The Relationship Between Perceived Control, Depression, and Medication Adherence in People with Parkinson's Disease

Dr Nicolò Zarotti

BSc, MSc, PhD, CPsychol, FHEA

Registration number: 100299502

Thesis submitted in partial fulfilment of

the degree of Doctorate in Clinical Psychology

Faculty of Medicine and Health Sciences

University of East Anglia

Submission Date: 21 May 2022

Word count: 30,853

Primary supervisor: Dr Katherine Deane

Secondary supervisors: Dr Catherine Ford, Prof Jane Simpson

Coelum, non animum mutant
qui trans mare currunt.

Acknowledgements

This was not an easy journey, for several reasons. However, I was lucky enough to have some amazing people beside me along the way, whose support made this endeavour possible and to whom I wish to express my heartfelt thanks. Starting with my research supervisors, Katherine, Cat, and Jane, for their guidance throughout the past three years. My advisor Paul, for his constant availability and understanding, especially during some very challenging times. The Hand of the King, for always being there as a mentor and, most importantly, a friend. Arianna, simply for being my rock. Greco, for his friendship and all the trash movie nights. The N group, for coming to my aid and restoring my trust and motivation when they were at their lowest. And Rebecca, for all the clinical and – above all – human lessons.

Finally, I would like to thank all the people with Parkinson's, their caregivers, and their dedicated organisations, without whom this thesis would have not been possible.

Table of Contents

List of Tables

List of Figures

Thesis Portfolio Abstract

Background: Parkinson's is an incurable neurodegenerative condition typically treated with highly complex medication regimens. However, medication adherence in people with Parkinson's (PwP) is problematic, with up to 70% of PwP reported non-adherent to prescribed medication regimens. Research suggests medication adherence in PwP may be influenced by psychological factors, such as depression and subconstructs of perceived control.

Methods: This thesis portfolio aimed to address some of the gaps in the current literature around perceived control, depression, and medication adherence in PwP. First, a scoping review was carried out to identify types of psychosocial interventions for PwP which measured perceptions of control as an outcome. Second, an online cross-sectional survey was conducted to investigate the role of perceived control as a predictor of medication adherence in 1210 PwP from 15 English-speaking countries.

Results: The scoping review identified 12 eligible studies investigating four categories of psychosocial interventions. Mixed findings were found for cognitive, educational, and physical interventions, while positive evidence was observed for a mindfulness-based lifestyle programme. In the survey, perceived control accounted for slightly greater variance in medication adherence than medication variables, and internal and external dimensions of locus of control emerged as independent predictors. Unexpectedly, depression shared no significant relationship with medication adherence.

Conclusions: In PwP, perceived control may exert a more significant impact on medication adherence than depression or medication-related factors. However, the literature on psychosocial interventions affecting perceived control in this population is still in its infancy. Directions for future research and implications for clinical psychology practice are discussed.

Chapter One

Introduction

Parkinson's[1] is a progressive neurodegenerative condition caused by the death of dopaminergic neurons in the substantia nigra pars compacta of the basal ganglia. This leads to disorders of movement including bradykinesia, muscular rigidity, rest tremor, and postural and gait impairment (Kalia & Lang, 2015). Other difficulties include problems with cognition, affect, sleep, pain, and gastrointestinal and autonomic symptoms (Chaudhuri & Schapira, 2006; Weintraub & Burn, 2011). Parkinson's is usually diagnosed after the age of 50, although earlier onset is also possible (known as 'young-onset Parkinson's'; Willis et al., 2013). It is the second most common neurodegenerative disease in older people (after Alzheimer's), affecting around one in 500 individuals in the UK (Mark, 2006). Worldwide prevalence estimates range from one to 418 per 100,000 (Zhang & Roman, 1993), with the highest rates found in Europe, North America, and South America (Strickland & Bertoni, 2004; Von Campenhausen et al., 2005).

While a small number of strong genetic links have been identified (Corti et al., 2011), for most people with Parkinson's (PwP) the cause of their illness is unclear (i.e., 'idiopathic') and likely to result from a complex interplay between genes and

[1] The term 'Parkinson's' has been adopted from this point onwards as it represents Parkinson's UK's preferred way to address this population in order to reduce the stigma associated with the term 'disease'.

environment. The most established risk factor is age, which reaches a peak after 80 (Driver et al., 2009), although age-specific prevalence can rise until the ninth decade (Zhang & Roman, 1993). With people living longer, the overall prevalence of the condition is expected to increase by 50% by 2030 (Dorsey et al., 2007).

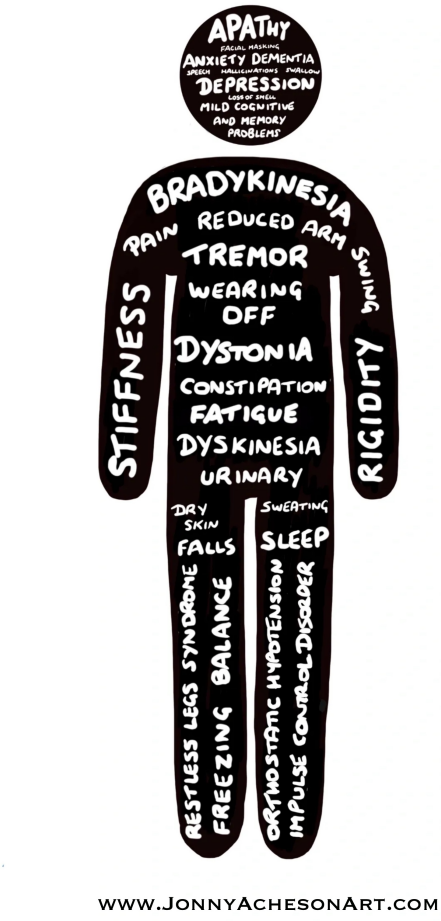
No definitive diagnostic test exists for Parkinson's, and the onset of motor symptoms may be preceded by a number of less noticeable issues, including psychological difficulties, anosmia, constipation, and sleep disorders (Goldman & Postuma, 2014; Postuma et al., 2012; Schrag et al., 2015). Following this phase, the progression of the condition is characterised by the onset and worsening of motor symptoms, and diagnosis is usually made after these emerge and other forms of parkinsonism and potentially similar conditions have been excluded (Gelb et al., 1999).

Throughout the course of the disease, PwP may also experience a number of cognitive impairments (Emre, 2007; McKeith & Burn, 2000). These may range from mild difficulties in specific domains (Parkinson's mild cognitive impairment, PDMCI; Litvan et al., 2012) to dementia (Parkinson's dementia, PDD; Emre et al., 2007), with impairments in executive functioning (e.g., working memory, planning) usually first to emerge (Foltynie et al., 2004; Muslimovic et al., 2005). Figure 1 shows a depiction

of the difficulties linked with Parkinson's which also includes less noticeable issues such as psychological and cognitive difficulties, constipation, and fatigue[2].

Figure 1

A visual representation of difficulties associated with Parkinson's.



[2] The Figures in this chapter are pictures drawn by Johnny Acheson, a British artist who was diagnosed with Parkinson's in 2016. He created them to provide a set of modern, gender-neutral, race-neutral, and ageless images to increase awareness on the condition. All the pictures are copyright-free and available to download from his website (www.jonnyachesonart.com).

Psychological Difficulties in People with Parkinson's

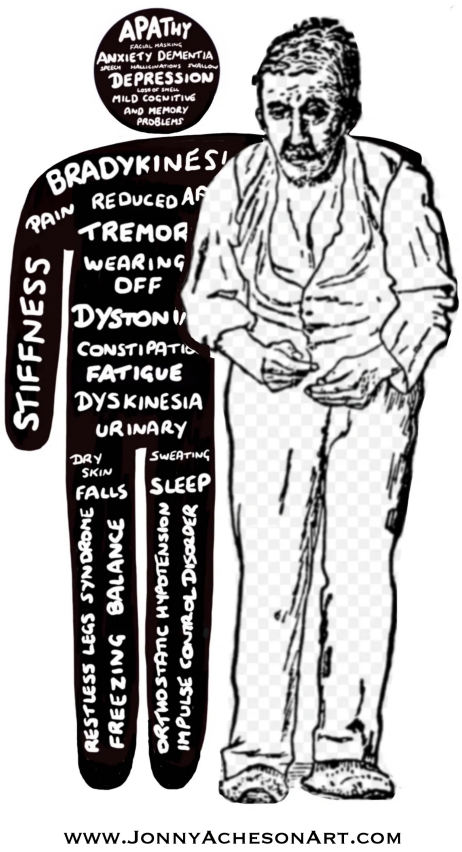
Historically, Parkinson's has been considered a motor disorder, and psychological difficulties are still often under-recognised by clinicians (Barbosa, 2013). However, the range of psychological issues associated with Parkinson's is wide, and includes depression, anxiety, apathy, impulse control disorders, and more rarely psychosis (Ffytche et al., 2017; Renouf, Ffytche, Pinto, Murray, & Lawrence, 2018; Simpson, McMillan, & Reeve, 2013). These difficulties may emerge at any point throughout the course of the disease, even many years prior to the onset of motor symptoms while being just as disabling (Goldman & Holden, 2014; Goldman & Postuma, 2014; Schrag et al., 2015; Truong et al., 2008). Research has also found that psychological difficulties represent the strongest predictors of health-related quality of life in PwP (Leroi et al., 2011; Soh et al., 2011). Among these, depression is particularly common, with up to 50% of all PwP estimated to have clinical levels of low mood which significantly affect their daily life (Reijnders et al., 2008). In turn, such difficulties have been linked to faster disease progression, lower independence, and greater caregiver burden (Chen & Marsh, 2014).

Historically, psychological difficulties associated with Parkinson's were assumed to reflect underlying pathophysiological processes (Brown & Jahanshahi, 1995). More recently, however, research has evidenced how these may be due to a combination of both neurobiological and psychological factors (Simpson, Lekwuwa, & Crawford, 2013; Weintraub & Burn, 2011). In fact, 205 years following James Parkinson's first description of the disease (1817), there appears to be a paradigm shift to conceptualise the difficulties experienced by PwP as reflecting interacting biopsychosocial factors, rather than neurobiological changes alone (Simpson et al.,

2021; Simpson, Lekwuwa, et al., 2013; Suzukamo et al., 2006; Zarotti et al., 2021). In this regard, Figure 2 presents a widely adopted historical illustration of an individual with Parkinson's from 1886 next to the abovementioned visual representation of difficulties linked with the condition.

Figure 2

Visual representation of difficulties associated with Parkinson's next to an 1886 illustration.



Parkinson's Treatment and Medication Profile

Since no cure is currently available for Parkinson's, symptomatic treatments represent the mainstay of clinical management of PwP (Kalia & Lang, 2015). While

medication regimens may be initially monotherapeutic, at later stages of the condition polypharmacy is always required (Daley et al., 2014). This includes a wide range of neurological (e.g., levodopa, dopamine receptor antagonists, anticholinergics) and psychiatric medications (e.g., antidepressants, anxiolytics, antipsychotics), all of which can cause severe side effects (e.g., motor fluctuations, tardive dyskinesias) and need to be constantly reviewed in response to symptom frequency and severity (Ahlskog, 2009). In addition, many Parkinson's medications are characterised by short plasma half-life, meaning that multiple daily doses are usually required to maintain adequate blood plasma levels and for the therapy to be effective (Malek & Grosset, 2014).

As the disease progresses, response to treatment tends to decrease, leading to the emergence of treatment-resistant symptoms (Nonnekes et al., 2016). This, combined with a life expectancy which is only slightly lower than the general population (Ishihara et al., 2007), often translates into PwP and their significant others spending multiple decades living with chronic illness and its related challenges. One of the most difficult of these challenges is represented by adherence to treatment recommendations themselves.

Medication Adherence in People with Parkinson's

Adherence[3] has been defined as "the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes – corresponds

[3] It is recognised that the terms 'adherence' and 'compliance' are considered to be synonymous and are used interchangeably in both research and clinical settings (Lehane & McCarthy, 2009). However, for

with agreed recommendations from a health care provider" (WHO, 2003, p. 3). It is associated with a wide range of positive consequences, including better clinical outcomes, fewer remissions, and increased quality of life (Mukhtar et al., 2014). Non-adherence is a major concern for modern healthcare, with as many as 50% of patients estimated to be non-adherent across diseases in developed countries (WHO, 2003). Due to the crucial role of medication for the management of long-term conditions, as well as the gradual improvement of life expectancy in the general population, adherence has also become increasingly important within healthcare (Jin et al., 2016; Mukhtar et al., 2014).

While no formal guidance is currently available for researchers and clinicians on the best way to measure medication adherence in clinical populations (Lam & Fresco, 2015; Lehmann et al., 2014), a very wide range of different methods have been developed for this purpose. These may be organised into five main categories (Lam & Fresco, 2015): a) direct measures (e.g., blood concentrations of active ingredients or metabolites); b) secondary database analysis (e.g., refill data from electronic prescription services); c) Electronic Medication Packaging or 'EMP' (e.g., devices automatically recording medication doses and use); d) pill count (e.g., number of dosage units taken between scheduled appointments); and e) clinician-rated and self-report measures (e.g., standardised questionnaires, medication diaries). All these methods show a number of varying strengths and limitations depending on the context of their intended use (e.g., clinical or research). As a consequence, no 'gold standard'

---

the sake of clarity and consistency, 'adherence' has been used throughout this thesis even when the cited literature referred to 'compliance'.

has been identified so far in the measurement of medication adherence (Lehmann et al., 2014)

From a theoretical standpoint, multiple medical causes have been proposed to explain non-adherence, and particularly biological and practical factors which can make adhering to medication regimens more difficult, such as comorbid health problems, side effects, and the frequency and complexity of treatments (Jin et al., 2016; Wright & Walker, 2013). However, psychological factors can also affect medication adherence (Horne, 2000; Marrero et al., 2020). In particular, these have been proposed to explain non-adherence in terms of a more deliberate behaviour, which is enacted not to 'oppose' medical advice, but rather to preserve meaningful control and decision-making and reduce psychological distress in the face of health-related challenges (Barber, 1995; David James Daley et al., 2012; Simpson, Zarotti, et al., 2021).

