Neurosurgery
 Queen Square, London
 WC1N 3BG

Carer Assessment Interview

Semi-structured interview schedule

Please note that not all carers are necessarily partners; therefore, there are some interview questions that can only apply to partners. Questions that only apply to partners are under a separate heading.

Interview length: 35-60 minutes

About the patient (to be extracted from patient notes)

Age of patient:

Neurological disorder of the patient:

Age of onset of neurological disorder:

Date:

Time:

INTRODUCTION

Thank you for agreeing to take part in an interview for this project.

This interview will be audio recorded. The main reason for this is to have an accurate set of data on this topic. This will help researchers analyze the data as the project develops. Rest assured that you would remain completely anonymous. All data collected is confidential. No records of the interview will be kept with your name or the name of the patient on it.

The following sections include questions about increased sexual behavior that has happened since the patient has developed (insert name of neurological disorder). This is called hypersexuality. Please remember that sexual acts involving physical harm to others or child abuse is against the law. For this reason, please do not answer any questions that show that the patient's sexual behavior has been a threat to others or that the patient has had sexual relationships with minors.

I understand how sensitive this topic is. If any questions make you uncomfortable, you are completely free not to answer, but we would be grateful if you can answer all questions. Also, if any questions are not understandable, please ask and they will be explained.

Carer Assessment Interview
Chief Investigator: Dr Jalesh Panicker
Participant Identification Number:
Date:

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Queen Square, London
WC1N 3BG

GENERAL BACKGROUND

1. **Question:** How old was the patient when they first became hypersexual?

Probe 1: How long have you been in this relationship?
Probe 2: (if applicable) When did the relationship end?
Probe 3: Was the hypersexuality a reason for the end of your relationship?

3. **Question:** Did the patient have any behavioral or cognitive disorders before the (insert name of neurological condition)?
Example of behavioral disorder is obsessive-compulsive disorder.
Example of cognitive disorder is perception and memory disorders.
Probe: Can you tell me what they are?

4. **Question:** Does the patient have any previous addictions, such as drugs or alcohol?
Probe: What addictions?

5. **Question:** Did/does the patient have any other impulse control disorders such as increased gambling behavior, increased eating behavior, or increased buying behavior?
Probe 1: Which ones?
Probe 2: When did they start?
Probe 3: How severe were/are these behaviors?

6. **Question:** Did/do you notice any other changes in the patient's behavior apart from these and the hypersexuality?
Probe 1: What are they?
Probe 2: When did these changes start?

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7. **Question:** Did you notice that the hypersexuality developed after use of any medications?
Probe: What medications?

SPECIFIC

8. **Question:** When did you first notice this increased sexual behavior?
Probe 1: When you first noticed this behavior, how did you feel?
Probe 2: Is the patient still showing this behavior?
9. **Question:** Do you believe the patient developed hypersexuality because of (insert name of neurological disorder)?
Probe: Why do you think so?
10. **Question:** Since the patient's (insert name of neurological disorder) started, did/do you feel the patient has lost interest in sex in general?
Probe: What makes you think so?
11. **Question:** Since the hypersexuality started, do you believe the patient has new sexual interests that were not there before the (insert name of neurological disorder)?
Probe 1: What are the new interests?
Probe 2: How did you notice them?
12. **Question:** How much time do you think the patient spent/spends on their new sexual interests?
13. **Question:** Since the hypersexuality started, do you believe that your physical relationship with the patient has changed?
Probe: Can you tell me how?

Carer Assessment Interview
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14. **Question:** Since the hypersexuality started, has the patient become more interested in sex with you?
Probe: What is your reaction?
15. **Question:** Since the hypersexual behavior started, do you think the patient had/has no control over their hypersexuality?
Probe: What makes you think so?
16. **Question:** Since the hypersexual behavior started, do you feel like the only thing the patient could/can think about is sex?
Probe: What makes you think so?
17. **Question:** Does the patient's hypersexuality cause problems in your relationship?
Probe 1: Can you please give elaborate? What kind of problems?
Probe 2: How does this make you feel?
Probe 3: How do you think this makes the patient feel?
18. **Question:** Do you believe the patient was/is more tempted to engage in sexual behavior when they have certain feelings, such as sadness or anxiety?
Probe: What feelings?
19. **Question:** Which of the following has your partner tried since developing hypersexuality? I will list them and you are required to just say yes or no to each.
Internet porn?
Pornographic novels?
Uncontrollable masturbation?
Prostitution?
Voyeurism: getting sexual satisfaction from spying on sexual objects or acts?
Exhibitionism: the act of showing your genitals to strangers?
Affairs?
Anonymous sexual encounters?

Carer Assessment Interview

Chief Investigator: Dr Jalesh Panicker

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One-night stands?

Bath houses: communal bath places?

Massage parlors?

Strip clubs?

Sexual encounters with gender not typically interested in?

Sexual misconduct in the workplace?

Being aggressive with sexual partner?

Asking for sexual partner to be aggressive?

Bestiality: sexual encounters with animals?

Any others that I haven't listed?

20. **Question:** Do you think the hypersexuality has negatively affected the patient's life?

Probe: Has it affected their

Marital life? How so?

Family life? How so?

Social life? How so?

Work? How so?

Finances? How so?

Health? How so?

Mood? How so?

Sleep? How so?

Self-confidence? How so?

Quality of life? How so?

21. **Question:** To your knowledge, has the patient tried to control their sexual behavior or stop it altogether?

Probe 1: Has it been successful?

Probe 2: How does this make the patient feel?

Carer Assessment Interview

Chief Investigator: Dr Jalesh Panicker

Participant Identification Number:

Date:

22. **Question:** To your knowledge, does the patient want to overcome their hypersexuality?

Probe: How can you tell?

23. **Question:** Did the patient ever seek advice for their sexual behavior?

Probe: What was the result of that?

24. **Question:** How did/does the patient's hypersexuality make you feel?

Probe 1: Do you think the patient knows this?

Probe 2: Have you tried to make them aware?

Probe 3: What has been the patient's reaction?

25. **Question:** Do you believe the hypersexual behavior was/is out of the patient's control?

Probe 1: Did/do you discuss this issue with the patient?

Probe 2: What has resulted from those conversations?

PARTNER QUESTIONS

26. **Question:** Since the hypersexual behavior started, did/do you feel there was/is less intimacy and confidence between you and your partner when you have sex?

Probe: Why do you think this has happened?

27. **Question:** Since the hypersexual behavior started, did/do you feel your partner was/is not sexually interested in you anymore?

Probe 1: How does this make you feel?

Probe 2: Have you talked to your partner about this?

Probe 3: What did they reply?

28. **Question:** Before the patient's (insert name of neurological condition) started, how often did you and your partner have sex?

29. **Question:** In the period between the start of the patient's (insert name of neurological condition) but before the start of hypersexuality, how often did you and your partner have

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sex?

30. **Question:** Since the hypersexuality started, how often do you and your partner have sex?
31. **Question:** Did/do you find your partner repulsive?
32. **Question:** Did/do you feel you lost respect for him?
33. **Question:** Do you think you will ever be able to forgive him?
34. **Question:** Do you ever blame yourself for the patient's hypersexuality?

CLOSURE

We have reached the end of our interview. I would like to thank you for being so patient. However, do you believe there is anything we have missed out that you would like to add?

Do you have any other comments about what we have discussed, or about the research as a whole?

We will send you a summary of the research findings when it becomes available.

Thank you so much for your participation.

Adult Carer Quality of Life Questionnaire

This questionnaire asks you about different aspects of your life as a carer. Please think about your experience as a carer within the last two weeks and please tick the box that applies next to each statement. There are no right or wrong answers; we are just interested in what life is like for you as a carer. The questionnaire shouldn't take more than 10 minutes.

Please answer all questions as honestly as you can.

Support for Caring

1. I have a good level of emotional support.
 1. Never
 2. Some of the time
 3. A lot of the time
 4. Always

2. My needs as a carer are considered by professionals.
 1. Never
 2. Some of the time
 3. A lot of the time
 4. Always

3. I am happy with the professional support that is provided to me.
 1. Never
 2. Some of the time
 3. A lot of the time
 4. Always

4. I feel able to get the help and information I need.
 1. Never
 2. Some of the time
 3. A lot of the time
 4. Always

5. I have all the practical support I need.
 1. Never
 2. Some of the time
 3. A lot of the time
 4. Always

Caring Choice

6. I feel that my life is on hold because of caring.
 1. Never
 2. Some of the time
 3. A lot of the time
 4. Always

7. My social life has suffered because of caring.
 1. Never
 2. Some of the time
 3. A lot of the time
 4. Always

8. I feel I have less choice about my future due to caring.
 1. Never
 2. Some of the time
 3. A lot of the time
 4. Always

9. I feel I have no control over my own life.
 1. Never
 2. Some of the time
 3. A lot of the time
 4. Always

10. Caring stops me doing what I want to do.
 1. Never
 2. Some of the time
 3. A lot of the time
 4. Always

Caring Stress

11. I feel depressed due to caring.
 1. Never
 2. Some of the time
 3. A lot of the time
 4. Always

12. I feel worn out as a result of caring.
 1. Never
 2. Some of the time
 3. A lot of the time
 4. Always

13. I am mentally exhausted by caring.
 1. Never
 2. Some of the time
 3. A lot of the time
 4. Always

14. I am physically exhausted by caring.
 1. Never
 2. Some of the time

- 3. A lot of the time
- 4. Always

15. I feel stressed as a result of caring.

- 1. Never
- 2. Some of the time
- 3. A lot of the time
- 4. Always

Money Matters

16. I worry about going into debt.

- 1. Never
- 2. Some of the time
- 3. A lot of the time
- 4. Always

17. I feel satisfied with my financial situation.

- 1. Never
- 2. Some of the time
- 3. A lot of the time
- 4. Always

18. I am able to save for a rainy day.

- 1. Never
- 2. Some of the time
- 3. A lot of the time
- 4. Always

19. I worry about money.

- 1. Never
- 2. Some of the time
- 3. A lot of the time
- 4. Always

20. There is enough money in our house to pay for the things we need.

- 1. Never
- 2. Some of the time
- 3. A lot of the time
- 4. Always

Personal Growth

21. I have become a more tolerant person through my caring role.

- 1. Never
- 2. Some of the time
- 3. A lot of the time
- 4. Always

22. Because of caring, I have learnt a lot about myself.
1. Never
 2. Some of the time
 3. A lot of the time
 4. Always
23. Because of caring, I feel that I have grown as a person.
1. Never
 2. Some of the time
 3. A lot of the time
 4. Always
24. I have experienced many positive things through caring.
1. Never
 2. Some of the time
 3. A lot of the time
 4. Always
25. I feel that I have become a better person by caring.
1. Never
 2. Some of the time
 3. A lot of the time
 4. Always