Considering the complexity of medication regimens for Parkinson's, it is perhaps unsurprising that up to 70% of PwP are estimated to be partially or fully non-adherent to their prescribed medication regimen (Malek & Grosset, 2014). This has been argued to make adherence a major problem in this specific population (Grosset et al., 2009), perhaps even more than in other complex conditions (McLean et al., 2017). Non-adherence in Parkinson's has been traditionally hypothesised to be caused by medical and ability-related factors such as comorbidity and polypharmacy (McLean et al., 2017), cognitive impairments (Sumbul-Sekerci et al., 2022), side effects (Straka et al., 2018), cost of treatment (Shin et al., 2015), and lack of knowledge about medications (Ahlskog, 2009). However, factors influencing motivation and intention, such as psychological difficulties, are also found to affect adherence in PwP (Daley et al., 2012; Erickson & Muramatsu, 2004). In particular, depression has been

consistently reported to be one of the strongest predictors of lower medication adherence across chronic conditions (for a meta-analysis, see Grenard et al., 2011), older populations (Krousel-Wood et al., 2011; Yap et al., 2016), and individuals with Parkinson's specifically (Daley et al., 2012; Erickson & Muramatsu, 2004; Fleisher & Stern, 2013; Leopold et al., 2004; Richy et al., 2013).

A potential explanation of this may lie in the concept of 'depressive realism' (Moore & Fresco, 2012), which postulates that people free from depression normally show an illusory 'self-serving' positive bias towards multiple aspects of life, including their health (Alloy et al., 2011; Keller et al., 2002). On the other hand, depressed individuals tend to show much fewer positively biased views of external reality (Rubenstein et al., 2016), which may induce them to adopt a more pessimistic attitude towards life (Alloy et al., 2011). Since higher optimism is known to be associated with better medication adherence across multiple chronic conditions (Keller et al., 2002; Kyngäs et al., 2000; Lo, 1999), its absence caused by depressive realism may in turn affect expectations around the effectiveness of treatments (Pence et al., 2007), and lead depressed individuals to adhere less to medication regimens.

In addition, the observation of a relationship between depression and medication adherence in PwP also appears to suggest that treating depression may have the potential to improve adherence in this population. However, a systematic review of factors associated with non-adherence in PwP has suggested this is, in fact, not the case, and that the psychological factors influencing how PwP adhere to medication regimens remain unclear and merit further investigation (Daley et al., 2012). One such psychological factor is perceived control (Rubenstein et al., 2016).

Perceived Control

Perceived control has been defined as "the belief that one can determine one's own internal states and behavior, influence one's environment, and/or bring about desired outcomes" (Wallston, Wallston, Smith, & Dobbins, 1987, p. 5). It is considered of paramount importance for the psychological well-being of people with chronic illness (Dempster et al., 2015) and, due to the loss of physical control caused by motor impairments, particularly so for people with motor neurodegenerative conditions, such as Huntington's disease (Zarotti, Simpson, & Fletcher, 2019), motor neuron disease (Zarotti et al., 2019), and Parkinson's (Verity et al., 2020).

However, the nature of perceived control does not consist of a unitary concept, but is rather characterised by multiple theoretical conceptualisations (Skinner, 1996; Walker, 2001). While a definite consensus among authors is yet to be reached (Eccles & Simpson, 2011), it may be currently construed as a broad abstract construct which encompasses a range of distinct, yet complementary, subconstructs or aspects (Chipperfield et al., 2012). More specifically, these may be identified with concepts covering multiple domains of an one's life – such as mastery, locus of control (LOC), symptom control, adaptive control, and self-efficacy (Reich & Infurna, 2016) – whose definitions are detailed in Table 1.

The importance of perceived control has been long recognised within models of clinical and health psychology (Holmes et al., 2014; Reich & Infurna, 2016). One such model is the theory of planned behaviour (TPB), which suggests that an individual's motivation to engage in a specific behaviour (called an 'intention' within the model) is guided by three main constructs: attitudes towards a behaviour, subjective norms regarding a behaviour, and perceived behavioural control (Ajzen,

1991; Rhodes & Courneya, 2004). The latter in particular – which is specifically conceptualised as the expectations an individual has regarding having the ability and resources to perform a behaviour – has been found to be the strongest positive predictor of intention towards adherence to medication (for a meta-analysis, see Rich et al., 2015). Thus, according to TPB, higher levels of perceived behavioural control translate into higher expectations to have the necessary resources to be adherent (whether psychological, social, or material), which in turn lead to increased intention to adhere (Rich et al., 2015).

Table 1

Definitions of Subconstructs of Global Perceived Control[4].

Subconstruct	Definition
Adaptive control	The extent to which an individual feels able to control their adaptation to events in life, as opposed to controlling the events themselves (Chipperfield et al., 2012).
Locus of control (LOC)	The extent to which an individual attributes control to their own actions (internal LOC) or external forces (external LOC; Rotter, 1966).

[4] Based on global subconstructs, several single-domain forms of control have also been conceptualised, which cover very narrow aspects (e.g., illness' symptoms, creativity, balance). While important for the wider literature on perceived control, these were beyond the scope of the thesis and its focus on medication adherence. Thus, except for clarification purposes in Chapter Two, the terms 'perceived control' and 'perceptions of control' are used to refer to global subconstructs throughout the portfolio.

Mastery	The extent to which an individual feels in control of their life, including health and social aspects of life (Pearlin & Schooler, 1978).
Self-efficacy	An individual's beliefs in their ability to execute the actions required by an outcome (Bandura, 1982).
Symptom control	An individual's beliefs in their ability to control their illness, including control over symptoms and/or treatment (Sirois, 2003).

Even outside the theoretical framework of TPB, higher global perceived control has been consistently associated with better medication adherence (Holmes et al., 2014), especially due to the drive to preserve control in health-related decision-making in chronic conditions (e.g., Barber, 1995; Daley, Myint, Gray, & Deane, 2012). In particular, subconstructs of perceived control have been consistently found to be associated with medication adherence in people with chronic diseases, with internal LOC, higher perceived personal and symptom control, and higher self-efficacy significantly associated with better adherence in several clinical populations (Cvengros et al., 2004; Náfrádi et al., 2017; Tucker et al., 2001), including Parkinson's (Grosset, Bone, & Grosset, 2005).

The relationship between perceived control and medication adherence may also have important implications for clinical practice. For instance, different subconstructs of perceived control can be targeted by psychological interventions, such as cognitive restructuring of control beliefs (Robinson & Lachman, 2016), touchscreen-based 3D games and techniques to improve feelings of mastery (Tyack

& Camic, 2017), educational workshops targeting health-related LOC (Barlow et al., 2015), and self-management programmes to enhance self-efficacy (Marks et al., 2005). Moreover, a recent review of psychological interventions in PwP has emphasised the potential role of perceived control in the implementation of multiple psychotherapeutic approaches (Zarotti et al., 2021). Along with the evidence of positive clinical implications for higher perceived control with regards to medication adherence in other chronic conditions (Cvengros et al., 2004; Náfrádi et al., 2017; Rich et al., 2015; Tucker et al., 2001), these findings highlight a need for further investigation of the construct in individuals with Parkinson's.

As yet, however, there has been no review of the scope and nature of interventions for perceived control in PwP. Moreover, it is currently unclear to what extent perceived control predicts medication adherence in individuals with Parkinson's, or whether its subconstructs (e.g., mastery, LOC) differ in the extent of their association with medication adherence. In fact, this appears be reflected across multiple conditions, with a meta-analysis highlighting that "to date, there has been little consistency in the type of control associated with adherence to medications" (Holmes et al., 2014; p.864).

Overview of the Thesis Portfolio

The overarching aim of this thesis portfolio was twofold. First, it sought to identify the scope of research on interventions affecting global perceived control in individuals with Parkinson's, which may provide opportunities to enhance medication adherence. Secondly, it aimed to assess the extent to which perceived control variables predict medication adherence in PwP over and above other known predictors such as depression and medication variables.

To this end, Chapter Two presents a scoping review of research on psychosocial interventions which addressed perceptions of control as an outcome in PwP, while Chapter Three presents a large-scale cross-sectional study of predictors of medication adherence in 1210 individuals with Parkinson's across 15 English-speaking countries. Both Chapters have been formatted as publishable research articles and have been submitted to a multidisciplinary peer-review journal (*Disability and Rehabilitation*), where they are currently under review.

Finally, Chapter Four provides a critical discussion of the research in this portfolio, briefly summarising the findings, presenting a critical appraisal of the methods, and identifying the implications for future research and clinical practice. References from the submitted papers are presented at the end of their relative chapter according to the journal's Instructions for Authors (Appendix A), while the references from the remaining chapters and the appendices are presented at the end of the portfolio.

Chapter Two

Scoping Review

Psychosocial Interventions Affecting Global Perceptions of Control in People with Parkinson's Disease: A Scoping Review

Nicolò Zarotti[a*], Katherine Helen O'Leary Deane[b],

Catherine Elaine Longworth Ford[a], Jane Simpson[c]

Submitted to *Disability and Rehabilitation* – Under Review

(Instructions for Authors in Appendix A)

[a] Department of Clinical Psychology and Psychological Therapies, University of East Anglia, Norwich, UK

[b] School of Health Sciences, University of East Anglia, Norwich, UK

[c] Division of Health Research, Lancaster University, Lancaster, UK

---

[*]Corresponding author. E-mail: n.zarotti@uea.ac.uk. Address: Department of Clinical Psychology and Psychological Therapies, Norwich Medical School, University of East Anglia, Norwich, UK

Abstract

Purpose: Perceived control is an important construct for the psychological well-being of people with chronic conditions, with higher perceived control associated with better outcomes. Psychosocial interventions have been trialled in these populations to improve both global and specific perceptions of control. However, most interventions involving people with Parkinson's have focused on single-domain forms of control, while those addressing global perceived control are yet to be reviewed. This study aimed to identify and map the types of psychosocial interventions in individuals with Parkinson's which have included forms of global perceived control as an outcome.

Materials and Methods: Scoping review based on a search across MEDLINE, PsycINFO, CINAHL, Academic Search Ultimate up to December 2021.

Results: From an initial return of 4388 citations, 12 citations were eventually included. These consisted of 8 quantitative and 4 qualitative studies, and covered 4 overarching categories of psychosocial interventions. Mixed results were found for cognitive, educational, and physical interventions, while a randomised controlled trial on mindfulness-based lifestyle programme showed more promising evidence.

Conclusions: Further rigorous research is required on the topic to build on these preliminary findings. In the meantime, clinicians may need to consider programmes which proved effective with populations similar to people with Parkinson's.

Implications for Rehabilitation

- Perceived control is a psychological construct important for people with chronic illnesses, which can be targeted by psychosocial interventions.
- This article reviewed psychosocial interventions targeting global forms of perceived control in Parkinson's, finding 4 types of interventions across 12 studies.
- Mixed results were reported for the cognitive, educational, and physical interventions identified, while an RCT on a mindfulness-based lifestyle programme showed more promising evidence.
- Further research is strongly needed on the topic. In the meantime, clinicians may need to consider programmes found to be effective with people with similar conditions to Parkinson's.

Introduction

Perceived control is a psychological construct which has been defined as "the belief that one can determine one's own internal states and behavior, influence one's environment, and/or bring about desired outcomes" [1] (p. 5). While there is a lack of theoretical consensus concerning this definition [2,3], it can be conceptualised as a broad construct encompassing a range of distinct yet complementary subconstructs, each with their own literature [3,4]. These include general perceptions of control covering multiple domains of an individual's life, such as feeling in control of health and social aspects in life ('mastery' [5]), having personal control over outcomes as opposed to attributing them to external forces ('locus of control' [6]), feeling able to execute the actions required by an outcome ('self-efficacy' [7]), and feeling capable of controlling one's adaptation to events in life, as opposed to controlling the events themselves ('adaptive control' [4]). Based on these global perceptions, a number of single-domain forms of control have also been theorised, often covering very specific aspects such as control over an illness' symptoms [8], creativity [9], and one's own body and balance [10,11].

Irrespective of its exact conceptualisation, perceived control is considered of paramount importance for the psychological well-being of people with chronic health conditions [12], with decades of literature showing a consistent link between higher levels of perceived control and better clinical outcomes, more successful adjustment to illness, fewer psychological difficulties, improved medication adherence, and higher quality of life [1,13–15]. In particular, perhaps due to the loss of physical control caused by motor impairments, perceived control has shown to play a pivotal

role in the well-being of people with motor neurodegenerative diseases [3,16–18], including Parkinson's disease [19,20].