Sense of Value

26. I feel valued by the person I am looking after.
1. Never
 2. Some of the time
 3. A lot of the time
 4. Always
27. The person I look after respects me for what I do.
1. Never
 2. Some of the time
 3. A lot of the time
 4. Always
28. The person I look after makes me feel good about myself.
1. Never
 2. Some of the time
 3. A lot of the time
 4. Always
29. I get a lot from the person I am looking after.
1. Never
 2. Some of the time

- 3. A lot of the time
- 4. Always

30. I have a good relationship with the person I am caring for.

- 1. Never
- 2. Some of the time
- 3. A lot of the time
- 4. Always

Ability to Care

31. I am satisfied with my performance as a carer.

- 1. Never
- 2. Some of the time
- 3. A lot of the time
- 4. Always

32. I can take care of the needs of the person I am caring for.

- 1. Never
- 2. Some of the time
- 3. A lot of the time
- 4. Always

33. I feel I am able to make the life of the person I am looking after better.

- 1. Never
- 2. Some of the time
- 3. A lot of the time
- 4. Always

34. I can manage most situations with the person I care for.

- 1. Never
- 2. Some of the time
- 3. A lot of the time
- 4. Always

35. I am able to deal with a difficult situation.

- 1. Never
- 2. Some of the time
- 3. A lot of the time
- 4. Always

Carer Satisfaction

36. Caring is important to me.

- 1. Never
- 2. Some of the time
- 3. A lot of the time
- 4. Always

37. I resent having to be a carer.

1. Never
2. Some of the time
3. A lot of the time
4. Always

38. I feel frustrated with the person I am caring for.

1. Never
2. Some of the time
3. A lot of the time
4. Always

39. I enjoy being a carer.

1. Never
2. Some of the time
3. A lot of the time
4. Always

40. I am satisfied with my life as carer.

1. Never
2. Some of the time
3. A lot of the time
4. Always

Summary scoring: Adult Carer Quality of Life Questionnaire

Subscale	Number of Items	Items	Minimum score	Maximum score	Scoring
Support for Caring	5	1, 2, 3, 4, 5	0	15	Never = 0 Some of the time = 1 A lot of the time = 2 Always = 3
Caring Choice	5	6*, 7*, 8*, 9*, 10*	0	15	Items denoted with (*) are reverse scored: Never = 3 Some of the time = 2 A lot of the time = 3 Always = 4
Caring Stress	5	11*, 12*, 13*, 14*, 15*	0	15	
Money Matters	5	16*, 17, 18, 19*, 20	0	15	Cut-off scores for each subscale:
Personal Growth	5	21, 22, 23, 24, 25	0	15	
Sense of Value	5	26, 27, 28, 29, 30	0	15	
Ability to Care	5	31, 32, 33, 34, 35	0	15	0 – 5 Indicates a low reported quality of life, and may suggest problems or difficulties
Carer Satisfaction	5	36, 37*, 38*, 39, 40	0	15	6 – 10 Indicates a mid-range reported quality of life on that subscale
					11+ Indicates a high reported quality of life on that subscale
<i>Overall quality of life</i>			0	120	Cut-off scores for Overall quality of life:
					0 – 40 Indicates a low reported quality of life, and may suggest problems or difficulties
					41 – 80 Indicates a mid-range reported quality of life
					81+ Indicates a high reported quality of life

+. Of interest in this study.

Leaflet
PD carers

Neurological disorders can sometimes be associated with changes in the desire for sex. In some disorders, the desire for sex can increase, but in others, desire for sex can decrease. This can cause significant problems for some patients and their partners/carers. However, because this is such a sensitive topic, such problems are often underreported.

A study that has been set up at National Hospital for Neurology and Neurosurgery, UCL at Queen Square seeks to further our understanding of this important issue, and hopefully lead to improved treatment. This will be done by investigating (1) the prevalence of any changes in sexual desire in neurological disorders; (2) the physical, psychological and cognitive factors associated with such changes; and (3) the impact of these on the patient and their carer.

This study aims to understand the changes in sexual behavior that may occur in Parkinson's disease and the impact this has on you. This will be done using a semi-structured interview and questionnaires.

Participants will be asked some general questions about the patient's health (including their Parkinson's disease) and their sexual behavior. Participants will then be asked about how the patient's changed sexual behavior has affected them.

We hope that the information we gain from this study will help us improve our care for people with neurological disorders and their carers. It is hoped that this research will inform (1) our understanding of the predisposing, precipitating, and prolonging factors involved in the development of hypersexuality, to reveal predictors of the disorder; and (2) the development of a feasible psychological intervention for people affected by hypersexuality, to reduce distress and promote wellbeing.

If you are interested to learn more about the study, please contact the researcher, Miss Natalie Tayim, at 07455002488 or email at skgttay@ucl.ac.uk

To be placed in dementia newsletters:

Hypersexuality in Frontotemporal Dementia

Hypersexuality is a problem that occurs in FTD, however often remains hidden. A study aiming to understand the problem of hypersexuality in FTD has been set up at Queen Square in collaboration between the DRC and Department of Urology. The study seeks to explore the problem of hypersexuality, and its impact on the carer and partner. The study involves carers and partners to fill a questionnaire and to be interviewed about the problem and its impact. If you are interested to learn more about the study, please contact the researcher, Miss Natalie Tayim, at 07455002488 or email at skgttay@ucl.ac.uk.

Hypersexuality in Alzheimer's disease

Hypersexuality is a problem that occurs in AD, however often remains hidden. A study aiming to understand the problem of hypersexuality in AD has been set up at Queen Square in collaboration between the DRC and Department of Urology. The study seeks to explore the problem of hypersexuality, and its impact on the carer and partner. The study involves carers and partners to fill a questionnaire and to be interviewed about the problem and its impact. If you are interested to learn more about the study, please contact the researcher, Miss Natalie Tayim, at 07455002488 or email at skgttay@ucl.ac.uk.

Participant Information Sheet

Chief Investigator: Dr Jalesh

Panicker

Participant Identification Number:

The National Hospital for Neurology and Neurosurgery

Queen Square, London

WC1N 3BG

Hypersexuality in Neurological Disorders***Parkinson's disease patients***

We would like to invite you to take part in our research study. Before you decide whether or not to take part, it is important that you understand why the research is being done and what it would involve for you. One of our team members will go through this information sheet with you and answer any questions you may have. Please take time to read this thoroughly and ask if there is anything that is unclear or if you would like more information.

1. What is the purpose of the study?

Neurological disorders can sometimes be associated with changes in the desire for sex. In some disorders, the desire for sex can increase, but in others, desire for sex can decrease. This can cause significant problems for some patients and their partners/carers. However, because this is such a sensitive topic, such problems are often underreported.

This study seeks to further our understanding of this important issue, and hopefully lead to improved treatment. This will be done by investigating (1) the prevalence of any changes in sexual desire in neurological disorders; (2) the physical, psychological and cognitive factors associated with such changes; and (3) the impact of these on the patient and their carer.

2. Why have I been invited?

You have already completed the initial screening questionnaire and have indicated that you would like to discuss your responses in further detail.

3. Do I have to take part?

Your participation in this study is voluntary. It is up to you to decide whether or not to take part. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time without giving a reason. This would not affect the standard of care you receive.

Participant Information Sheet

Chief Investigator: Dr Jalesh

Panicker

Participant Identification Number:

The National Hospital for Neurology and Neurosurgery

Queen Square, London

WC1N 3BG

4. What will happen to me if I take part?

This study aims to understand the changes in sexual behaviour that may occur in Parkinson's disease and the impact this has on quality of life and your carer using an interview, questionnaires, and psychological tests.

You will be asked to complete some questionnaires, which will assess your mood.

In total, this may take up to three to four hours to complete, with as many breaks as you like.

All the information you provide will remain confidential if it is not harmful to others.

Your partner may also be invited to take part and will be asked about the impact that the changes in your sexual desire have had upon them, and to fill in some questionnaires. This may take up to one hour to complete.

Interviews will be conducted using a Dictaphone to allow for better concentration on the discussion rather than note taking. The recorded material will only be used in writing up the case study, which will be done almost immediately, and will not be passed on. The recorded material will be deleted at the end of transcription.

No treatment will be withheld because you are taking part in the study.

You are free to withdraw at any time without giving a reason. This would not affect the standard of care you receive.

5. Expenses and payments

We should be able to pay reasonable travel expenses that you may incur upon being given a receipt for the journey.

6. What are the possible disadvantages and risks of taking part?

As the research is focused on sexual behaviour, the interviews may focus on topics felt to be sensitive and/or potentially embarrassing. You can refuse to answer any of the questions or stop participating at any time, and this will not affect your medical care. If you disclose any behaviour that is deemed to be risky to you, or to others, this information will be shared with your medical consultant and GP, as is routine clinical practice. The law requires us to report to the authorities acts of physical harm to others, and child abuse.