Parkinson's disease is a progressive motor neurodegenerative condition causing a number of issues which include slowed movements, muscular rigidity, rest tremor, postural and gait impairments, as well as cognitive difficulties which can eventually lead to dementia [21,22]. Parkinson's is the second most common neurodegenerative disease in older people [23], and is usually diagnosed after the age of 50 [24]. Since no cure is currently available, symptomatic treatments represent the mainstay of its clinical management [21] and frequently involve high levels of polypharmacy [25]. In addition to motor and cognitive issues, people with Parkinson's (PwP[1]) can experience a wide range of psychological difficulties, including depression, anxiety, apathy, impulse control disorders, and more rarely psychosis [26–28]. These may also be coupled with a number of socio-relational issues, which can include stigma, loss of independence, loneliness, dehumanisation, as well as difficulties of social cognition such as impaired communication, emotion expression, and identification of emotional cues [29–31]. Moreover, the combination of these biopsychosocial issues often leads PwP to have lower perceived control compared to the general population [3,32].

[1] The terms 'Parkinson's' and 'people with Parkinson's' (or 'PwP') have been adopted in this article in lieu of the more common 'Parkinson's disease' and 'people with Parkinson's disease' (or 'pwPD') as the former currently represent Parkinson's UK's preferred way to describe this population in order to reduce the stigma associated with the term 'disease'.

Interventions have been trialled to improve both global and specific perceptions of control in people living with chronic illness. These interventions have traditionally taken the form of a wide range of behavioural approaches, such as psychological therapy focused on cognitive restructuring of control beliefs [33], cognitive rehabilitation based on touchscreen technologies [34], educational workshops [35], and self-management programmes [36]. However, with regards to Parkinson's in particular, most interventions appear to have focused on single-domain forms of control revolving around the body – and especially falls efficacy and fear of falling (for a review see [37]) – while little is currently known about psychosocial interventions addressing global perceptions of control in PwP. This gap represents a considerable limitation in the literature, since global perceptions of control have been extensively identified as independent subconstructs compared to single-domain forms of control [20,38–41]. Their development or improvement has also been suggested to play a more dominant role in an individual's adjustment to new life demands (i.e., after the diagnosis of a chronic illness), particularly by exerting a top-down effect which extends into more specific domains [38,42].

As a consequence, the overarching aim of the present review was to scope the current literature on psychosocial interventions for PwP which have included global perceptions of control as an outcome. This was seen as having not only the potential to help shed light on the gap in the current literature, but also to inform the development of more targeted and effective psychosocial interventions to improve perceived control in individuals with Parkinson's.

Methods

Research Question

Based on the issues discussed above, the present review aimed to address the following research question: *what are the types of psychosocial interventions studies which have measured global perceptions of control as an outcome in people with Parkinson's and what are their findings?*

Method Selection and Rationale

Scoping reviews [43] "systematically map the literature available on a topic, identifying key concepts, theories, sources of evidence and gaps in the research" [44] (p. 34). Their development has been particularly noticeable in the field of mental health research, in response to the need to scope underdeveloped or complex areas and topics not previously reviewed [45]. Like systematic reviews, which address narrowly defined questions and inclusion criteria [44], scoping reviews feature an explicit and transparent search strategy, standardised data extraction, and PRISMA-based reporting. They differ from systematic reviews, however, in their focus on mapping available research on a developing topic, rather than providing the comprehensive synthesis and appraisal of evidence possible in more developed areas of research [43]. As such, they act as precursors to further research and associated systematic reviews [46] typically permitting the exploration of a wider range of conceptual and methodological topics related to developing areas, highlighting gaps and limitations to inform future investigations [43] while retaining a systematic and replicable methodology [44,45]. Another difference is that "a critical appraisal or risk of bias assessment is generally not recommended in scoping reviews" [46] (p. 2124), as they

"do not tend to produce and report results that have been synthesized from multiple evidence sources following a formal process of methodological appraisal to determine the quality of the evidence" [43] (p. 408).

Given the limited and underdeveloped nature of research on psychosocial interventions targeting global perceptions of control in Pw and the breadth of the research question, a scoping review was deemed more appropriate than a systematic review for the present study [45]. The details of the methodology used are outlined below, organised in accordance with the latest guidance for the conduct of scoping reviews available from The Joanna Briggs Institute [46].

Identifying Relevant Studies

The inclusion criteria required studies to: a) be related to individuals with a clinically confirmed diagnosis of Parkinson's; b) involve people aged 18 or above; c) describe the delivery of any behavioural intervention addressing global perceptions of control as primary or secondary outcomes in PwP, and d) be published fully in the English language. Reports of original empirical data and qualitative studies that evaluated interventions were included. Psychosocial interventions were conceived as non-pharmacological and non-surgical interventions aimed to affect actions which individuals may take to change health-related behaviours [47]. 'Global perceptions of control' were conceptualised as either the assessment of a general form of control (e.g., general or non-specified perceived control, self-efficacy; [32,48,49] or a multi-domain assessment of control (e.g., multidimensional health locus of control [50]). Reviews, commentaries, editorials, conference proceedings, unpublished theses, and letters were excluded.

Study Selection

Following a preliminary search of the extant literature, free text and subject terms were identified to build a logic grid for the full search strategy (Table 1). Based on this, a comprehensive search string was developed (Table 2) to search four bibliographic databases – Academic Search Ultimate, CINAHL, PsycINFO, MEDLINE – from inception until December 2021 via the EBSCO platform. Hand searches were also carried out across the reference lists of key reviews and shortlisted citations to identify additional relevant studies. While the present review focused on global perceptions of control, search terms covering most domains of perceived control were included to ensure citations were not overlooked due to terminological issues.

Based on the defining characteristics of scoping reviews outlined above [44,45], the latest guidance from the Joanna Briggs Institute [46], and the related difficulty in selecting a quality assessment relevant to the different study designs included in this study specifically, a formal quality appraisal of the evidence was not performed in the present review. However, efforts were made to highlight any theoretical, methodological, and clinical limitations in the included studies whenever feasible and appropriate.

Charting the Data

Initial search results were checked for duplicates and languages other than English, and then study titles and abstracts were screened against the inclusion and exclusion criteria. All remaining full-text articles were screened for eligibility by one reviewer (NZ) and double checked and confirmed by three more (KHOD, CF, JS),

with any doubts or disagreements between reviewers solved through collective discussions. Figure 1 illustrates the PRISMA flow diagram for the study selection and data charting processes. An extension of the PRISMA Checklist for scoping reviews ('PRISMA-ScR') is also available as a Supplementary Material (Appendix B).

Collating, Summarising, and Reporting the Results

Following the screening and charting of the search results, all included studies were organised digitally. Data were then extracted from each study by one reviewer (NZ) and double-checked for accuracy by further three (KHOD, CF, JS).

Results

From an initial return of 4388 citations, a total of 2377 was left following the preliminary filtering for duplicates and languages other than English. Screening titles and abstracts identified 39 full-text articles to inspect. Twelve studies met criteria for inclusion in the review, eight of which were quantitative investigations (including four RCTs [51–54]), while the remaining four reported qualitative findings. Two of these reported quantitative and qualitative findings from the same sample [53,55]. Five investigations were carried out in the USA, three in Australia, two in the UK, one in Canada, and one in Norway.

Table 3 illustrates the key results and characteristics of the included studies, while Table 4 lists the remaining full-texts with reasons for exclusion. The findings are outlined below, categorised by the types of psychosocial interventions identified – i.e., cognitive, educational, mindfulness-based, or physical. In each category, randomised controlled trials (RCTs) are highlighted when available.

Cognitive Interventions

Only one study investigated a cognitive intervention which measured global perceptions of control in PwP. Hindle and colleagues [51] carried out a single-blinded pilot RCT to compare a goal-oriented cognitive rehabilitation programme in 10 people with Parkinson-related dementia with relaxation training and treatment as usual (TAU). The intervention consisted of eight weekly 1-hour sessions exploring the use of compensatory or restorative strategies to cope with deficits involving planning, orientation, and memory skills. A measure of self-efficacy (General Self-Efficacy Scale, GSE [48]) was included as a secondary outcome. The results showed a statistically significant improvement in self-efficacy in the intervention group compared to relaxation training post-intervention. However, this was not maintained at 6-month follow-up, and no significant differences were observed between the intervention group and TAU at any time points.

Educational Interventions

Educational interventions were investigated by three studies. Connor et al. [52] enrolled 162 veterans with Parkinson's in an RCT examining the effectiveness of the Care Coordination for Health Promotion and Activities in Parkinson's Disease (CHAPS) programme for improving quality of care compared to TAU. The intervention consisted of guided care management sessions and resources administered by registered nurses. At post-intervention, the results showed no significant changes between the intervention group and TAU in levels of self-efficacy (measured by the GSE as a secondary outcome).

Similar findings were reported by a non-randomised trial [56] which administered the Stanford Chronic Disease Self-Management Program (CDSMP) to 27 PwP and found no significant changes in self-efficacy measured as a secondary outcome post-intervention using the Chronic Disease Self-Efficacy Scale (CDSES; [57]). However, a sense of increased self-efficacy with regards to resource access and disease management appeared to emerge as relevant themes from qualitative semi-structured interviews with the participants following the intervention.

Soundy and colleagues [58] also carried out qualitative semi-structured interviews to explore the experiences of PwP participating in 'First Steps', a peer-led educational intervention developed by Parkinson's UK for newly diagnosed individuals. The results, based on a hermeneutic phenomenological analysis, highlighted perceptions of control as playing a pivotal role in allowing participants to take action, 'fight back', and promote optimal adjustment following their diagnosis.

Mindfulness-Based Interventions

Two articles reported findings from a mixed-methods RCT exploring the effectiveness of a mindfulness-based lifestyle programme for improving Parkinson-related functioning and well-being against a control wait list [53,55]. The intervention consisted of six weekly 2-hour group sessions including mindfulness techniques such as the body scan, attention to breath, and letting go of negative thoughts. Perceived control was assessed as a secondary outcome through a multi-domain measure, the Multidimensional Health Locus of Control (MHLC) Form B [59]. At post-intervention, the results showed a significant group effect only for the internal dimension of locus of control [53], suggesting that the participants of the intervention group reported significantly higher perceptions of internal causal attributions.

However, the effect size was small (Cohen's d = .28) and no group differences were observed at the 6-month follow-up. Moreover, the study suffered from considerable attrition, with over one third of the participants in the intervention group lost from baseline to post-intervention (from 35 to 23) and in the control group from post-intervention to follow-up (from 37 to 25).

Semi-structured interviews carried out with the RCT participants at post-intervention and follow-up [55] identified general (i.e., non-specified) perceptions of control as a fundamental and pervasive theme for PwP, who appeared to feel a more achievable view of control at the end of the programme. At 6-month follow-up, some participants also felt that mindfulness training had allowed them to achieve a renewed view of control as part of taking responsibility and ownership over thoughts.

Physical Interventions

Six studies measured global perceptions of control in PwP following physical interventions. Sajatovic et al. [54] carried out an RCT to test the impact of a tailored group exercise self-management programme ('Enhanced EXerCisE thErapy for PD', 'EXCEED') on depression, compared to individual self-guided exercise and self-management. The group intervention consisted of 1-hour exercise sessions, three times a week, including low-resistance cycling and strength training. Self-efficacy was measured as a secondary outcome with the GSE. At post-intervention, no significant difference was observed in self-efficacy between groups, and there were no significant within-group changes for participants undergoing EXCEED.

Ritter and Bonsaksen [60] recruited 83 PwP to an uncontrolled pre-post study of a physical rehabilitation intervention based on the principles of the Parkinson Wellness Recovery® programme. This consisted of three weeks of exercises to slow

the progression of the disease and improve symptoms, functioning, and quality of life. Self-efficacy, assessed with the GSE, was a primary outcome. Following the interventions, the authors found a significant improvement in self-efficacy, albeit with a small effect size (Cohen's d = 0.28).

A further uncontrolled pre-post study investigated a Parkinson's therapeutic dance programme ('Let's Dance!') twice a week for eight weeks with six PwP [61]. The post-intervention assessment found no significant changes in self-efficacy as a primary outcome measured with the GSE. Positive results were instead reported by a qualitative content analysis [62] concerning the subjective experiences of 10 PwP who underwent a similar programme ('Dancing with Parkinson's'). These highlighted general increases in perceptions of control over life and Parkinson's, and a shift towards more internal locus of control. Similarly, a thematic analysis of the experiences of 13 PwP undergoing an online dance therapy feasibility programme ('ParkinDANCE Online') identified an increased sense of mastery post-intervention [63].

Finally, Cucca and colleagues [64] investigated a 10-week art therapy programme for 18 PwP with an uncontrolled pre-post design. The intervention consisted of 20 sessions of 90 minutes administered twice a week. At post-intervention, the results showed no significant changes in self-efficacy measured as a secondary outcome with a multidomain scale (PROMIS Self-Efficacy for Managing Chronic Conditions; [65]).

Discussion

Summary of Main Findings

This scoping review mapped the types of psychosocial interventions for individuals with Parkinson's which have measured global perceptions of control as an outcome, and their associated findings. To our knowledge, this is the first review of this type in PwP. From 4388 initially identified citations, 12 were eventually found eligible for inclusion.

Our results indicate that general or multi-domain perceived control has been an outcome assessed in studies of four main types of behavioural intervention for PwP: cognitive, educational, mindfulness-based, and physical interventions. These studies have evaluated four different global perceptions of control: general perceived control, locus of control, mastery, and self-efficacy. Of these, the most commonly investigated is self-efficacy, evaluated with the GSE in five investigations and the CDSES or PROMIS Self-Efficacy for Managing Chronic Conditions in other two. A further study used the MHLC Form B as a multidimensional measure of locus of control. While all these measures have been previously used in clinical populations including PwP [66–68], only the GSE has undergone a formal validation for Parkinson's specifically, showing excellent psychometric properties (Cronbach's $\alpha = .95$; [69]). Moreover, none of these measures have cut-off scores available to permit evaluation of clinically significant changes.

To date, only one study investigated a cognitive intervention (i.e., goal-oriented cognitive rehabilitation) with PwP using self-efficacy as a secondary outcome [51] (RCT). This showed significantly higher scores compared to relaxation training at post-intervention in the short term, but no significant difference in the longer term

(i.e., after six months) or in comparison to TAU at any timepoint. Similarly mixed results were found by the three studies which tested educational interventions, with no significant impact observed for self-efficacy compared to TAU when measured quantitatively with the GSE [52] (RCT) or the CDSES [56]. However, positive findings were reported for self-efficacy and general perceived control from qualitative interviews with PwP following participation in educational interventions [56,58].

Despite the long-recognised association between the subconstructs of perceived control and mindfulness [70], only one RCT testing the impact of mindfulness-based interventions on global perceptions of control was identified in this review. This appeared to show some promising results, with significant improvements in internal locus of control compared to TAU in the quantitative analysis [53] and increased feelings of general perceived control emerging post-intervention qualitative interviews [55].

Finally, the six studies testing physical interventions reported very mixed results. In particular, therapeutic dance programmes reported positive findings for general perceived control and mastery when using qualitative methods [62,63], while no changes were found for self-efficacy at post-intervention when an uncontrolled quantitative design was adopted [61]. Similar negative results were reported for self-efficacy following the administration of art therapy [64] and enhanced exercise therapy for Parkinson's [54] (RCT), while a significant improvement was observed after a tailored rehabilitation programme [60].

Implications for Future Research

A noticeable contrast between the findings of quantitative and qualitative studies could be observed in the present review, with the latter consistently reporting

more positive outcomes, even when they were part of the same mixed-methods intervention (e.g., [53,55]). A number of reasons may account for this. On one hand, the theoretical fragmentation which has traditionally characterised the construct of perceived control might make it harder to carry out accurate standardised measurements of subconstructs [14]. This may be especially challenging when studies do not include perceived control tools specifically built for Parkinson's, such as the Parkinson's UK Scale of Perceived Control (PUKSoPC [32]). Moreover, only two out of eight of the identified quantitative studies included perceived control as a primary outcome, meaning that most interventions (including all the RCTs) were not designed to have an effect on this construct specifically, and only one of the measures used was validated with PwP. Thus, future investigations should aim to include global perceptions of control as one of the primary outcomes of interventions while also adopting measures which are at least specifically validated (if not purposely built) for the Parkinson's population.

On the other hand, the subjective and interpretative nature of the qualitative analyses, based on participants' personal accounts filtered through the personal lens of researchers, means that specific subconstructs and psychological models of perceived control are less likely to be investigated or described when positive findings are reported. Future studies should be particularly mindful of these theoretical and methodological limitations. More specifically, quantitative investigations should aim to contain threats to validity and reliability by adopting robust validated tools to measure perceived control as a primary outcome (ideally based on the COMET initiative's principles [71]), while meeting essential criteria for rigour and trustworthiness (e.g., transparency, credibility; [72]) should be prioritised when using qualitative methods.

In addition, despite the construct of perceived control being psychological in nature [1,14], no psychotherapeutic interventions for global perceived control in PwP were identified. Therefore, future studies investigating the adoption of different psychotherapy models to improve global perceptions of control in individuals with Parkinson's are strongly warranted. These may draw inspiration from models already adopted successfully with PwP (e.g., cognitive behavioural therapy, acceptance and commitment therapy; [27]), as well as other neurodegenerative conditions [73–75].

Implications for Clinical Practice

While the current literature investigating the impact of psychosocial interventions on global perceptions of control in PwP is limited, our review indicates a number of potential implications for clinicians. First, although preliminary, the positive results around mindfulness-based lifestyle programmes add to the evidence in favour of adopting third wave mindfulness-based models (e.g., mindfulness-based stress reduction or mindfulness-based cognitive therapy; [76,77]) to target perceived control [70], particularly in light of their feasibility in this population [27]. Therefore, this may represent an avenue worth considering for clinicians until more evidence on other psychotherapeutic models becomes available.

Similarly, until further research is carried out specifically with PwP, clinicians may want to consider behavioural and/or psychological programmes which have shown to be effective at addressing perceived control with older people and other populations with chronic disability. In particular, these may include cognitive restructuring around control beliefs [33], cognitive training to improve internal locus of control [35], touchscreen techniques to address feelings of mastery [34],

educational workshops on shifting health-related locus of control [35], and self-management programmes to enhance self-efficacy [36].

Limitations

When considering the present findings, the intrinsic limitations of scoping reviews should be borne in mind. As mentioned previously, scoping reviews map emerging evidence at a stage when there are relatively few studies, typically featuring heterogenous methods and mixed results [44,45]. As such, formal recommendations for clinical practice or policy based on assessment of risk of bias and quality of research are precluded until further evidence accrues and systematic reviews can be conducted at a more advanced stage of research [46].

Conclusions

Research on psychosocial interventions to improve global perceptions of control in individuals with Parkinson's is considerably limited. While a small number of potentially promising results have been identified, further rigorous research is warranted to build on these findings and investigate new approaches, such as targeted psychological interventions. In the meantime, clinicians may need to consider programmes which have been found to have good efficacy with populations similar to people with Parkinson's.

Declaration of Interest

Katherine Deane, UEA, is supported by the National Institute for Health and Care Research (NIHR) Applied Research Collaboration East of England (NIHR ARC EoE) at Cambridge and Peterborough NHS Foundation Trust. The views expressed

are those of the author[s] and not necessarily those of the NIHR or the Department of Health and Social Care.

Funding

The authors received no funding from an external source.

References

1. Wallston KA, Wallston BS, Smith S, Dobbins CJ. Perceived control and health. Curr Psychol. 1987;6:5–25.

2. Skinner EA. A guide to constructs of control. J Pers Soc Psychol [Internet]. 1996;71:549–570.

3. Eccles FJR, Simpson J. A review of the demographic, clinical and psychosocial correlates of perceived control in three chronic motor illnesses. Disabil Rehabil [Internet]. 2011;33:1065–1088.

4. Chipperfield JG, Perry RP, Stewart TL. Perceived Control. 2nd ed. Elsevier Inc.; 2012.

5. Pearlin LI, Schooler C. The Structure of Coping. J Health Soc Behav. 1978;19:2–21.

6. Rotter J. Generalized expectancies for internal versus external control of reinforcement. Psychol Monogr Gen Appl [Internet]. 1966 [cited 2014 August 23];80.

7. Bandura A. Self-efficacy mechanism in human agency. Am Psychol. 1982;37:122–147.

8. Sirois FM. The Control Beliefs Inventory. Carleton University: Unpublished manual; 2003.

9. Shaw A, Kapnek M, Morelli NA. Measuring Creative Self-Efficacy: An Item Response Theory Analysis of the Creative Self-Efficacy Scale. Front Psychol. 2021;12.

10. Tinetti ME, Richman D, Powell L. Falls efficacy as a measure of fear of falling. Journals Gerontol. 1990;45:239–243.

11. Fuchs T, Koch SC. Embodied affectivity: on moving and being moved. Front Psychol. 2014;5:1–12.

12. Dempster M, Howell D, McCorry NK. Illness perceptions and coping in physical health conditions: A meta-analysis. J Psychosom Res [Internet]. 2015;79:506–513.

13. Thompson SC, Kyle DJ. The role of perceived control in coping with the losses associated with chronic illness. Loss trauma Gen close Relatsh Perspect [Internet]. 2000 [cited 2018 August 9]:131–145.

14. Reich JW, Infurna FJ. Perceived Control: Theory, Research, and Practice in the First 50 Years. New York: Oxford University Press; 2016.

15. Walker J. Control and the Psychology of Health: Theory, Measurement, and Applications. Open University; 2001.

16. Zarotti N, Simpson J, Fletcher I. 'I have a feeling I can't speak to anybody': A thematic analysis of communication perspectives in people with Huntington's disease. Chronic Illn [Internet]. 2019 [cited 2018 January 15];15:61–73.

17. Zarotti N, Coates E, McGeachan A, Williams I, Beever D, Hackney G, Norman P, Stavroulakis T, White D, White S, et al. Health care professionals' views on psychological factors affecting nutritional behaviour in people with motor neuron disease: A thematic analysis. Br J Health Psychol [Internet]. 2019 November;24:953–969.

18. Bishop M, Frain MP, Tschopp MK. Self-management, perceived control, and subjective quality of life in multiple sclerosis: An exploratory study. Rehabil Couns Bull [Internet]. 2008 October;52:46–56.

19. Verity D, Eccles FJRR, Boland A, Simpson J. Does perceived control mediate the relationship between stigma and well-being for individuals with Parkinson's disease? J Neurol Sci [Internet]. 2020 July 15;414:116841.

20. Walihagen MI, Brod M, Reimer M, Lindgren CL. Perceived Control and Well-Being in Parkinson's Disease. West J Nurs Res [Internet]. 1997 February 1;19:11–31.

21. Kalia L V, Lang AE. Parkinson's disease. Lancet [Internet]. 2015;24:92–98.

22. Weintraub D, Burn DJ. Parkinson's disease: the quintessential neuropsychiatric disorder. Mov Disord [Internet]. 2011 May;26:1022–1031.

23. Dorsey ER, Constantinescu R, Thompson JP, Biglan KM, Holloway RG, Kieburtz K, Marshall FJ, Ravina BM, Schifitto G, Siderowf A, et al. Projected

number of people with Parkinson disease in the most populous nations, 2005 through 2030. Neurology [Internet]. 2007 January 30 [cited 2019 November 17];68:384–386.

24. Willis AW, Schootman M, Kung N, Racette BA. Epidemiology and neuropsychiatric manifestations of Young Onset Parkinson's Disease in the United States. Park Relat Disord [Internet]. 2013;19:202–206.

25. Daley DJ, Deane KHOO, Gray RJ, Clark AB, Pfeil M, Sabanathan K, Worth PF, Myint PK. Adherence therapy improves medication adherence and quality of life in people with Parkinson's disease: a randomised controlled trial. Int J Clin Pract [Internet]. 2014 August 1;68:963–971.

26. Simpson J, McMillan H, Reeve D. Reformulating psychological difficulties in people with Parkinson's disease: The potential of a social relational approach to disablism. Parkinsons Dis. 2013;2013.

27. Zarotti N, Eccles FJR, Foley JA, Paget A, Gunn S, Leroi I, Simpson J. Psychological interventions for people with Parkinson's disease in the early 2020s: Where do we stand? Psychol Psychother Theory, Res Pract. 2021;94:760–797.

28. Ghazi-Noori S, Chung TH, Deane K, Rickards HE, Clarke CE. Therapies for depression in Parkinson's disease. Cochrane Database Syst Rev. 2003;2010.

29. Maffoni M, Giardini A, Pierobon A, Ferrazzoli D, Frazzitta G. Stigma Experienced by Parkinson's Disease Patients: A Descriptive Review of Qualitative Studies. Parkinsons Dis. 2017;2017.

30. Macleod AD, Grieve JWK, Counsell CE. A systematic review of loss of independence in Parkinson's disease. J Neurol. 2016;263:1–10.

31. Prenger MTM, Madray R, Van Hedger K, Anello M, Macdonald PA. Social Symptoms of Parkinson's Disease Stocchi F, editor. Parkinsons Dis [Internet]. 2020 December 31;2020:1–10.

32. Simpson J, Chatzidamianos G, Fletcher I, Perpetuo L, Eccles FJRR. A new scale measuring adaptive perceived control for people with Parkinson's: Initial construction and further validation. J Neurol Sci [Internet]. 2018 August 15;391:77–83.

33. Robinson SA, Lachman ME. Perceived Control and Behavior Change. In: Perceived Control. ; 2016. pp 201–228.

34. Tyack C, Camic PM. Touchscreen interventions and the well-being of people with dementia and caregivers: A systematic review. Int Psychogeriatrics. 2017;29:1261–1280.

35. Barlow MA, Liu SY, Wrosch C. Chronic illness and loneliness in older adulthood: The role of self-protective control strategies. Heal Psychol. 2015;34:870–879.

36. Marks R, Allegrante JP, Lorig K. A Review and Synthesis of Research Evidence for Self-Efficacy-Enhancing Interventions for Reducing Chronic Disability: Implications for Health Education Practice (Part II). Health Promot Pract. 2005;6:37–43.

37. Abou L, Alluri A, Fliflet A, Du Y, Rice LA. Effectiveness of Physical Therapy Interventions in Reducing Fear of Falling Among Individuals with Neurologic Diseases: A Systematic Review and Meta-analysis. Arch Phys Med Rehabil [Internet]. 2021;102:132–154.

38. Grether T, Sowislo JF, Wiese BS. Top-down or bottom-up? Prospective relations between general and domain-specific self-efficacy beliefs during a work-family transition. Pers Individ Dif [Internet]. 2018;121:131–139.