Participant Information Sheet

Chief Investigator: Dr Jalesh

Panicker

Participant Identification Number:

The National Hospital for Neurology and Neurosurgery

Queen Square, London

WC1N 3BG

In the case that you become uncomfortable, anxious, or distressed, you will be given the opportunity to take a break or stop your participation entirely. You may also choose to seek support and are free to contact either Dr Jennifer Foley, a consultant neuropsychologist, or Dr Caroline Selai, a chartered health psychologist, whose contact details are listed at the end of this document.

7. What are the possible benefits of taking part?

We know that the study will not be of help to you, but we hope that the information we gain will help us improve our care for people with neurological disorders. It is hoped that this research will inform (1) our understanding of the predisposing, precipitating, and prolonging factors involved in the development of hypersexuality, to reveal predictors of the disorder; and (2) the development of a psychological intervention for people affected by hypersexuality, to reduce distress and promote wellbeing.

8. What happens when the research study stops?

You will be advised that you will have the opportunity to receive a copy of the study's findings. The findings will only be described on a group basis – all data will be completely anonymous and it will not be possible to identify any individual.

9. What if there are any problems?

If you have any concerns about your participation in the study, please contact a member of the research team (see contact details at the end). We will do our best to answer your questions or concerns. If you are not satisfied with this you can make a formal complaint to the Patient Advice and Liaison Service. Postal addresses are: PALS, Ground Floor Atrium, University College Hospital, 235 Euston Road, London, NW1 2BU or PALS, Box 25, National Hospital for Neurology and Neurosurgery, Queen Square, London, WC1N 3BG. You may also choose to visit their offices at UCH on the ground floor atrium between 9:00 and 16:00 Monday to Friday (excluding public holidays), 02034473042 or at the NHNN next to Basil Samuels Outpatients Department between the hours of 8:00 and 18:00 on Mondays, 9:00 and 17:00 on Tuesdays and 8:00 to 18:00 on Wednesdays, 02034483237.

Email : PALS@uclh.nhs.uk

In the unlikely event that taking part in this study harms you, you may be able to claim compensation. After discussing with a member of the team, please make the claim in writing to Dr Jalesh Panicker who is the Chief Investigator for this study and

University College London Hospitals

NHS Foundation Trust

Participant Information Sheet

Chief Investigator: Dr Jalesh Panicker

The National Hospital for Neurology and Neurosurgery
Queen Square, London
WC1N 3BG

Participant Identification Number:

is based at The National Hospital for Neurology and Neurosurgery. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's

office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

Further, if you were to become unexpectedly distressed and/or anxious during the course of the interviews or questionnaires, you will be given the opportunity to take a break or stop your participation entirely. You may also choose to contact Dr. Jennifer A. Foley, a consultant neuropsychologist, or Dr. Caroline Selai, a chartered health psychologist, whose contact details are listed at the end of this document.

10. Will my taking part in the study be kept confidential?

Your GP will be told that you have decided to take part in this study. Your health records will remain strictly confidential at all times. To enhance confidentiality, all data collected will be labeled with a unique identification number rather than your name, and only suitably qualified and authorized people will be able to link this code number with your personal details. However, these may need to be made available to other neuropsychologists, UCLH and UCL research and development monitors, and the Independent Ethics Committee members.

By signing the consent form you agree to this access. However, we will take steps to protect your personal information and will not include your name on any forms, reports, and publications or in any future disclosures. If you withdraw from the study or in the unlikely event that you should lose capacity to consent during the study, we will no longer collect any data from you. The data already collected will be retained and used in the research.

If you consent to take part in this study, the records obtained while you are in this study as well as related health records will remain strictly confidential at all times. The information will be held securely on paper and electronically at The National Hospital for Neurology and Neurosurgery/Institute of Neurology under the provisions of the 1998 Data Protection Act. Your name will not be passed to anyone else outside the research team or the UCL, who is not involved in the study. Any information about you that leaves the hospital, surgery or institute will have your name and address removed so that you cannot be recognized.

Participant Information Sheet

Chief Investigator: Dr Jalesh Panicker

The National Hospital for Neurology and Neurosurgery
Queen Square, London
WC1N 3BG

Participant Identification Number:

In line with the regulations, at the end of the study your data will be securely archived for a minimum of 20 years. Arrangements for confidential destruction will then be made.

You have the right to check the accuracy of data held about you and correct any errors.

11. What if relevant new information becomes available?

Sometimes we get new information about the issue being investigated. If this happens, we will tell you about it and discuss whether you want to or should continue in the study. If you decide to continue in the study we will ask you to sign an updated consent form. It is also possible that upon receiving new information, we might consider it to be in your best interests to withdraw from the study. If so, we will explain the reasons and this will have no effect on your standard medical care. The same applies in the case that the study stops for whatever reason. Other instances where early termination from the study can occur is in the case that you become unexpectedly distressed during the course of the interviews or questionnaires. If this does happen, you will be given the opportunity to take a break or stop your participation entirely. You may also choose to contact Dr. Jennifer A. Foley, a consultant neuropsychologist, whose contact details are listed at the end of this document.

12. Who is organising and funding the research?

This research is being conducted in fulfillment of a research degree, which is being sponsored by University College London. The investigators involved in this research will not be paid for taking part in this study.

13. Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the NHS Research Ethics Committee.

14. Further information and contact details

You are encouraged to ask any questions you wish, before, during or after your study participation. If you decide you would like to take part then please read and sign the consent form. You will be given a copy of this information sheet and signed consent form to keep. A copy of the consent form will be filed in the study records and one may be sent to the Research Sponsor.

University College London Hospitals

NHS Foundation Trust

Participant Information Sheet

Chief Investigator: Dr Jalesh

Panicker

Participant Identification Number:

The National Hospital for Neurology and Neurosurgery

Queen Square, London

WC1N 3BG

Thank you for taking the time to read this information sheet and to consider this study. If you have any questions, please feel free to contact a member of the research team by either phone (07455002488) or email.

Dr. Jalesh N. Panicker
Consultant Neurologist
(Chief Investigator)
j.panicker@ucl.ac.uk

Dr. Jennifer A. Foley
Consultant Neuropsychologist
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Dr. Caroline Selai
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Natalie Tayim
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skgttay@live.ucl.ac.uk

Participant Information Sheet

Chief Investigator: Dr Jalesh

Panicker

Participant Identification Number:

The National Hospital for Neurology and Neurosurgery

Queen Square, London

WC1N 3BG

Hypersexuality in Neurological Disorders***Parkinson's disease carers***

We would like to invite you to take part in our research study. Before you decide whether or not to take part, it is important that you understand why the research is being done and what it would involve for you. One of our team members will go through this information sheet with you and answer any questions you may have. Please take time to read this thoroughly and ask if there is anything that is unclear or if you would like more information.

1. What is the purpose of the study?

Neurological disorders can sometimes be associated with changes in the desire for sex. In some disorders, the desire for sex can increase, but in others, desire for sex can decrease. This can cause significant problems for some patients and their partners/carers. However, because this is such a sensitive topic, such problems are often underreported.

This study seeks to further our understanding of this important issue, and hopefully lead to improved treatment. This will be done by investigating (1) the prevalence of any changes in sexual desire in neurological disorders; (2) the physical, psychological and cognitive factors associated with such changes; and (3) the impact of these on the patient and their carer.

2. Why have I been invited?

The patient has already completed the initial screening questionnaire and has indicated that there is a problem they would like discussed further.

3. Do I have to take part?

Your participation in this study is voluntary. It is up to you to decide whether or not to take part. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time without giving a reason. This would not affect the standard of care the patient receives.

Participant Information Sheet

Chief Investigator: Dr Jalesh

Panicker

Participant Identification Number:

The National Hospital for Neurology and Neurosurgery

Queen Square, London

WC1N 3BG

4. What will happen to me if I take part?

This study aims to understand the changes in sexual behaviour that may occur in Parkinson's disease and the impact this has on you. This will be done using semi-structured interview and questionnaires.

You will be asked some general questions about the patient's health (including their Parkinson's disease) and their sexual behavior. You will then be asked about how the patient's changed sexual behavior has affected you. You will be interviewed and asked to complete some questionnaires.

In total, this may take up to an hour to complete, with as many breaks as you like.

Interviews will be conducted using a Dictaphone to allow for better concentration on the discussion rather than note taking. The recorded material will only be used in writing up the case study, which will be done almost immediately, and will not be passed on. The recorded material will be deleted at the end of transcription.

No treatment will be withheld from the patient because you are taking part in the study.

You are free to withdraw at any time without giving a reason. This would not affect the standard of care the patient receives.

5. Expenses and payments

We should be able to pay reasonable travel expenses that you may incur upon being given a receipt for the journey.

6. What are the possible disadvantages and risks of taking part?

As the research is focused on sexual behaviour, the interviews may focus on topics felt to be sensitive and/or potentially embarrassing. You can refuse to answer any of the questions or stop participating at any time, and this will not affect the patient's medical care. If you disclose any behavior that is deemed to be risky to you, to others, or to the patient themselves, this information will be shared with the patient's medical consultant and GP, as is routine clinical practice. The law requires us to report to the authorities acts of physical harm to others, and child abuse.

In the case that you become uncomfortable, anxious, or distressed, you will be given the opportunity to take a break or stop your participation entirely. You may also

Participant Information Sheet

Chief Investigator: Dr Jalesh

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choose to seek support and are free to contact either Dr. Jennifer Foley, a consultant neuropsychologist, or Dr. Caroline Selai, a chartered health psychologist, whose contact details are listed at the end of this document.

7. What are the possible benefits of taking part?

We know that the study will not be of help to you, but we hope that the information we gain will help us improve our care for people with neurological disorders and their carers. It is hoped that this research will inform (1) our understanding of the predisposing, precipitating, and prolonging factors involved in the development of hypersexuality, to reveal predictors of the disorder; and (2) the development of a psychological intervention for people affected by hypersexuality, to reduce distress and promote wellbeing.