39. Shelton SH. Developing the construct of general self-efficacy. Psychol Rep. 1990;66:987–994.

40. Hortop EG, Wrosch C, Gagné M. The why and how of goal pursuits: Effects of global autonomous motivation and perceived control on emotional well-being. Motiv Emot. 2013;37:675–687.

41. Chipperfield JG, Greenslade L. Perceived control as a buffer in the use of health care services. Journals Gerontol - Ser B Psychol Sci Soc Sci. 1999;54:146–154.

42. Emirza S, Öztürk EB, Şengönül AS. The quality of international mobility experiences, general self-efficacy and job search self-efficacy: A time-lagged investigation. Curr Psychol. 2021;40:1580–1591.

43. Peters M, Godfrey C, McInerney P, Munn Z, Tricco A, Khalil H. Chapter 11: Scoping Reviews (2020 version). In: Aromataris E, Munn Z, editors. JBI Manual for Evidence Synthesis. JBI; 2020. pp 406–451.

44. Grimshaw J. A knowledge synthesis chapter. Canadian Institute of Health Research. 2010.

45. Arksey H, O'Malley L. Scoping studies: towards a methodological framework. Int J Soc Res Methodol [Internet]. 2005;8:19–32.

46. Peters MDJ, Marnie C, Tricco AC, Pollock D, Munn Z, Alexander L, McInerney P, Godfrey CM, Khalil H. Updated methodological guidance for the conduct of scoping reviews. JBI Evid Implement [Internet]. 2021;19.

47. Cutler DM. Behavioral Health Interventions: What Works and Why? In: National Research Council (US) Panel on Race, Ethnicity and H in LL, editor. Critical Perspectives on Racial and Ethnic Differences in Health in Late Life. National Academies Press (US); 2004. pp 643–676.

48. Schwarzer R, Jerusalem M. Generalized Self-Efficacy scale. In: Weinman J, editor. Measures in health psychology: a user's portfolio. Causal and control beliefs. Windsor: NFER-NELSON; 1995. pp 35–37.

49. Thompson SC, Spacapan S. Perceptions of Control in Vulnerable Populations. J Soc Issues. 1991;47:1–21.

50. Wallston KA, Stein MJ, Smith CA. Form C of the MHLC Scales: A Condition-Specific Measure of Locus of Control. J Pers Assess. 1994;63:534–553.

51. Hindle J V, Watermeyer TJ, Roberts J, Brand A, Hoare Z, Martyr A, Clare L. Goal-orientated cognitive rehabilitation for dementias associated with Parkinson's disease-A pilot randomised controlled trial. Int J Geriatr Psychiatry [Internet]. 2018 May;33:718–728.

52. Connor KI, Cheng EM, Barry F, Siebens HC, Lee ML, Ganz DA, Mittman BS, Connor MK, Edwards LK, McGowan MG, et al. Randomized trial of care management to improve Parkinson disease care quality. Neurology [Internet]. 2019;92:E1831–E1842.

53. Advocat J, Enticott J, Vandenberg B, Hassed C, Hester J, Russell G. The effects of a mindfulness-based lifestyle program for adults with Parkinson's disease: A mixed methods, wait list controlled randomised control study. BMC Neurol [Internet]. 2016 September 8;16:166.

54. Sajatovic M, Ridgel AL, Walter EM, Tatsuoka CM, Colón-Zimmermann K, Ramsey RK, Welter E, Gunzler SA, Whitney CM, Walter BL. A randomized trial of individual versus group-format exercise and self-management in individuals with Parkinson's disease and comorbid depression. Patient Prefer Adherence [Internet]. 2017 May 19;11:965–973.

55. Vandenberg BE, Advocat J, Hassed C, Hester J, Enticott J, Russell G. Mindfulness-based lifestyle programs for the self-management of Parkinson's disease in Australia. Health Promot Int [Internet]. 2019 August 1;34:668–676.

56. Pappa K, Doty T, Taff SD, Kniepmann K, Foster ER. Self-Management Program Participation and Social Support in Parkinson's Disease: Mixed Methods Evaluation. Phys Occup Ther Geriatr [Internet]. 2017 April;35:81–98.

57. Lorig K, Stewart A, Ritter P, González V, al et. Outcome measures for health education and other health care interventions. Thousand Oaks, CA, US: Sage Publications, Inc; 1996.

58. Soundy A, Collett J, Lawrie S, Coe S, Roberts H, Hu M, Bromley S, Harling P, Reed A, Coeberg J, et al. A qualitative study on the impact of first steps-a peer-led educational intervention for people newly diagnosed with Parkinson's disease. Behav Sci (Basel) [Internet]. 2019 October 10;9:107.

59. Wallston BS, Wallston K a, Kaplan GD, Maides S a. Development and validation of the health locus of control (HLC) scale. J Consult Clin Psychol [Internet]. 1976 August;44:580–5.

60. Ritter VC, Bonsaksen T. Improvement in quality of life following a multidisciplinary rehabilitation program for patients with Parkinson's disease. J Multidiscip Healthc [Internet]. 2019 March 20;12:219–227.

61. Prewitt CM, Charpentier JC, Brosky JA, Urbscheit NL. Effects of Dance Classes on Cognition, Depression, and Self-Efficacy in Parkinson's Disease. Am J Danc Ther [Internet]. 2017 June;39:126–141.

62. Bognar S, DeFaria A, O'Dwyer C, Pankiw E, Simic J, Nyhof-Young J, Teixeira S, Evans C. More Than Just Dance: Experiences of People with Parkinson's Disease in a Dance Program...Canadian Physiotherapy Association National Congress 2016 May 26-28 Victoria BC. Physiother Canada [Internet]. 2016 May 2;68:37.

63. Morris ME, Slade SC, Wittwer JE, Blackberry I, Haines S, Hackney ME, McConvey VB. Online Dance Therapy for People with Parkinson's Disease: Feasibility and Impact on Consumer Engagement. Neurorehabil Neural Repair [Internet]. 2021 September 29:15459683211046254.

64. Cucca A, Di Rocco A, Acosta I, Beheshti M, Berberian M, Bertisch HC, Droby A, Ettinger T, Hudson TE, Inglese M, et al. Art therapy for Parkinson's disease. Park Relat Disord [Internet]. 2021 March;84:148–154.

65. Gruber-Baldini AL, Velozo C, Romero S, Shulman LM. Validation of the PROMIS® measures of self-efficacy for managing chronic conditions. Qual Life Res An Int J Qual Life Asp Treat Care Rehabil [Internet]. 2017 July;26:1915–1924.

66. Wallston KA. The validity of the Multidimensional Health Locus of Control scales. J Health Psychol. 2005;10:623–631.

67. Estrada-Bellmann I, Meléndez-Flores JD, Cámara-Lemarroy CR, Castillo-Torres SA. Determinants of self-efficacy in patients with Parkinson's disease. Arq Neuropsiquiatr [Internet]. 2021 August;79:686–691.

68. Shulman LM, Velozo C, Romero S, Gruber-Baldini AL. Comparative study of PROMIS® self-efficacy for managing chronic conditions across chronic neurologic disorders. Qual Life Res An Int J Qual Life Asp Treat Care Rehabil [Internet]. 2019 July 26;28:1893–1901.

69. Nilsson MH, Hagell P, Iwarsson S. Psychometric properties of the General Self-Efficacy Scale in Parkinson's disease. Acta Neurol Scand [Internet]. 2015 August;132:89–96.

70. Pagnini F, Bercovitz K, Langer E. Perceived control and mindfulness: Implications for clinical practice. J Psychother Integr. 2016;26:91–102.

71. Prinsen CAC, Vohra S, Rose MR, King-Jones S, Ishaque S, Bhaloo Z, Adams D, Terwee CB. Core Outcome Measures in Effectiveness Trials (COMET) initiative: Protocol for an international Delphi study to achieve consensus on how to select outcome measurement instruments for outcomes included in a "core outcome set." Trials. 2014;15:1–7.

72. Nowell LS, Norris JM, White DE, Moules NJ. Thematic Analysis: Striving to Meet the Trustworthiness Criteria. Int J Qual Methods. 2017;16:1–13.

73. Zarotti N, Dale M, Eccles F, Simpson J. Psychological Interventions for People with Huntington's Disease: A Call to Arms. J Huntingtons Dis [Internet]. 2020 September 4 [cited 2020 September 5];9:231–243.

74. Zarotti N, Mayberry E, Ovaska-Stafford N, Eccles F, Simpson J. Psychological interventions for people with motor neuron disease: a scoping review. Amyotroph Lateral Scler Front Degener. 2021;22:1–11.

75. Simpson J, Eccles FJ, Zarotti N. Extended evidence-based guidance on psychological interventions for psychological difficulties in individuals with Huntington's disease, Parkinson's disease, motor neurone disease, and multiple sclerosis. 2021.

76. Kabat-Zinn J. Mindfulness-Based Interventions in Context: Past, Present, and Future. Clin Psychol Sci Pract [Internet]. 2006 May 11 [cited 2019 September 8];10:144–156.

77. Teasdale JD, Segal Z V., Williams JMG, Ridgewaya VA, Soulsby JM, Lau MA. Prevention of relapse/recurrence in major depression by mindfulness-based cognitive therapy. J Consult Clin Psychol. 2000;68:615–623.

78. Bognar S, DeFaria AM, O'Dwyer C, Pankiw E, Simic Bogler J, Teixeira S, Nyhof-Young J, Evans C. More than just dancing: experiences of people with Parkinson's disease in a therapeutic dance program. Disabil Rehabil [Internet]. 2017 June;39:1073–1078.

79. Adams E V., Van Puymbroeck M, Walter A, Hawkins BL, Schmid AA, Sharp JL. Predictors of Functional Improvements After Therapeutic Yoga Intervention for People with Parkinson's Disease. Int J Yoga Therap [Internet]. 2020 January 1;30:9–18.

80. Allen NE, Canning CG, Sherrington C, Lord SR, Latt MD, Close JCT, O'Rourke SD, Murray SM, Fung VSC. The effects of an exercise program on fall risk factors in people with Parkinson's disease: A randomized controlled trial. Mov Disord [Internet]. 2010 July 15;25:1217–1225.

81. Annesi JJ. Effects of a Group Protocol on Physical Activity and Associated Changes in Mood and Health Locus of Control in Adults with Parkinson Disease and Reduced Mobility. Perm J [Internet]. 2019;23:18–128.

82. Bae YS, Kim DH. The Applied Effectiveness of Clay Art Therapy for Patients with Parkinson's Disease. J Evidence-Based Integr Med [Internet]. 2018 January;23:2515690X18765943.

83. Bar A, Czamanski-Cohen J, Federman JD. I Feel Like I Am Flying and Full of Life: Contemporary Dance for Parkinson's Patients. Front Psychol [Internet]. 2021 July 5;12:623721.

84. Bryans LA, Palmer AD, Anderson S, Schindler J, Graville DJ. The impact of Lee Silverman Voice Treatment (LSVT LOUD®) on voice, communication, and participation: Findings from a prospective, longitudinal study. J Commun Disord [Internet]. 2021 January;89:106031.

85. Colón-Semenza C, Latham NK, Quintiliani LM, Ellis TD. Peer coaching through mhealth targeting physical activity in people with parkinson disease: Feasibility study. JMIR mHealth uHealth [Internet]. 2018 February 15;6:e42.

86. Disbrow EA, Russo KA, Higginson CI, Yund EW, Ventura MI, Zhang L, Malhado-Chang N, Woods DL, Sigvardt KA. Efficacy of tailored computer-based neurorehabilitation for improvement of movement initiation in Parkinson's disease. Brain Res [Internet]. 2012 May 3;1452:151–164.

87. Eggers C, Dano R, Schill J, Fink GR, Hellmich M, Timmermann L, Adams S, Assmann K, Böhme A, Bonmann E, et al. Patient-centered integrated healthcare improves quality of life in Parkinson's disease patients: a randomized controlled trial. J Neurol [Internet]. 2018 April;265:764–773.

88. Finnimore A, Theodoros D, Rumbach AF. PD Check-In: The development and trial of a supported self-management program for people with Parkinson's disease following intensive speech intervention. Int J Lang Commun Disord [Internet]. 2021 November 12:1.

89. Fontanesi C, DeSouza JFX. Beauty That Moves: Dance for Parkinson's Effects on Affect, Self-Efficacy, Gait Symmetry, and Dual Task Performance. Front Psychol. 2021;11:1–18.

90. Ghahari S, Packer TL, Passmore AE. Development, standardisation and pilot testing of an online fatigue self-management program. Disabil Rehabil [Internet]. 2009;31:1762–1772.

91. Hermanns M, Haas BK, Lisk J. Engaging Older Adults with Parkinson's Disease in Physical Activity Using Technology: A Feasibility Study. Gerontol Geriatr Med [Internet]. 2019 April 30;5:233372141984267.

92. Joseph C, Leavy B, Franzén E. Predictors of improved balance performance in persons with Parkinson's disease following a training intervention: analysis of data from an effectiveness-implementation trial. Clin Rehabil [Internet]. 2020 June;34:837–844.

93. Koch SC, Mergheim K, Raeke J, Machado CB, Riegner E, Nolden J, Diermayr G, von Moreau D, Hillecke TK. The embodied self in Parkinson's Disease: Feasibility of a single tango intervention for assessing changes in psychological health outcomes and aesthetic experience. Front Neurosci [Internet]. 2016 July 7;10:287.

94. Larson D, Yeh C, Rafferty M, Bega D. High satisfaction and improved quality of life with Rock Steady Boxing in Parkinson's disease: results of a large-scale survey. Disabil Rehabil [Internet]. 2021 August 3;0:1–8.

95. Lebrun C, Gély-Nargeot MC, Rossignol A, Geny C, Bayard S. Efficacy of cognitive behavioral therapy for insomnia comorbid to Parkinson's disease: A focus on psychological and daytime functioning with a single-case design with multiple baselines. J Clin Psychol [Internet]. 2020 March;76:356–376.

96. López-Larrosa S. Quality of Life, Treatment Adherence, and Locus of Control: Multiple Family Groups for Chronic Medical Illnesses. Fam Process [Internet]. 2013 December;52:685–696.

97. Lyons KS, Zajack A, Greer M, Chaimov H, Dieckmann NF, Carter JH. Benefits of a Self-Management Program for the Couple Living With Parkinson's Disease: A Pilot Study. J Appl Gerontol [Internet]. 2021 August;40:881–889.

98. Macht M, Gerlich C, Ellgring H, Schradi M, Rusiñol ÀB, Crespo M, Prats A, Viemerö V, Lankinen A, Bitti PER, et al. Patient education in Parkinson's disease: Formative evaluation of a standardized programme in seven European countries. Patient Educ Couns [Internet]. 2007 February;65:245–252.

99. Murdoch KC, Larsen D, Edey W, Arsenault C, Howell A, Joyce A, Sandham T, Miyasaki JM. The efficacy of the Strength, Hope and Resourcefulness Program for people with Parkinson's disease (SHARP-PWP): A mixed methods study. Park Relat Disord [Internet]. 2020;70:7–12.

100. Nelson N, Wong D, Lai E. A self-management program for veterans and spouses living with Parkinson's disease. J Nurs Healthc Chronic Illn [Internet]. 2011 December;3:496–503.

101. Pacchetti C, Mancini F, Aglieri R, Fundaró C, Martignoni E, Nappi G. Active music therapy in Parkinson's disease: An integrative method for motor and emotional rehabilitation. Psychosom Med [Internet]. 2000 May;62:386–393.

102. Pretzer-Aboff I, Galik E, Resnick B. Feasibility and impact of a function focused care intervention for Parkinson's disease in the community. Nurs Res [Internet]. 2011 July;60:276–283.

103. Rodgers SH, Schütze R, Gasson N, Anderson RA, Kane RT, Starkstein S, Morgan-Lowes K, Egan SJ. Modified Mindfulness-Based Cognitive Therapy for Depressive Symptoms in Parkinson's Disease: A Pilot Trial. Behav Cogn Psychother [Internet]. 2019 July;47:446–461.

104. Rutten S, Vriend C, Smit JH, Berendse HW, Van Someren EJW, Hoogendoorn AW, Twisk JWR, Van Der Werf YD, Van Den Heuvel OA. Bright light therapy for depression in Parkinson disease: A randomized controlled trial. Neurology [Internet]. 2019;92:E1145–E1156.

105. Song J, Paul SS, Caetano MJD, Smith S, Dibble LE, Love R, Schoene D, Menant JC, Sherrington C, Lord SR, et al. Home-based step training using videogame technology in people with Parkinson's disease: a single-blinded randomised controlled trial. Clin Rehabil [Internet]. 2018 March;32:299–311.

Table 1

Logic Grid for Search Strategy.

Population	Subconstructs of control
Parkinson* disease	Adaptive control
	Control belief*
	Learn* helplessness
	Loc* of control
	Mastery
	Perceived control
	Perception* of control
	Personal control
	Primary control
	Secondary control
	Self-efficacy
	Symptom* control

Table 2

Overview of Adopted Search Terms and Identified Items per Database.

Search terms
(Parkinson* disease AND Adaptive control) OR (Parkinson* disease AND Control belief*) OR (Parkinson* disease AND Learn* helplessness) OR (Parkinson* disease AND Loc* of control) OR (Parkinson* disease AND Mastery) OR (Parkinson* disease AND Perceived control) OR (Parkinson* disease AND Perception* of control) OR (Parkinson* disease AND Personal control) OR (Parkinson* disease AND Primary control) OR (Parkinson* disease AND Secondary control) OR (Parkinson* disease AND Self-efficacy) OR (Parkinson* disease AND Symptom* control)

Table 3

Key Characteristics of Included Studies.

Study	Category	Country	Design	Sample	Intervention	Relevant outcome	Type of outcome	Relevant measures	Type of measure	Key results
[51]	Cognitive	UK	RCT	I: 10 RT: 10 TAU: 9	Goal-orientated cognitive rehabilitation	Self-efficacy	Secondary	GSE	General	Significant improvement for self-efficacy in the intervention group compared to RT at post-intervention not maintained at 6 months. No change compared to TAU.
[52]	Educational	USA	RCT	I: 162 C: 166	Care Coordination for Health Promotion and Activities in Parkinson's Disease (CHAPS)	Self-efficacy	Secondary	GSE	General	No significant changes in self-efficacy between groups or within-participants at post-intervention.
[53]	Mindfulness-based	Australia	RCT	I: 35 C: 37	Mindfulness-based lifestyle program	Locus of control	Secondary	MHLC Form B	Multi-domain	Significant difference between groups observed only in internal locus of control at post-intervention, but small effect size (Cohen's d = 0.28) and not maintained at 6-month follow-up.

										Relatively high attrition – samples reduced from 35-37 at baseline to 24-33 at post-intervention and 23-25 at 6-month at follow-up.
[54]	Physical	USA	RCT	I: 15 C: 15	Enhanced EXerCisE thErapy for PD (EXCEED)	Self-efficacy	Secondary	GSE	General	No significant changes in self-efficacy between groups or within-participants at post-intervention.
[55]	Mindfulness-based	Australia	Qualitative (thematic – part of Advocat et al., 2016)	12	Mindfulness-based lifestyle programme	General perceived control	N/A	N/A	General	Perceived control identified as a fundamental and pervasive theme. Some PwP suggested they developed a more achievable view of control following the programme. At follow-up, some PwP reported a renewed view of control as part of taking responsibility and ownership over thoughts through mindfulness training.
[56]	Educational	USA	Non-randomised trial Qualitative (thematic)	I: 27 C: 19	Stanford Chronic Disease Self-Management Program (CDSMP)	Self-efficacy	Secondary	CDSES	Multi-domain	No significant changes in self-efficacy at post-intervention. Increased self-efficacy in accessing resources and addressing disease-related challenges reported by PwP in qualitative interviews.

[57]	Educational	UK	Qualitative (phenomenological)	18	Peer-led Educational Intervention (‘First Steps’)	General perceived control	N/A	N/A	General	Importance of perceived control, particularly taking control and action to enable living with Parkinson’s, emerged as a subtheme.
[60]	Physical	Norway	Uncontrolled pre-post	83	Rehabilitation programme based on Parkinson Wellness Recovery®	Self-efficacy	Primary	GSE	General	Significant improvement in self-efficacy of PwP at post-intervention, but small effect size (Cohen's d = 0.28).
[61]	Physical	USA	Uncontrolled pre-post	6	Dance programme (‘Let's Dance!’)	Self-efficacy	Primary	GSE	General	No significant changes in self-efficacy of PwP at post-intervention.
[63]	Physical	Australia	Qualitative (thematic)	13	Online dance therapy (ParkinDANCE Online)	Mastery	N/A	N/A	N/A	Increased sense of mastery reported by participants as result of the programme.
[64]	Physical	USA	Uncontrolled pre-post	I: 15 C: 12	Art therapy	Self-efficacy	Secondary	PROMIS SEMCC	Multi-domain	No significant changes in self-efficacy for PwP post-intervention.
[78]	Physical	Canada	Qualitative (content analysis)	10	Therapeutic dance programme	General perceived control Locus of control	N/A	N/A	N/A	Increased sense of control over life and disease and shift to more internal locus of control reported by PwP following the programme.

Note. C = control; CDSES = Chronic Disease Self-Efficacy Scale; GSE = General Self-Efficacy Scale; I = intervention; MHLC Form B = Multidimensional Health Locus of Control Form B; PROMIS SEMCC = Patient-Reported Outcomes Measurement Information System Self-Efficacy for Managing Chronic Conditions; RCT = randomised controlled trial; RT = relaxation training; TAU = treatment as usual.

Table 4

Studies Excluded Following Full-Text Review.

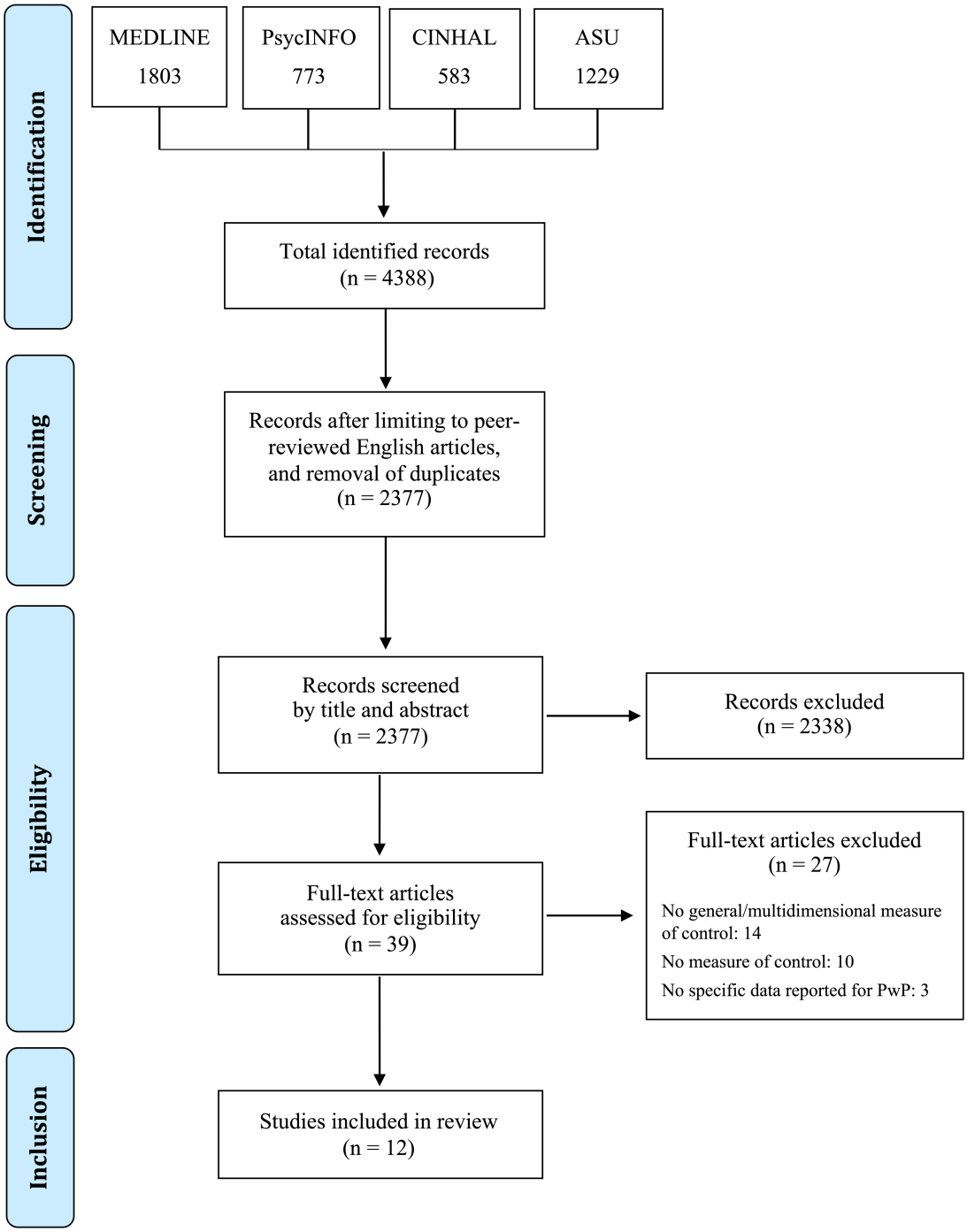
Study	Design	Intervention	Reason for exclusion
[79]	RCT	Therapeutic yoga	No general/multidimensional measure of control
	RCT	Exercise programme	No general/multidimensional measure of control
[80]	Uncontrolled pre-post (post-hoc)	Physical activity/self-regulatory skills intervention	No general/multidimensional measure of control
	Non-randomised trial	Clay art therapy	No measure of control
[81]	Non-randomised trial	Contemporary dance classes	No general/multidimensional measure of control
	Uncontrolled pre-post	Lee Silverman Voice Treatment (LSVT LOUD®)	No measure of control
[82]	Uncontrolled pre-post	Peer mentored walking programme	No general/multidimensional measure of control
	Non-randomised trial	Computer-based neurorehabilitation	No measure of control
[83]	RCT	Integrated patient- centred healthcare approach	No measure of control
	Uncontrolled pre-post	Supported self-management program (PD Check-In)	No measure of control
[84]	Uncontrolled pre-post	Dance classes	No general/multidimensional measure of control
	Uncontrolled pre-post	Online fatigue self-management programme	No specific data reported for PwP
[85]	Uncontrolled pre-post	Physical intervention using Fitbits and iPads	No general/multidimensional measure of control
	RCT	Balance training	No measure of control
[86]	Uncontrolled pre-post	Single tango intervention	No general/multidimensional measure of control
	Uncontrolled pre-post (post-hoc)	Rock Steady Boxing (RSB)	No general/multidimensional measure of control
[87]	Multiple-baseline single-case experimental design	CBT for insomnia	No general/multidimensional measure of control

	Uncontrolled pre-post	Multiple Family Groups intervention	No specific data reported for PwP
[88]	Non-randomised trial	Self-management program for couples living with Parkinson's	No general/multidimensional measure of control
	Uncontrolled pre-post	Patient education programme	No measure of control
[89]	RCT	Strength, Hope, and Resources Program for People with PD (SHARP-PWP)	No general/multidimensional measure of control
	RCT	Self-management program for veterans with PD and their partners	No specific data reported for PwP
[90]	RCT	Music therapy	No measure of control
	Uncontrolled pre-post	Function focused care intervention	No general/multidimensional measure of control
[91]	RCT	Mindfulness-Based Cognitive Therapy	No measure of control
	RCT	Bright light therapy	No measure of control
[92]	RCT	Home-based videogame step training	No general/multidimensional measure of control

Note. CBT = cognitive behavioural therapy; PwP = people with Parkinson's; RCT = randomised controlled trial.