8. What happens when the research study stops?

You will be advised that you will have the opportunity to receive a copy of the study's findings. The findings will only be described on a group basis – all data will be completely anonymous and it will not be possible to identify any individual.

9. What if there are any problems?

If you have any concerns about your participation in the study, please contact a member of the research team (see contact details at the end). We will do our best to answer your questions or concerns. If you are not satisfied with this you can make a formal complaint to the Patient Advice and Liaison Service. Postal addresses are: PALS, Ground Floor Atrium, University College Hospital, 235 Euston Road, London, NW1 2BU or PALS, Box 25, National Hospital for Neurology and Neurosurgery, Queen Square, London, WC1N 3BG. You may also choose to visit their offices at UCH on the ground floor atrium between 9:00 and 16:00 Monday to Friday (excluding public holidays), 02034473042 or at the NHNN next to Basil Samuels Outpatients Department between the hours of 8:00 and 18:00 on Mondays, 9:00 and 17:00 on Tuesdays and 8:00 to 18:00 on Wednesdays, 02034483237.

Email : PALS@uclh.nhs.uk

In the unlikely event that taking part in this study harms you, you may be able to claim compensation. After discussing with a member of the team, please make the claim in writing to Dr Jalesh Panicker who is the Chief Investigator for this study and is based at The National Hospital for Neurology and Neurosurgery. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's

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Participant Information Sheet

Chief Investigator: Dr Jalesh Panicker

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office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

Furthermore, in the case that you become uncomfortable, anxious, or distressed, you will be given the opportunity to take a break or stop your participation entirely. You may also choose to seek support and are free to contact either Dr. Jennifer Foley, a consultant neuropsychologist, or Dr. Caroline Selai, a chartered health psychologist, whose contact details are listed at the end of this document.

10. Will my taking part in the study be kept confidential?

Yes. Ethical and legal practice will be followed and all information about you will be handled in confidence. To enhance confidentiality, all data collected will be labeled with a unique identification number rather than your name, and only suitably qualified and authorized people will be able to link this code number with your personal details. However, these may need to be made available to other neuropsychologists, UCLH and UCL research and development monitors, and the Independent Ethics Committee members.

By signing the consent form you agree to this access. However, we will take steps to protect your personal information and will not include your name on any forms, reports, and publications or in any future disclosures. If you withdraw from the study or in the unlikely event that you should lose capacity to consent during the study, we will no longer collect any data from you. The data already collected will be retained and used in the research.

If you consent to take part in this study, the records obtained while you are in this study as well as related health records will remain strictly confidential at all times. The information will be held securely on paper and electronically at The National Hospital for Neurology and Neurosurgery/Institute of Neurology under the provisions of the 1998 Data Protection Act. Your name will not be passed to anyone else outside the research team or the UCL, who is not involved in the study. Any information about you that leaves the hospital, surgery or institute will have your name and address removed so that you cannot be recognized.

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You have the right to check the accuracy of data held about you and correct any errors.

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11. What if relevant new information becomes available?

Sometimes we get new information about the issue being investigated. If this happens, we will tell you about it and discuss whether you want to or should continue in the study. If you decide to continue in the study we will ask you to sign an updated consent form. It is also possible that upon receiving new information, we might consider it to be in your best interests to withdraw from the study. If so, we will explain the reasons and this will have no effect on the patient's standard medical care. The same applies in the case that the study stops for whatever reason.

12. Who is organising and funding the research?

This research is being conducted in fulfillment of a research degree, which is being sponsored by University College London. The investigators involved in this research will not be paid for taking part in this study.

13. Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the NHS Research Ethics Committee.

14. Further information and contact details

You are encouraged to ask any questions you wish, before, during or after your study participation. If you decide you would like to take part then please read and sign the consent form. You will be given a copy of this information sheet and signed consent form to keep. A copy of the consent form will be filed in the study records and one may be sent to the Research Sponsor.

Thank you for taking the time to read this information sheet and to consider this study. If you have any questions, please feel free to contact a member of the research team by either phone (07455002488) or email.

Dr. Jalesh N. Panicker
Consultant Neurologist
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Dr. Jennifer A. Foley
Consultant Neuropsychologist
jennifer.foley@uclh.nhs.uk

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Participant Information Sheet

Chief Investigator: Dr Jalesh

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Dr. Caroline Selai

Chartered Health Psychologist

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Natalie Tayim

Research student

skgttay@live.ucl.ac.uk

Participant Information Sheet

Chief Investigator: Dr Jalesh

Panicker

Participant Identification Number:

The National Hospital for Neurology and Neurosurgery

Queen Square, London

WC1N 3BG

Hypersexuality in Neurological Disorders***Frontotemporal dementia and Alzheimer's disease carers***

We would like to invite you to take part in our research study. Before you decide whether or not to take part, it is important that you understand why the research is being done and what it would involve for you. One of our team members will go through this information sheet with you and answer any questions you may have. Please take time to read this thoroughly and ask if there is anything that is unclear or if you would like more information.

1. What is the purpose of the study?

Neurological disorders can sometimes be associated with changes in the desire for sex. In some disorders, the desire for sex can increase, but in others, desire for sex can decrease. This can cause significant problems for some patients and their partners/carers. However, because this is such a sensitive topic, such problems are often underreported.

This study seeks to further our understanding of this important issue, and hopefully lead to improved treatment. This will be done by investigating (1) the prevalence of any changes in sexual desire in neurological disorders; (2) the physical, psychological and cognitive factors associated with such changes; and (3) the impact of these on the patient and their carer.

2. Why have I been invited?

You have already completed the initial screening questionnaire and have indicated that there is a problem you would like discussed further.

3. Do I have to take part?

Your participation in this study is voluntary. It is up to you to decide whether or not to take part. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time without giving a reason. This would not affect the standard of care the patient receives.

Participant Information Sheet

Chief Investigator: Dr Jalesh

Panicker

Participant Identification Number:

The National Hospital for Neurology and Neurosurgery

Queen Square, London

WC1N 3BG

4. What will happen to me if I take part?

This study aims to understand the changes in sexual behaviour that may occur in dementia and the impact this has on you. This will be done using a semi-structured interview and questionnaires.

You will be asked some general questions about the patient's health (including their dementia) and their sexual behavior. You will then be asked about how the patient's changed sexual behavior has affected you. You will be interviewed and asked to complete some questionnaires.

In total, this may take up to an hour to complete, with as many breaks as you like.

Interviews will be conducted using a Dictaphone to allow for better concentration on the discussion rather than note taking. The recorded material will only be used in writing up the case study, which will be done almost immediately, and will not be passed on. The recorded material will be deleted at the end of transcription.

No treatment will be withheld from the patient because you are taking part in the study.

You are free to withdraw at any time without giving a reason. This would not affect the standard of care the patient receives.

5. Expenses and payments

We should be able to pay reasonable travel expenses that you may incur upon being given a receipt for the journey.

6. What are the possible disadvantages and risks of taking part?

As the research is focused on sexual behaviour, the interviews may focus on topics felt to be sensitive and/or potentially embarrassing. You can refuse to answer any of the questions or stop participating at any time, and this will not affect the patient's medical care. If you disclose any behavior that is deemed to be risky to you, to others, or to the patient themselves, this information will be shared with the patient's medical consultant and GP, as is routine clinical practice. The law requires us to report to the authorities acts of physical harm to others, and child abuse.

University College London Hospitals

NHS Foundation Trust

Participant Information Sheet

Chief Investigator: Dr Jalesh

Panicker

Participant Identification Number:

The National Hospital for Neurology and Neurosurgery

Queen Square, London

WC1N 3BG

In the case that you become uncomfortable, anxious, or distressed, you will be given the opportunity to take a break or stop your participation entirely. You may also choose to seek support and are free to contact either Dr. Jennifer Foley, a consultant neuropsychologist, or Dr. Caroline Selai, a chartered health psychologist, whose contact details are listed at the end of this document.

7. What are the possible benefits of taking part?

We know that the study will not be of help to you, but we hope that the information we gain will help us improve our care for people with neurological disorders and their carers. It is hoped that this research will inform (1) our understanding of the predisposing, precipitating, and prolonging factors involved in the development of hypersexuality, to reveal predictors of the disorder; and (2) the development of a psychological intervention for people affected by hypersexuality, to reduce distress and promote wellbeing.

8. What happens when the research study stops?

You will be advised that you will have the opportunity to receive a copy of the study's findings. The findings will only be described on a group basis – all data will be completely anonymous and it will not be possible to identify any individual.

9. What if there are any problems?

If you have any concerns about your participation in the study, please contact a member of the research team (see contact details at the end). We will do our best to answer your questions or concerns. If you are not satisfied with this you can make a formal complaint to the Patient Advice and Liaison Service. Postal addresses are: PALS, Ground Floor Atrium, University College Hospital, 235 Euston Road, London, NW1 2BU or PALS, Box 25, National Hospital for Neurology and Neurosurgery, Queen Square, London, WC1N 3BG. You may also choose to visit their offices at UCH on the ground floor atrium between 9:00 and 16:00 Monday to Friday (excluding public holidays), 02034473042 or at the NHNN next to Basil Samuels Outpatients Department between the hours of 8:00 and 18:00 on Mondays, 9:00 and 17:00 on Tuesdays and 8:00 to 18:00 on Wednesdays, 02034483237.

Email : PALS@uclh.nhs.uk

In the unlikely event that taking part in this study harms you, you may be able to claim compensation. After discussing with a member of the team, please make the

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Panicker

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WC1N 3BG

claim in writing to Dr Jalesh Panicker who is the Chief Investigator for this study and is based at The National Hospital for Neurology and Neurosurgery. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

Furthermore, in the case that you become uncomfortable, anxious, or distressed, you will be given the opportunity to take a break or stop your participation entirely. You may also choose to seek support and are free to contact either Dr. Jennifer Foley, a consultant neuropsychologist, or Dr. Caroline Selai, a chartered health psychologist, whose contact details are listed at the end of this document.

10. Will my taking part in the study be kept confidential?

Yes. Ethical and legal practice will be followed and all information about you will be handled in confidence. To enhance confidentiality, all data collected will be labeled with a unique identification number rather than your name, and only suitably qualified and authorized people will be able to link this code number with your personal details. However, these may need to be made available to other neuropsychologists, UCLH and UCL research and development monitors, and the Independent Ethics Committee members.

By signing the consent form you agree to this access. However, we will take steps to protect your personal information and will not include your name on any forms, reports, and publications or in any future disclosures. If you withdraw from the study or in the unlikely event that you should lose capacity to consent during the study, we will no longer collect any data from you. The data already collected will be retained and used in the research.

If you consent to take part in this study, the records obtained while you are in this study as well as related health records will remain strictly confidential at all times.

The information will be held securely on paper and electronically at The National Hospital for Neurology and Neurosurgery/Institute of Neurology under the provisions of the 1998 Data Protection Act. Your name will not be passed to anyone else outside the research team or the UCL, who is not involved in the study. Any information

University College London Hospitals

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Participant Information Sheet

Chief Investigator: Dr Jalesh

Panicker

Participant Identification Number:

The National Hospital for Neurology and Neurosurgery

Queen Square, London

WC1N 3BG

about you that leaves the hospital, surgery or institute will have your name and address removed so that you cannot be recognized.

In line with the regulations, at the end of the study your data will be securely archived for a minimum of 20 years. Arrangements for confidential destruction will then be made.

You have the right to check the accuracy of data held about you and correct any errors.

11. What if relevant new information becomes available?

Sometimes we get new information about the issue being investigated. If this happens, we will tell you about it and discuss whether you want to or should continue in the study. If you decide to continue in the study we will ask you to sign an updated consent form. It is also possible that upon receiving new information, we might consider it to be in your best interests to withdraw from the study. If so, we will explain the reasons and this will have no effect on the patient's standard medical care. The same applies in the case that the study stops for whatever reason.

12. Who is organising and funding the research?

This research is being conducted in fulfillment of a research degree, which is being sponsored by University College London. The investigators involved in this research will not be paid for taking part in this study.

13. Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the NHS Research Ethics Committee.

14. Further information and contact details

You are encouraged to ask any questions you wish, before, during or after your study participation. If you decide you would like to take part then please read and sign the consent form. You will be given a copy of this information sheet and signed consent form to keep. A copy of the consent form will be filed in the study records and one may be sent to the Research Sponsor.

University College London Hospitals

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Participant Information Sheet

Chief Investigator: Dr Jalesh
Panicker

The National Hospital for Neurology and Neurosurgery
Queen Square, London
WC1N 3BG

Participant Identification Number:

Thank you for taking the time to read this information sheet and to consider this study. If you have any questions, please feel free to contact a member of the research team by either phone (07455002488) or email.

Dr. Jalesh N. Panicker
Consultant Neurologist
(Chief Investigator)
j.panicker@ucl.ac.uk

Dr. Jennifer A. Foley
Consultant Neuropsychologist
jennifer.foley@uclh.nhs.uk

Dr. Caroline Selai
Chartered Health Psychologist
c.selai@ucl.ac.uk

Natalie Tayim
Research student
skgttay@live.ucl.ac.uk

Informed Consent Form

Chief Investigator: Dr Jalesh Panicker

The National Hospital for Neurology and Neurosurgery

Patient Identification Number:

Queen Square, London

Date:

WC1N 3BG

Hypersexuality in Neurological Disorders*Parkinson's disease patients*

1. I confirm that I have read and understand the information sheet version _____ and dated _____ for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I confirm that I have had sufficient time to consider whether or not I want to be included in the study.
3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
4. I understand that relevant sections of data collected during the study may be looked at by the study investigators, individuals from the sponsor of the trial (University College London) and responsible persons authorised by the sponsor, from regulatory authorities, or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
5. I agree that in the unlikely event that I should lose capacity to consent during the study or choose to withdraw from the study, my data already collected will be retained and will not be shared with anyone other than those mentioned in the previous point. I understand that this data will be anonymized.
6. I agree that in the unlikely event that I should lose capacity to consent during the study or choose to withdraw from the study, anonymized data already collected will be used in the research.
7. I agree that my GP be informed about the study.
8. I agree to having a Dictaphone record conversations with the researchers.
9. I allow the researcher to use verbatim quotations that will not be identifiable to anyone outside of the direct research team.
10. I understand that the law requires researchers to report to the authorities acts of physical harm to others and/or child abuse.
11. I agree to take part in the study.

Name of study participant_____
Date_____
Signature

University College London Hospitals



NHS Foundation Trust

Informed Consent Form

Chief Investigator: Dr Jalesh Panicker

The National Hospital for Neurology and Neurosurgery

Patient Identification Number:

Queen Square, London

Date:

WC1N 3BG

Name of person taking consent

Date

Signature

Comments or concerns during the study: If you have any comments or concerns you may discuss these with the investigator. If you wish to go further and complain about any aspect of the way you have been approached or treated while partaking in the study, you should write or get in touch with the Complaints Manager, UCL hospitals.

When completed: 1 form for the participant; 1 to be kept as part of the study documentation

Informed Consent Form

Chief Investigator: Dr Jalesh Panicker

Patient Identification Number:

Date:

The National Hospital for Neurology and Neurosurgery

Queen Square, London

WC1N 3BG

Hypersexuality in Neurological Disorders*Parkinson's disease carers*

1. I confirm that I have read and understand the information sheet version _____ and dated _____ for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I confirm that I have had sufficient time to consider whether or not I want to be included in the study.
3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without the patient's medical care or legal rights being affected.
4. I understand that relevant sections of data collected during the study may be looked at by the study investigators, individuals from the sponsor of the trial (University College London) and responsible persons authorised by the sponsor, from regulatory authorities, or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
5. I agree that in the unlikely event that I choose to withdraw from the study my data already collected will be retained and will not be shared with anyone other than those mentioned in the previous point. I understand that this data will be anonymized.
6. I agree that in the unlikely event that I choose to withdraw from the study, anonymized data already collected will be used in the research.
7. I agree to having a Dictaphone record conversations with the researchers.
8. I allow the researcher to use verbatim quotations that will not be identifiable to anyone outside of the direct research team.
9. I understand that the law requires researchers to report to the authorities acts of physical harm to others and/or child abuse.
10. I agree to take part in the study.

Name of study participant_____
Date_____
Signature

University College London Hospitals

NHS Foundation Trust

Informed Consent Form

Chief Investigator: Dr Jalesh Panicker

Patient Identification Number:

Date:

The National Hospital for Neurology and Neurosurgery

Queen Square, London

WC1N 3BG

Name of person taking consent

Date

Signature

Comments or concerns during the study: If you have any comments or concerns you may discuss these with the investigator. If you wish to go further and complain about any aspect of the way you have been approached or treated while partaking in the study, you should write or get in touch with the Complaints Manager, UCL hospitals.

When completed: 1 form for the participant; 1 to be kept as part of the study documentation

Informed Consent Form

Chief Investigator: Dr Jalesh Panicker
 Patient Identification Number:
 Date:

NHS Foundation Trust

The National Hospital for Neurology and Neurosurgery
 Queen Square, London
 WC1N 3BG

Hypersexuality in Neurological Disorders***Frontotemporal dementia and Alzheimer's disease carers***

1. I confirm that I have read and understand the information sheet version _____ and dated _____ for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I confirm that I have had sufficient time to consider whether or not I want to be included in the study.
3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without the patient's medical care or legal rights being affected.
4. I understand that relevant sections of data collected during the study may be looked at by the study investigators, individuals from the sponsor of the trial (University College London) and responsible persons authorised by the sponsor, from regulatory authorities, or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
5. I agree that in the unlikely event that I choose to withdraw from the study my data already collected will be retained and will not be shared with anyone other than those mentioned in the previous point. I understand that this data will be anonymized.
6. I agree that in the unlikely event that I choose to withdraw from the study, anonymized data already collected will be used in the research.
7. I agree to having a Dictaphone record conversations with the researchers.
8. I allow the researcher to use verbatim quotations that will not be identifiable to anyone outside of the direct research team.
9. I understand that the law requires researchers to report to the authorities acts of physical harm to others and/or child abuse.
10. I agree to take part in the study.

 Name of study participant

 Date

 Signature

 Name of person taking consent

 Date

 Signature

University College London Hospitals

Informed Consent Form

Chief Investigator: Dr Jalesh Panicker

Patient Identification Number:

Date:

NHS Foundation Trust

The National Hospital for Neurology and Neurosurgery
Queen Square, London
WC1N 3BG

Comments or concerns during the study: If you have any comments or concerns you may discuss these with the investigator. If you wish to go further and complain about any aspect of the way you have been approached or treated while partaking in the study, you should write or get in touch with the Complaints Manager, UCL hospitals.

When completed: 1 form for the participant; 1 to be kept as part of the study documentation

Letter to the GP

REC Study Number:		Date:
Patient Number:		

Dear Dr.

I am writing to inform you that your patient has expressed an interest in taking part in a study entitled “Hypersexuality in neurological disorders”. This study is aimed at assessing the phenomenology and impact of hypersexuality in patients with neurological disorders.

I am enclosing a copy of the participant information leaflet. For the period of this study I will be grateful if you could inform me, should you see the patient at your surgery for any reason.