Figure 1

PRISMA Diagram for Selection of Studies.



Chapter Three

Empirical Paper

Perceived Control as a Predictor of Medication Adherence in People with Parkinson's: A Large-Scale Cross-Sectional Study

Nicolò Zarotti[a*], Katherine Helen O'Leary Deane[b],

Catherine Elaine Longworth Ford[a], Jane Simpson[c]

Submitted to the *Disability and Rehabilitation* – Under Review

(Instructions for Authors in Appendix A)

[a] Department of Clinical Psychology and Psychological Therapies, University of East Anglia, Norwich, UK

[b] School of Health Sciences, University of East Anglia, Norwich, UK

[c] Division of Health Research, Lancaster University, Lancaster, UK

---

[*] Corresponding author. E-mail: n.zarotti@uea.ac.uk. Address: Department of Clinical Psychology and Psychological Therapies, Norwich Medical School, University of East Anglia, Norwich, UK

Abstract

Purpose: Medication adherence is a multi-faceted construct associated with several positive consequences in people with chronic conditions. However, non-adherence currently represents a major issue in Parkinson's, potentially due to low perceptions of control. This study investigated the predictive ability of several subconstructs of perceived control on adherence in people with Parkinson's, while accounting for previously established predictors such as depression and medication variables.

Materials and Methods: An online cross-sectional survey was carried out with 1210 adults with Parkinson's from 15 English-speaking countries. Demographic and clinical questions, as well as measures of depression, subconstructs of perceived control, and medication adherence were included. Pearson's correlations and a 4-block hierarchical regression analysis were performed to assess the relationship between the variables.

Results: Perceived control explained a slightly higher amount of variance in medication adherence compared to medication variables when entered in the last block. Internal locus of control was an independent negative predictor of adherence, while external dimensions of locus of control emerged as independent positive predictors. Unexpectedly, depression was not significantly related with adherence.

Conclusions: In people with Parkinson's, perceptions of control may have a larger impact on adherence compared to medication variables. Implications for clinical practice and future research are discussed.

Implications for Rehabilitation

- Perceived control and depression are considered important constructs for medication adherence in Parkinson's, which in turn is often problematic for affected individuals.
- The specific predictive value of different subconstructs of perceived control on medication adherence in Parkinson's is currently unclear.
- This large-scale study found that perceptions of control may have a greater impact on adherence compared to medication variables, while depression was unrelated to it.
- Although treating depression might not help with adherence in Parkinson's, increasing patients' sense of control may represent an effective therapeutic avenue for clinicians.

Introduction

Parkinson's[1] is the second most common neurodegenerative condition in older people after Alzheimer's disease [1]. It is associated with movement disorders, including bradykinesia, muscular rigidity, resting tremor, and postural and gait impairment, as well as cognitive difficulties leading to dementia [2]. In addition, a range of psychological difficulties – such as low mood, anxiety, apathy, reduced impulse control, and more rarely hallucinations [3] – can be experienced by people with Parkinson's (PwP). As there is currently no cure for the condition, symptomatic treatments represent the cornerstone of its clinical management [2]. Many PwP take a number of different medications, especially at later stages [4], and are 40% more likely to be on five to nine repeated prescriptions compared to the general population [5]. These medications often include neurological (e.g., levodopa) and psychiatric (e.g., antidepressants, anxiolytics) treatments, need to be taken at very specific times, and have potentially serious side effects that require close monitoring and multiple daily doses [6]. As a consequence, it is perhaps not surprising that up to 70% of PwP do not adhere partially or completely to the prescribed medication regimen [6], making medication adherence a major issue in Parkinson's, arguably more than in other complex conditions [5,7].

Medication adherence can be defined as the extent to which patients' medication behaviour is consistent with the medical guidance provided [8]. It is

[1] The term 'Parkinson's' has been adopted in this manuscript as Parkinson's UK's preferred way to address this population in order to reduce the stigma associated with the term 'disease'.

associated with a wide range of positive consequences, including better clinical outcomes, fewer remissions, and increased quality of life [9]. As a consequence, non-adherence represents a major issue in modern healthcare, and is believed to be influenced by multiple components, such as healthcare settings, socio-economic variables, therapy regimens, health conditions, and patients' behaviour [10]. Accordingly, factors such as comorbid health problems, side effects, and the frequency and complexity of treatments have all been traditionally proposed to explain non-adherence in individuals with Parkinson's [11,12]. Psychological factors also play a pivotal role [13], as psychological difficulties have been shown to influence medication adherence in PwP [14,15]. In particular, higher levels of depression have consistently proved to predict lower adherence [16–19], mirroring a finding which has been historically reported with older people in general [20,21]. As depression is estimated to affect up to 50% of PwP [22], it could be hypothesised that its successful management would be a viable route to tackle non-adherence in this population. However, this was not supported by a systematic review suggesting that the association between depression and adherence in PwP is unclear and needs further investigation [14].

Perceived control – defined as beliefs about the extent of one's influence over internal states, behaviours, environments, and outcomes [23] – may also affect medication adherence in PwP [24]. These beliefs are often conceptualised as a number of distinct subconstructs [25,26], which may include: a) mastery (feeling in control of health and social aspects of life; [27]); b) locus of control (or 'LOC', attributing outcomes to own's effort rather than external forces; [28]; symptom control (feeling in control over symptoms and treatment; [29]); c) adaptive control (feeling capable of

adapting to events in life; [25]); and d) self-efficacy (control over the execution of actions required by an outcome; [30]). Along with its subconstructs, perceived control is thought to play a pivotal role in the successful adjustment not only to chronic illness in general [31], but also to neurodegenerative diseases specifically [32,33], including Parkinson's [34]. Moreover, it has been consistently associated with medication adherence in people with chronic conditions, with internal locus of control, increased feelings of personal and symptom control, and higher self-efficacy found to predict higher levels of adherence in several clinical populations [35,36] – again including Parkinson's [37,38].

A number of studies have tested the extent to which depression and specific subconstructs of perceived control predict medication adherence in PwP (e.g., [37–39]). However, to our knowledge no study to date has investigated the role of these constructs as predictors of adherence in Parkinson's within the same multifactorial model, nor which subconstruct of perceived control most strongly predicts adherence. This represents a considerable limitation in the current literature, since evidence has shown that psychosocial interventions can successfully improve perceptions of control in individuals with Parkinson's [40–42] as well as other chronic conditions [43,44].

As a consequence, the aim of the present study was to test the extent to which different subconstructs of perceived control predict medication adherence in PwP after taking into account demographics as well as medication and clinical variables, including depression. More specifically, it was hypothesised that perceived control would explain a higher amount of variance in adherence after controlling for the predictive value of other variables.

Methods

Design

The present study adopted an online cross-sectional survey design, consisting of demographic and clinical questions, as well as measures of depression, different subconstructs of perceived control (mastery, adaptive control, symptom control, self-efficacy, locus of control), and medication adherence.

Participants

Convenience sampling methods were used. Eligible and potentially interested PwP were offered the opportunity to participate by voluntary sector organisations (e.g., Parkinson's organisations) and through social media channels (Facebook and Twitter; see Appendix D for the advertising materials). To be eligible for the study, participants had to be a) aged 18 or older; b) living in a country where English was one of the official languages; c) diagnosed with idiopathic Parkinson's disease; d) currently taking any medications for Parkinson's disease. Informed consent was obtained from all participants via an electronic form presented on a webpage at the beginning of the survey (Appendix G).

An a priori power calculation based on the overall R^2 significance for a multiple regression analysis – assuming a medium effect size (f^2 = .15) with a projected inclusion of 10 to 20 predictors and an α level of p = 0.05 – indicated that between 118 and 157 participants were required to achieve a .80 level of power.

Measures

The following measures were adopted in the present study. For full copyright-free copies, please refer to Appendix I.

Predictors

Demographic and Clinical Information. Participants responded to questions about demographic variables (e.g., age, gender, country, and ethnicity) and their condition and its treatment (e.g., time since diagnosis, disease severity, comorbidities, complexity of medication regime, access to medication).

Parkinson's Disease Questionnaire - 8 (PDQ-8; [45]). The PDQ-8 measures perceived disease severity over eight dimensions: mobility, activities of daily life, emotional well-being, social support, cognition, communication, bodily discomfort, and stigma. It yields a standardised score (0 – 100), with higher scores indicating higher disease impact, and has consistently demonstrated good validity and reliability (Cronbach's α = .73 - .88 [46]).

Geriatric Depression Scale – Short Form (GDS-15; [47]). The GDS-15 is a 15-item self-report questionnaire which measures depression in older adults. The items are based on yes/no questions, with a cumulative higher score indicating higher levels of depression. It is among the most frequently adopted measures for depression in PwP due to its excellent psychometric properties (e.g., high discriminant validity and Cronbach's α of .92; [48]) as well as low overlap with symptoms of potential physical comorbidities [49]. A cut-off of 4/5 is suggested as optimal to distinguish between depressed and non-depressed individuals [50].

Pearlin Mastery Scale (PMS; [27]). The PMS is a self-report measure of perceived mastery, consisting of seven items rated on a 7-point rating scale. It yields a total score out of 35, with higher scores representing higher perceived mastery. The scale has been previously used with PwP [51], showing good validity and reliability (Cronbach's α = .70).

Multidimensional Health Locus of Control – Form C (MHLC-C; [52]). The MHLC-C is an 18-item self-report measure assessing LOC in people with an existing health condition on a 6-point rating scale. It examines four main LOC dimensions, each yielding an independent score: Internal (i.e., attributing control of outcomes to oneself), Chance (i.e., attributing control of outcomes to chance), Doctors (i.e., attributing control of outcomes to doctors or other clinicians), and Other People (i.e., attributing control of outcomes to significant others). Higher scores indicate the higher prominence of each attributional style. The MHLC-C has been used with PwP before, showing good validity as well as acceptable to good reliability across its dimensions (e.g., Cronbach's α ranging from .60 to .80; [53,54].

Symptom Control Scale (SCS, [29]). The SCS consists of six items rated on a 6-point rating scale, with higher scores indicating higher levels of perceived symptom control in people with an existing health condition. Although it has not been used with PwP before, it has consistently shown good to excellent psychometric properties when used with people with other chronic diseases (Cronbach's α = .80 - .89; [55]).

Parkinson's UK Scale of Perceived Control (PUKSoPC; [56]). The PUKSoPC is a self-report 15-item questionnaire evaluating adaptive control in PwP.

It consists of a 5-point rating scale yielding a total out of 75, with higher scores indicating higher levels of adaptive control. The PUKSoPC has been extensively validated with a sample of over 200 PwP, showing good face, concurrent and convergent validity, as well as good test-retest reliability and internal consistency (Cronbach's α ranging from .77 to .92; [56]).

General Self-Efficacy Scale (GSE; [57]). The GSE is a 5-item self-report measure of self-efficacy beliefs about difficult demands in life. It is rated on a 5-point rating scale, yielding a total score ranging out of 50, with higher scores representing higher levels of perceived self-efficacy. The GSE has been previously validated with a sample of PwP, showing excellent psychometric properties (Cronbach's α = .95; [58]).

Outcome variable

Medication Adherence Report Scale (MARS-5; [59,60]). The MARS-5 is a 5-item self-report measure of medication adherence based on a 5-point rating scale. It is worded neutrally to be applicable to any disease and yields a total score out of 25, with higher scores indicating higher levels of adherence. Currently, no self-report adherence scale has been validated for Parkinson's specifically, and none of the scales used previously with PwP fully capture all its components [61]. Therefore, the MARS-5 was chosen in light of its good validity and reliability (Cronbach's α ranging from .67 to .89; [59]), its recognised usefulness in populations with chronic conditions [59], as well as its previous use with PwP [62]. A score below 23 has been suggested as a highly sensitive cut-off for non-adherence (i.e., 89.5%; [63]).

Patient and Public Involvement

Prior to beginning the data collection, Patient and Public Involvement was sought with five individuals with Parkinson's who assessed the acceptability and feasibility of the full draft of the survey.