If you have any concerns or comments regarding this participation please feel free to contact Natalie Tayim, the research student (07455002488; skgttay@live.ucl.ac.uk) or any of the following individuals of the research team at the contact details provided below:

Dr. Jalesh N. Panicker
 Consultant Neurologist
 j.panicker@ucl.ac.uk
 020 3448 4713

Dr. Jennifer A. Foley
 Consultant Neuropsychologist
 jennifer.foley@uclh.nhs.uk
 020 3448 4713

Dr. Caroline Selai
 Chartered Health Psychologist
 c.selai@ucl.ac.uk

Yours Sincerely,

Dr. Jalesh N. Panicker

Patient scale scores and descriptives

Scale (n)	P 1	P 2	P 3	P 4	P 5	P 6	P 7	P 8	P 9	Total mean (SD) (Range)
MMSE (9)	28	30	27	29	30	29	30	30	30	29.22 (1.09) (27.00 – 30.00)
QUIP (9)										
Impulse Control Disorder										
Compulsive gambling	2	0	0	0	0	0	0	0	0	0.22 (0.67) (0.00 – 2.00)
Compulsive sexual behaviour	3	3	2	2	2	5	3	3	5	3.11 (1.17) (2.00 – 5.00)
Compulsive eating	2	0	0	5	0	2	5	0	0	1.33 (1.73) (0.00 – 5.00)
Compulsive buying	3	0	0	0	1	2	1	0	5	1.56 (2.13) (0.00 – 5.00)
Other Behaviors										
Hobbyism	1	1	1	1	1	1	0	0	0	0.67 (0.50) (0.00 – 1.00)
Punding	1	1	1	1	0	0	0	0	0	0.44 (0.53) (0.00 – 1.00)
Walkabout	0	0	0	0	0	0	0	0	0	0.00 (0.00) (0.00 – 0.00)
Medication use	0	0	0	0	0	0	0	0	0	0.00 (0.00) (0.00 – 0.00)
SAST-R (8)										
Core item	15	5	6	0	4	15	NA	2	9	7.00 (5.61) (0.00 – 15.00)
Addiction dimension										
Preoccupation	4	0	3	2	1	2	NA	0	2	1.75 (1.39) (0.00 – 4.00)
Loss of control	3	1	1	0	1	4	NA	1	2	1.63 (1.30) (0.00 – 4.00)
Relationship disturbance	1	2	1	0	1	4	NA	0	1	1.25 (1.28) (0.00 – 4.00)
Affect disturbance	5	1	0	0	1	4	NA	1	4	2.00 (2.00) (0.00 – 5.00)
URICA (8)	8.28	10.43	-0.14	7.72	3.42	8.43	NA	4.71	5.86	6.09 (3.37) (-0.14 – 8.43)
IEF (6)										

Patient scale scores and descriptives

Erectile function	21	30	29	-	-	8	-	10	18	19.33 (9.24) (8.00 – 30.00)
FSFI (2)										
Full	-	-	-	16.5	15.6	-	NA	-	-	16.05 (0.64) (15.60 – 16.50)
BIS-11 (8)	77	68	58	63	65	66	NA	55	73	65.63 (7.25) (55.00 – 77.00)
UPPS-P (8)	184	112	116	136	127	137	NA	82	158	131.50 (30.71) (82.00 – 184.00)
Sensation seeking (ssUPPS-P)	45	37	42	32	28	29	NA	18	37	33.50 (8.64) (18.00 – 45.00)
BIS/BAS (7)	65	64	74	74	61	56	NA	57	NA	64.43 (7.32) (56.00 – 74.00)
BIS	19	26	22	21	23	22	NA	25	NA	22.57 (2.37) (19.00 – 25.00)
BAS	46	38	52	53	38	34	NA	32	NA	41.86 (8.49) (32.00 – 53.00)
IRI (7)										
Perspective-taking	22	16	17	17	20	17	NA	19	NA	18.29 (2.14) (16.00 – 22.00)
Empathic concern	28	28	23	23	18	12	NA	11	NA	20.43 (7.00) (11.00 – 28.00)
Personal distress	16	15	13	3	20	16	NA	18	NA	14.43 (5.50) (3.00 – 20.00)
Fantasy	20	22	20	18	19	20	NA	10	NA	18.43 (3.91) (10.00 – 22.00)
RMET (7)	21	26	30	29	31	25	NA	17	NA	25.57 (5.09) (17.00 – 31.00)
PDQ-39 (7)	41.21	67.04	18.81	20.06	21.40	36.16	NA	31.31	NA	34.11 (18.61) (18.81 – 67.04)
NART (7)										
Full IQ	102	123	119	122	119	121	NA	113	NA	117.00 (7.37) (102.00 – 123.00)
RCPM (7)	24	35	32	33	26	31	NA	31	NA	30.29 (3.90) (24.00 – 35.00)
HSCT total score (7)	4	3	6	5	3	1	NA	6	NA	4.00 (1.83) (1.00 – 6.00)
HSCT converted score	28	27	2	3	20	23	NA	9	NA	16.00 (11.14) (2.00 – 28.00)
BSAT (7)	2	10	1	7	6	5	NA	4	NA	5.00 (3.06) (1.00 – 10.00)
Rule adherence	9	0	3	1	3	2	NA	0	NA	2.57 (3.10) (0.00 – 9.00)

Patient scale scores and descriptives

HADS (7)

Anxiety	13	9	2	9	9	8	NA	7	NA	8.14 (3.29) (2.00 – 13.00)
Depression	3	7	2	7	7	6	NA	9	NA	5.86 (2.48) (2.00 – 9.00)

BIS-11: Barratt Impulsiveness Scale; BIS/BAS: Behavioral Inhibition System/Behavioral Activation System; BSAT: Brixton Spatial Anticipation Task; FSFI: Female Sexual Function Index; HADS: Hospital Anxiety and Depression Scale; HSCT: Hayling Sentence Completion Task; IIEF: International Index of Erectile Function; IRI: Interpersonal Reactivity Index; MMSE: Mini Mental State Exam; NA: not available; NART: National Adult Reading Test; PDQ-39: Parkinson's Disease Quality of Life Questionnaire-39; QUIP: Parkinson's Disease Impulsive-Compulsive Disorders Questionnaire; RCPM: Raven's Colored Progressive Matrices; RMET: Reading the Mind in the Eyes Test; SAST-R: Sexual Addiction Screening Test-Revised; SD: standard deviation; ssUPPS-P: Sensation Seeking scale of UPPS-P; UPPS-P: UPPS-P Impulsive Behavior Scale; URICA: University of Rhode Island Change Assessment Scale.

-. Signifies patient was not eligible to complete questionnaire.

NA. Signifies patient did not complete respective assessment tool.

Normality analysis and single sample t-test results for the questionnaires without cut off scores or categorical measures

Domain (questionnaire)	Study sample			Normative data samples			Single sample t-test results
	Mean score (SD)	Mean age (SD)	Normality analysis results <i>(Shapiro-Wilk test)</i>	Sample	Mean score (SD)	Mean age (SD)	
Impulsivity (UPPS-P)	131.50 (30.71)	62.13 (11.63)	$W(8) = 0.98, p = .97, ns$	Individuals with CSB ⁽¹²⁴⁾	151.72 (18.33)	28.5 (8.57)	$t(7) = -1.86, p = .11, ns$
				Healthy controls ⁽¹²⁴⁾	129.27 (22.94)	27.88 (7.52)	$t(7) = 0.21, p = .84, ns$
Risk-taking (ssUPPS-P)	33.50 (8.64)	62.13 (11.63)	$W(8) = 0.97, p = .86, ns$	Pathological gamblers ⁽¹²⁵⁾	33.40 (5.90)	40.1 (12.3)	$t(7) = 0.03, p = .98, ns$
				Healthy controls ⁽¹²⁵⁾	34.70 (6.90)	35.8 (12.2)	$t(7) = -0.39, p = .71, ns$
Sensitivity to punishment and reward (BIS/BAS)							
Sensitivity to punishment (BIS)	22.57 (2.37)	61.43 (12.38)	$W(7) = 0.97, p = .89, ns$	PD patients ⁽¹²⁶⁾	19.20 (3.70)	57.7 (10.0)	$t(6) = 3.76, p = .009*$
				Healthy controls ⁽¹²⁶⁾	18.80 (3.20)	59.6 (7.1)	$t(6) = 4.21, p = .006*$
Sensitivity to reward (BAS)	41.86 (8.49)	61.43 (12.38)	$W(7) = 0.89, p = .30, ns$	PD patients ⁽¹²⁶⁾	40.80 (4.10)	57.7 (10.0)	$t(6) = 0.33, p = .75, ns$
				Healthy controls ⁽¹²⁶⁾	39.80 (3.70)	59.6 (7.1)	$t(6) = 0.64, p = .55, ns$
Quality of life (PDQ-39)	34.11 (18.61)	61.43 (12.38)	$W(7) = 0.85, p = .14, ns$	PD patients ⁽¹²⁷⁾	44.00 (15.85)	NA	$t(6) = -1.60, p = .16, ns$
Social cognition							
Empathy (IRI)							
Perspective- taking	18.29 (2.14)	61.43 (12.38)	$W(7) = 0.89, p = .26, ns$	Undergraduate students ⁽¹²⁸⁾	16.94 (4.95)	20.07 (1.9)	$t(6) = 1.67, p = .15, ns$
Empathic concern	20.43 (7.00)	61.43 (12.38)	$W(7) = 0.89, p = .26, ns$	Undergraduate students ⁽¹²⁸⁾	18.40 (4.71)	20.07 (1.9)	$t(6) = 0.77, p = .47, ns$
Personal distress	14.43 (5.50)	61.43 (12.38)	$W(7) = 0.83, p = .07, ns$	Undergraduate students ⁽¹²⁸⁾	12.23 (5.00)	20.07 (1.9)	$t(6) = 1.06, p = .33, ns$

Normality analysis and single sample t-test results for the questionnaires without cut off scores or categorical measures

Fantasy	18.43 (3.91)	61.43 (12.38)	$W(7) = 0.89, p = .26, ns$	Undergraduate students ⁽¹²⁸⁾	15.41 (5.62)	20.07 (1.9)	$t(6) = 2.04, p = .09, ns$
Social sensitivity and emotional perception (RMET)	25.57 (5.09)	61.43 (12.38)	$W(7) = 0.93, p = .53, ns$	PD patients ⁽¹²⁹⁾	20.59 (5.15)	57.97 (7.20)	$t(6) = 2.59, p = .041^*$
				Healthy controls ⁽¹²⁹⁾	23.40 (4.65)	56.32 (6.35)	$t(6) = 1.13, p = .30, ns$
General cognitive ability							
Current intellectual ability (RCPM)	30.29 (3.90)	61.43 (12.38)	$W(7) = 0.91, p = .39, ns$	PD patients ⁽¹³⁰⁾	27.78 (5.98)	62.25 (10.23)	$t(6) = 1.70, p = .14, ns$
				Healthy controls ⁽¹³⁰⁾	31.27 (3.90)	59.27 (1.98)	$t(6) = -0.67, p = .53, ns$

BAS: Behavioural Activation Scale; BIS: Behavioural Inhibition Scale; BIS/BAS: Behavioral Inhibition System/Behavioral Activation System; IRI: Interpersonal Reactivity Index; PDQ-39: Parkinson's Disease Quality of Life Questionnaire-39; RCPM: Raven's Colored Progressive Matrices; RMET: Reading the Mind in the Eyes Test; SD: standard deviation; ssUPPS-P: Sensation Seeking scale of UPPS-P; UPPS-P: UPPS-P Impulsive Behavior Scale

*. Statistically significant difference.

Carer scale scores and descriptives

Scale (n)	Carer 1	Carer 2	Carer 3	Carer 4	Carer 5	Carer 6	Carer 7	Carer 8	Total mean (SD) (Range)
HADS (8)									
Anxiety	2	9	8	7	11	9	4	17	8.38 (4.53) (2.00 – 17.00)
Depression	0	8	4	5	7	8	1	12	5.63 (3.96) (0.00 – 12.00)
AC-QoL (8)	60	52	33	99	55	38	84	50	58.88 (22.33) (33.00 – 99.00)
AC-QoL: Adult Carer Quality of Life Questionnaire; HADS: Hospital Depression and Anxiety Scale									

Triangulation: Impulse control disorders

Assessment tool	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5*	Patient 6	Patient 7*	Patient 8	Patient 9
Questionnaire (QUIP)	Gambling	Sexual behaviour	Sexual behaviour	Sexual behaviour	Sexual behaviour	Sexual behaviour	Sexual behaviour	Sexual behaviour	Sexual behaviour
	Sexual behaviour			Buying		Buying	Buying		Eating
	Buying					Eating			
	Eating								
Interview	Gambling	Sexual behaviour	Sexual behaviour	Sexual behaviour	Sexual behaviour	Sexual behaviour	Sexual behaviour	Sexual behaviour	Sexual behaviour
	Sexual behaviour			Buying	Eating**	Buying	Buying		Eating
	Buying					Eating	Eating**		
	Eating								
QUIP: Parkinson's Disease Impulsive-Compulsive Disorders Questionnaire *. Indicates which patients showed a disparity between assessment tools. **. Indicates the behaviour which has not been identified in both assessment tools.									

Triangulation: Preoccupation with sex

Assessment tool	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5*	Patient 6	Patient 7**	Patient 8	Patient 9
Questionnaire (SAST-R)	Preoccupied	Not preoccupied	Preoccupied	Preoccupied	Not preoccupied	Preoccupied	NA	Not preoccupied	Preoccupied
Interview	Preoccupied	Not preoccupied	Preoccupied	Preoccupied	Preoccupied	Preoccupied	NA	Not preoccupied	Preoccupied
SAST-R: Sexual Addiction Screening Test-Revised *. Indicates which patients showed a disparity between assessment tools. **. Indicates the patient who did not complete assessment tools.									

Triangulation: Loss of control over sex

Assessment tool	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5	Patient 6	Patient 7**	Patient 8	Patient 9*
Questionnaire (SAST-R)	Loss of control	No loss of control	No loss of control	No loss of control	No loss of control	Loss of control	NA	No loss of control	Loss of control
Interview	Loss of control	No loss of control	No loss of control	No loss of control	No loss of control	Loss of control	NA	No loss of control	No loss of control
SAST-R: Sexual Addiction Screening Test-Revised *. Indicates which patients showed a disparity between assessment tools. **. Indicates the patient who did not complete both assessment tools.									

Triangulation: Readiness for change

Assessment tool	Patient 1	Patient 2*	Patient 3	Patient 4	Patient 5	Patient 6	Patient 7**	Patient 8	Patient 9
Questionnaire (URICA)	C	C	PC	PC	PC	C	NA	PC	PC
Interview	C	PC	PC	PC	PC	C	NA	PC	PC
C: contemplation; PC: precontemplation; URICA: University of Rhode Island Change Assessment Scale *. Indicates which patients showed a disparity between assessment tools. **. Indicates the patient who did not complete both assessment tools.									

Triangulation: Patient 2 and Carer 2

Theme	Patient 2	Carer 2
Manifestation		
Desire Behavior*	Increased desire for wife Having sex more frequently	Increased desire for wife and generally “Rekindled” old behaviors such as swallowing, anal sex; wanted her to dress more suggestively and be more sexual; wanted to have sex with her while she was “sweaty” and “dirty”; inappropriately and inconveniently asked for blowjob
Preoccupation*	No	Yes
Compulsivity	No	No
Sexual practices		
With partner	Increased frequency when first became hypersexual then gradual decrease	Increased frequency when first became hypersexual then gradual decrease
With himself	Masturbation and use of pornographic materials	Masturbation and use of pornographic materials
With others	No	No, but threatens to leave her if she does not do what he wants of her sexually
Deviant practices	No	No
Control		
Loss of control*	No, has control	Yes, has no control
Attempt to reduce/stop	Yes, abstained from sex for wife, now better able to manage it	Yes, “I think he’s doing a good job in trying to keep a lid on it... it’s still there but more controlled...”
Desire to overcome*	No, has already overcome	Yes, has not overcome it yet
Impact		
Marital life	Negative effect	Negative effect
Family life	Negative effect	Negative effect
Social life*	No effect	Negative effect

Triangulation: Patient 2 and Carer 2

Work and daily activities	No effect	No effect
Finances	No effect	No effect
Health	No effect	No effect
Mood	Negative effect	Negative effect
Sleep*	No effect	Negative effect
Self-confidence*	Negative effect	Positive effect
Quality of life	Negative effect	Negative effect
*. Indicates the presence of a disparity between the answers of the patient and their carer for the respective item.		

Triangulation: Patient 5 and Carer 4

Theme	Patient 5	Carer 4
Manifestation		
Desire	Increased desire for husband and therapist	Increased desire for husband
Behavior	Having sex more frequently	Having sex more frequently; wanted to have sex on stairs; not too much foreplay
Preoccupation*	Yes	No
Compulsivity*	No	Yes
Sexual practices		
With partner	Increased frequency of sex with husband; watching pornography with husband	Increased frequency of sex with husband; enjoying watching pornography together; a hint of being sexually aggressive
With himself*	Masturbation	Use of pornographic materials
With others*	No	Yes, developed attraction to therapist; relationships with other women became more intense
Deviant practices	No	No
Control		
Loss of control*	No, has control	Yes, has no control
Attempt to reduce/stop*	No	Unsure
Desire to overcome*	No	Unsure
Impact		
Marital life*	Negative effect	No effect
Family life	No effect	No effect
Social life	No effect	No effect
Work and daily activities	Positive effect	Positive effect
Finances	No effect	No effect
Health	No effect	No effect

Triangulation: Patient 5 and Carer 4

Mood	Negative effect	Negative effect
Sleep	Negative effect	Negative effect
Self-confidence*	No effect	Positive effect
Quality of life*	Negative effect	Positive effect

*. Indicates the presence of a disparity between the answers of the patient and their carer for the respective item.

Triangulation: Patient 7 and Carer 3

Theme	Patient 7	Carer 3
Manifestation		
Desire	Insatiable increased desire to masturbate	Insatiable increased desire for husband and masturbation
Behavior	Increased masturbation	Increased masturbation
Preoccupation	NA**	Yes
Compulsivity	NA**	Yes
Sexual practices		
With partner*	Same frequency of sex with husband	Increased frequency of sex with husband
With himself	Uncontrollably masturbating and use of pornographic materials	Uncontrollably masturbating and use of pornographic materials
With others	No	No
Deviant practices	No	No
Control		
Loss of control	Yes, has no control	Yes, has no control
Attempt to reduce/stop	Yes, but not successful	Yes, but not successful
Desire to overcome	Yes	Yes
Impact		
Marital life*	No effect	Negative effect
Family life	No effect	No effect
Social life*	No effect	Negative effect
Work and daily activities	No effect	No effect
Finances	No effect	No effect
Health	No effect	No effect
Mood	Negative effect	Negative effect
Sleep*	No effect	Unsure
Self-confidence*	No effect	Negative effect

Triangulation: Patient 7 and Carer 3

Quality of life	Negative effect	Negative effect
*. Indicates the presence of a disparity between the answers of the patient and their carer for the respective item.		
**. Indicates the patient did not answer the corresponding question.		

Triangulation: Patient 8 and Carer 5

Theme	Patient 8	Carer 5
Manifestation		
Desire	Increased desire for sex with wife; an increased desire for wife to dress up in lingerie	Increased desire for sex with wife; an increased desire for wife to dress up in lingerie; increased desire for role-play; increased desire for sex more generally
Behavior*	Always been “highly sexed” but more intense now	Increased use of pornographic materials; use of sex phone lines; use of dating sites; pretending to be wife online to attract men; leaving sexual notes around the house
Preoccupation*	No	Yes
Compulsivity*	No	Yes
Sexual practices		
With partner	“Virtually nonexistent” frequency	No sex
With himself*	Masturbating on “very odd occasions”	Increased masturbation and use of pornographic materials
With others*	No	Yes, sex phone lines and messaging services
Deviant practices	No	No
Control		
Loss of control*	No, has control	Yes, has no control
Attempt to reduce/stop*	Yes, but only temporarily successful	No
Desire to overcome*	Yes	No
Impact		
Marital life*	No effect	Negative effect
Family life	No effect	No effect
Social life	No effect	No effect
Work and daily activities	No effect	No effect

Triangulation: Patient 8 and Carer 5

Finances	No effect	No effect
Health	No effect	No effect
Mood*	Negative effect	No effect
Sleep	No effect	No effect
Self-confidence*	Negative effect	No effect
Quality of life*	Negative effect	No effect

*. Indicates the presence of a disparity between the answers of the patient and their carer for the respective item.

Website Feedback Form

For each statement, please rate your satisfaction by placing an 'x'.

Statement	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
The website is easy to use.					
The website is informative.					
The information on the website is sufficient.					
The information on the website is clear.					
It would be helpful for patients with neurological disorders who have hypersexuality and their partners to have a look over this website.					
Overall, I am satisfied with this website.					
I would recommend this website for other patients and/or carers who need some information about hypersexuality in neurological disorders.					
Any further comments?					

Website content

Introduction

Some individuals with neurological disorders may notice a change in their desire for sex. In some cases, the desire for sex can increase, and this is called hypersexuality. Hypersexuality may cause significant problems for you, your partner, and others around you.

The following information is for patients with neurological disorders who have hypersexuality, and their partners.

What is hypersexuality?

An individual with hypersexuality experiences a change or increase in sexual thoughts, desires, and behaviors. Some of the things that they may experience include:

1. Difficulty resisting sexual desires
2. Increased frequency of sexual desires, thoughts, and/or behaviors
3. Developing new sexual desires, thoughts, and/or behaviors that were not present before the neurological disorder
4. Feeling preoccupied with sex, sometimes to the extent that it disrupts daily living
5. Continuing the sexual behavior despite the negative impact these are having
6. Feeling frustrated and annoyed when unable to engage in the desired sexual behavior

In what neurological disorders has hypersexuality been reported?

1. Parkinson's disease
2. Dementia
3. Epilepsy
4. Kluver-Bucy syndrome
5. Kleine-Levin syndrome
6. Traumatic brain injury
7. Multiple sclerosis
8. Restless legs syndrome
9. Progressive supranuclear palsy
10. Multiple system atrophy
11. Stroke
12. Huntington's disease
13. Encephalitis
14. Brain disease
15. Fatal familial insomnia
16. Tourette's syndrome
17. Spinocerebellar ataxia 3

After reading through the information on this website, you may feel like you want to further discuss the issue. Below are the contact details for two people at UCL who you can contact to discuss the issue. They are ready to talk to you and offer advice as is suitable to you. If any contact is made, please be assured that any correspondence will remain confidential unless otherwise requested by you.

Natalie Tayim
skgttay@ucl.ac.uk

Caroline Selai
c.selai@ucl.ac.uk

Website content

You may choose to click on the Contact Us tab, which will automatically take you to a contact form.

Hypersexuality in patients with neurological disorders

Why do individuals with neurological disorders become hypersexual?

The exact cause of hypersexuality remains uncertain; however, please be reassured that it is not your fault. Do not feel guilty or question yourself. Research shows that hypersexuality can present in individuals with neurological disease either as a manifestation of the neurological disorder itself, or as a result of certain treatments used to manage the disorder. For example, hypersexuality has been known to occur in individuals with dementia, during the course of the disease. In Parkinson's disease, hypersexuality has been known to occur and is thought to be related to some of the medications used to manage the disorder. Please be aware that this does not mean that the patient should stop taking their medications.

Please inform the patient's GP or neurologist about the changes experienced, and they will be able to assist accordingly.

How common is hypersexuality in different neurological disorders?

Although it is difficult at this point in time to say how common hypersexuality is in individuals with neurological disorders, please know that you are not alone in what you are experiencing. It is not an uncommon experience, and many others experience similar sexual changes and are affected by them.

How does hypersexuality manifest?

Individuals can be affected by the hypersexuality in different ways. Some of the things that may be noticed include:

1. An increased desire for sex with partner or otherwise
2. A change in sexual orientation
3. An increased desire to please oneself sexually
4. An increased desire for pornography and prostitutes
5. An increased desire for people and/or objects that the patient would not typically feel sexually attracted to
6. An increased desire to experiment sexually with partner or otherwise

These are only a few examples that could be experienced after developing hypersexuality. You should remain aware of the way these can affect you and those around you.

How can I talk about this when sex is such a taboo?

Sex was a taboo subject many years ago. A lot has changed since then. Cultures and societies have changed and it is now often easier to talk about sex. Although the discussion of this topic is still challenging to some people, sex and sexual identity are natural things. Stigmas are constructed by the world around us and attitudes can therefore change. If it is important to you to discuss sex and your sexual life, you should look for an opportunity to do so that will help you. You might feel hesitant at first opening up a discussion about the hypersexuality, but please be reassured that there are people available to talk to. As with any other health condition in the world, the sooner you take steps to talk about it, the sooner it can be discussed and managed.

How do I talk to the people in my life about the hypersexuality?

You might feel nervous about discussing the hypersexuality with your partner, your family, and/or your friends. You might also be worried about the consequences of such a discussion, especially if those around you are not aware of the extent of the hypersexuality. You might feel nervous because you do not want to cause them hurt. You might not want to feel embarrassment. You might even choose not to tell them because you are concerned that it could possibly put an end to your

Website content

hypersexuality. You must be aware, however, that not discussing the hypersexuality does not mean it does not exist in the eyes of the people closest to you. The people around you care about you and care about what you are going through. If you find that you need expert help, please be assured that you have access to professionals who can help through your GP.

What can I do if I find it difficult to find a health professional who can support me?

You will probably be under the care of a GP and as with all professionals, they may choose to seek additional help on the matter of hypersexuality. Since hypersexuality has only recently become more and more recognized, it may take a while to find someone with expertise who can help you. You might feel discouraged, embarrassed, and frustrated that you have not been able to access the help you want. Do not give up. Every patient can access health care through their GP. Please be reassured that many people are conducting research all over the world in search of more and more answers about hypersexuality to be able to help you and others experiencing this.

How do I get the appropriate help for the hypersexuality and its consequences?

You are not alone. You do not have to suffer alone. There are options for you to be able to speak only about your worries and feelings in a safe and supportive environment. Below are the contact details for two people at UCL who you can contact to discuss the issue. They are ready to talk to you and offer advice as is suitable for you. If any contact is made, please be assured that any correspondence will remain confidential unless otherwise requested by you.

Natalie Tayim
skgttay@ucl.ac.uk

Caroline Selai
c.selai@ucl.ac.uk

If you are a partner of a patient with hypersexuality, please access the “More information for partners” tab.

More information for partners

How do I know if my partner is hypersexual?

Sometimes it is difficult to know whether someone close to you has developed hypersexuality. Your partner might hide the sexual behavior or you might not know exactly what to look for. Some things to look for might include:

1. An increased interest in pornography of any kind (Internet, magazines, televisions, etc....)
2. An increased interest in pleasing themselves
3. New sexual interests not present before your partner's neurological disorder
4. Increased demands for sex
5. Calls to sex phone lines
6. Increasingly spending money
7. Increased use of medication used to treat erectile dysfunction
- 8.

Please be aware that not all patients with neurological disorders develop hypersexuality. Unless there is a persistent change or intensification in your partner's sexual behavior, it is likely that they are not hypersexual.

How am I supposed to react to my partner's hypersexuality?

There is no right or wrong way to react to your partner's hypersexuality. You may feel frustrated. You may feel depressed. You may feel angry and hurt. You may feel neglected and unappreciated. It may feel overwhelming to deal with your partner's hypersexuality, as well as their neurological disorder.

You might feel that not many people are able to understand what you are going through.

It is important for you to know that all those feelings can be managed. You might not be hearing what you want from your partner but the consequences of your partner's hypersexuality, like all disorders, can be discussed when proper help is accessed.

Why can't my partner control their sexual behavior?

Although it may seem difficult amidst your partner's unusual behavior, you should try to remember that your partner's hypersexuality is not purposeful, and is a result of their neurological disorder or treatments. Most people with hypersexuality would stop if they could. They had no control over their neurological disorder developing and consequently had no control over their hypersexuality. This, of course, does not mean that there is nothing to be done or that you should just stand by and watch it unfold. There is always something that can be done to help alleviate the pain you might be experiencing.

Why is it so difficult to discuss the hypersexuality with my partner?

You might have tried to have unsuccessful conversations with your partner about hypersexuality.

Research shows that neurological patients with hypersexuality often lack insight into the problem.

Insight is when the patient recognizes that their hypersexuality is a problem and have a true desire to overcome it. It might often feel difficult to get through to a patient without insight and for this reason, you might need to consider other options, including accessing professional help through your GP.

How do I get the appropriate help for the hypersexuality and its consequences?

You are not alone. You do not have to suffer alone. There are options for you to be able to speak only about your worries, feelings, and experiences in a safe and supportive environment. You should not feel ashamed for feeling the way you do about the hypersexuality. Below are the contact details for two people at UCL who you can contact to discuss the issue. They are ready to talk to you and offer advice as is suitable for you. If any contact is made, please be assured that any correspondence will remain confidential unless otherwise requested by you.

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