Procedure

Participants were approached via collaborating associations and social media with a weblink to an information sheet outlining the details of the project (Appendix E). If interested, they were asked to fill in a written consent form (Appendix G) and answer a number of questions to check whether they met the inclusion criteria. Those responding negatively were redirected to another page which politely explained why they were not eligible for the study (Appendix H). Following positive confirmation of the criteria, the full survey was opened (Appendix L), with the order of the standardised questionnaires randomised to prevent any order effects [64]. Missing data were avoided by requiring responses to all of the online questions and recording them only when participants submitted the complete survey. The data collection was carried out between January and June 2021.

Data Analysis

Data were analysed using IBM® SPSS® Statistics 28. Descriptive statistics were collated and compared with established cut-offs where available and the absence of concerning numbers of outliers was confirmed [65]. Two-tailed Pearson's correlations were used to investigate the degree of relationship between variables. Following this, a hierarchical regression analysis was conducted to investigate the

differences in predictive values between demographic, clinical, and medication variables, and different subconstructs of perceived control.

Predictors were entered into the regression model if they correlated significantly with the outcome variable ($p < .05$; [66]). Based on previous similar research [67,68], a 4-block structure theoretically relevant for the hypothesis was planned: 1) Demographics (age, gender); 2) Clinical Variables (time since diagnosis, impact of Parkinson's, comorbidities, depression; 3) Medication Variables (e.g., number of daily doses, paying for medications); 4) Perceived Control Variables (adaptive control, symptom control, mastery, self-efficacy, Internal LOC, Doctors LOC, Other People LOC). This allowed for testing the extent to which variation in medication adherence in PwP could be explained by perceived control after controlling for demographic, clinical, and medication variables, and if so, which subconstruct of perceived control best predicted adherence.

Ethical Approval

This study was reviewed and approved by the Faculty of Medicine and Health Sciences Research Ethics Committee at the University of East Anglia (ref: 2020/21-045). Please refer to Appendix C for the full approval letter.

Results

Characteristics of the Sample

In total, 1210 individuals with Parkinson's from 15 English-speaking countries participated. The majority were female (60.5%, $n = 732$), white ($n = 1143$; 94.5%), native English speakers (96.2 %, $n = 1164$), and 65 years old on average (SD = 9.08,

range: 26 - 89). Most participants came from the United Kingdom (65.3%, *n* = 790), with the second largest group residing in the United States (17.9%, *n* = 217) and the third in Canada (4.2%, *n* = 51). The mean time since diagnosis was 6.58 years (*SD* = 5.30, range: 1 month – 30 years), while the mean perceived impact of Parkinson's was 32.93/100 (i.e., within one *SD* from the PDQ-8 normative sample; [45]). Just over half of the participants reported clinical levels of depression (i.e., GDS-15 > 4; 52.2%, *n* = 632), with a mean score of 5.72 (*SD* = 4.10, range: 0 – 15), corresponding to mild depression. Similarly, the majority reported sub-optimal medication adherence (i.e., MARS-5 < 23; 54.3%, *n* = 657), with a mean score of 21.47 (*SD* = 2.99, range: 9 - 25).

The average number of medication doses per day was 4.36 (*SD* = 1.94, range: 1 – 18). Medications were taken alone (i.e., without the support of a carer) by the majority of PwP (96%; *n* = 1162), typically without having to pay for medication (67.7%, *n* = 819), experiencing physical issues accessing medication (85%, *n* = 1028), and without varying the dosage or the number of doses with their clinical team's approval (76%, *n* = 919). On average, the participants rated their knowledge of the purpose of their Parkinson's medication as moderately high (*M* = 7.23/10; 0 = low, 10 = high), albeit with considerable variability among them (*SD* = 4.40). Slightly less than half of PwP had comorbid physical issues (47.4%, *n* = 573), but the majority took other types of medication besides those for Parkinson's (77.8%, *n* = 941). These included psychiatric medication for around one third of the participants (36.2%, *n* = 438). When asked whether they received any form of psychological support for mental health difficulties, only 8.5% of the participants (*n* = 103) answered positively. The analysis of reliability showed internal consistencies ranging from acceptable to

excellent for all measures (Cronbach's α = .60 – .92; [69]), except for the Other People subscale of the MHLC-C (Cronbach's α = .56), potentially due to its 3-item structure [70]. Table 1 summarises demographic information and Table 2 summarises the participants' scores on standardised measures and the reliability figures.

Correlations

The correlation matrix is illustrated in Table 3. This indicated that only age could be entered in the Demographics block (Block 1), showing a significant negative relationship with adherence (r = -.059, p < .040). In the Clinical Variables block (Block 2), time since diagnosis (r = -.231, p < .001), number of daily doses (r = -.131, p < .001), and perceived impact of Parkinson's (r = -.160, p < .001) were significantly correlated with medication adherence. However, this was not the case with depression, for which no significant relationship was found with the outcome variable (r = -.030, p = .294).

With regards to the Medication Variables, the following emerged as significant correlates of adherence and were entered in Block 3: number of doses per day (r = -.131, p < .001), varying doses with the clinical team's approval (r = -.435, p = <.001), paying for medications (r = -.099, p < .001), knowledge about medication (r = .067, p = .020), physical issues accessing medications (r = -.165, p < .001), and taking medications other than Parkinson's (r = -.074, p = .010).

Finally, Block 4 (Perceived Control Variables) consisted of all tested subconstructs of perceived control, except for symptom control (r = .054, p = .059) and the Chance dimension of LOC (r = .050, p = .083): mastery (r = .058, p = .045), self-efficacy (r = .068, p = .019), adaptive control (r = .058, p = .043), and Internal (r

= -.066, p = .022), Doctors (r = -.235, p < .001) and Other People (r = -.124, p < .001) LOC.

Hierarchical Regression

The hierarchical regression model used is summarised in Table 4. As depression did not correlate significantly with medication adherence, it was not included among the clinical variables in Block 2. All the data were checked to ensure that the assumptions of multiple regression were met. The scatterplots of predictor and outcome variables showed these were linearly related and that the residuals were uncorrelated (Durbin - Watson = 2.062; [71]). Variance inflation factors (VIFs) and tolerance were below 10 and above .2 respectively, indicating no significant multicollinearity, while any issues with heteroscedasticity and non-normality of residuals were resolved via bootstrapping based on 1000 samples [69].

The final regression model was significant ($F_{(15, 1194)}$, p < .001) and explained 15.3% of variance in medication adherence (R^2_{adj} = .153). Age alone (Block 1) explained 0.4% of the variance (p = .004), while the Clinical Variables (Block 2) contributed a further significant 6.6% of variance (ΔR^2 = .066, p < .001). The addition of the Medication Variables (Block 3) accounted for a further significant 4.2% of variance in medication adherence (ΔR^2 = .042, p < .001). Finally, the Perceived Control Variables (Block 4) accounted for an additional significant 5.2% of variance in medication adherence (ΔR^2 = .052, p < .001).

In the final model (Block 4), time since diagnosis (β = -.154, p < .001) and perceived impact of Parkinson's (β = -.101, p = .005) emerged as significant negative predictors among the Demographic Variables. Almost all Medication Variables were

significant predictors – taking other medications (β = .075, p = .006), knowledge of medication: (β = .073, p = .009), having problems physically accessing medication (β = -.093, p = .001), paying for medication (β = -.066, p = .021), varying doses with the clinical team's approval (β = -.122, p < .001).

Among the Perceived Control Variables, the degree to which PwP viewed themselves as having control over outcomes emerged as a negative predictor of medication adherence (Internal LOC; β = -.095, p < .001), whereas attributing more control to doctors (β = .177, p < .001) and other people (β = .086, p = .004) both predicted higher levels of adherence.

Discussion

To our knowledge, this is the largest cross-sectional survey to date to investigate medication adherence in people with Parkinson's (PwP), with most previous studies recruiting fewer than 500 participants (for the latest reviews see [15,72]) – i.e., less than half the sample in the present study.

The results showed that longer disease duration, higher disease impact, physical issues accessing medications, varying doses with the clinical team's approval, and paying for medication significantly predicted lower levels of adherence, while having more knowledge of the condition predicted better adherence. All these findings are consistent with previous evidence [14,15,39,73]. However, more unexpectedly, taking medications other than Parkinson's was a significant predictor of higher medication adherence. While this result appears to contradict the traditional link between polypharmacy and low adherence [11], it may also be seen as a form of

adaptive behaviour, whereby PwP who need to take multiple medications become better at managing them over time.

All subconstructs of perceived control investigated, with the exception of having a sense of control over symptoms or attributing control to chance, were significantly associated with medication adherence. Perceived control explained a slightly higher portion of variance (ΔR^2 = .052) than medication variables (ΔR^2 = .042), even after controlling for all other types of variables, confirming our hypothesis. Internal LOC emerged as a weakly negative predictor of adherence (i.e., if PwP attributed more control over outcomes to themselves, they were slightly less likely to adhere to medication as prescribed). In contrast, Doctors LOC was a stronger positive predictor of adherence (i.e., if PwP attributed more control over outcomes to doctors or other clinicians, they were more likely to adhere to medication as prescribed) and the same was true for those who believed 'Other People' to have control, but to a lesser extent. This suggests that individuals with Parkinson's who attribute more control to themselves are more likely to be non-adherent, whereas those attributing more control to their doctors or significant others show higher levels of adherence.

These findings appear to contradict the traditional view that higher internal LOC is more adaptive from a general psychological perspective [74], and potentially for medication adherence [75]. However, alternative explanations could be hypothesised. First, due to the high heterogeneity and complex medication profile of Parkinson's [76], some PwP may feel an increased need for external advice compared to people with other chronic conditions. This would explain a higher impact of external attributions of control on adherence in our study, and would be consistent with evidence that external LOC may be more advantageous for specific populations (e.g.,

[77,78]). In addition, the way medication adherence is measured by most standardised scales may not fully capture some of the dynamics underlying its relationship with different types of LOC. In particular, patient empowerment, which plays a pivotal role in medication adherence [79], may be overlooked by measures which do not cover intentional deviations from medication regimens agreed with the clinical team. This may be especially relevant for Parkinson's, as a recent systematic review has highlighted that most adherence scales used with PwP to date focus on non-intentional factors [61]. Thus, high levels of adherence on such measures may fail to account for patients' empowerment and agreed shared responsibility over time (Internal LOC), and only reflect the value of medical advice (Doctors LOC; [35]). In turn, this may lead to a systematic misrepresentation of adherence in this population, and may be the case of our results as well, as almost a quarter of the participants in the current study reported varying their doses with the approval of their clinical team – a factor which emerged as a significant negative predictor of adherence in the final regression model. Accordingly, higher levels of Internal LOC predicting lower adherence may suggest that patient empowerment may be captured as a non-adherent behaviour by current measures. As Chance LOC was also found to have no significant relationship with adherence, the present study ultimately appears to support the need, previously highlighted with PwP, "for looking into the interaction effects between Internal LOC and External LOC as well as External LOC subdimensions on medical regimen adherence" [35] (p. 10).

Finally, based on previous studies [14–16,18,19,72], depression was initially predicted to be strongly associated with medication adherence. The fact that it was not in the current study constitutes an unexpected yet major finding in itself, as it fails to

replicate most previous results and may at least partially explain why addressing depression does not seem to improve adherence in PwP [14]. Most explanations for an association between depression and medication adherence in Parkinson's can be traced back to the well-established impact of depression on medication adherence in older people in general [20,21], sometimes associated with a threefold increase in non-adherence rates [80]. The hypothesis that depression is a strong predictor of medication adherence in Parkinson's may reflect an overgeneralisation of evidence from older adults in general, which evolved into a suggestion that "studies on non-Parkinson's populations can help us infer the impact of depression treatment on medication adherence for those with Parkinson's" [15] (p. 10). However, while Parkinson's is a condition that most frequently affects older people [1,2], it is also characterised by high levels of clinical complexity and heterogeneity and may affect people differently than other aspects of ageing or chronic illnesses associated with later life [81,82].

In addition, this surprising finding may at least in part be the product of several methodological issues affecting previous studies. More specifically, the wide and diverse range of subjective and objective measures of adherence adopted, including electronic devices [37], brief dichotomous questionnaires [68], and qualitative accounts [19], feature an equally wide range of advantages and disadvantages which makes it difficult to achieve consistency and standardisation in the process of conducting adherence assessments [15]. Moreover, some studies found a significant relationship between depression and medication adherence when dichotomising continuous data [39] or only at the basic univariate correlation level [68], with no evidence observed when adopting a multiple regression model which included other variables. Finally, most of these studies recruited samples less than half the size of the

current investigation (e.g., N = 1 – 418) and did not provide effect sizes for outcome measures [15,19,37,39], making it difficult to exclude the possibility that the previously reported association between depression and medication adherence was artefactual.

Overall, the overgeneralisation of research from other populations and impact of methodological issues and current findings suggests a need to rethink the relationship between depression and medication adherence in PwP.

Clinical Implications

Our results have several implications for clinical practice. First, the lack of a significant relationship between depression and medication adherence adds to evidence that addressing depression may not improve medication adherence in this population [14]. Secondly, since different subconstructs of perceived control can be targeted selectively by interventions [43,83], psychologically-informed interventions addressing LOC (e.g., cognitive training, empowerment programmes; [35,84]) may have the potential to affect medication adherence in PwP. In addition, only 8.5% of the participants reported receiving any psychological support in this survey, suggesting that the provision of psychological services represents a major issue for PwP and should receive further attention from commissioners and healthcare providers.

Finally, considering the high levels of heterogeneity and complexity which characterise the everyday clinical management of Parkinson's, the development of person-centred approaches to medication management revolving around a shared sense of control between patients and clinicians should be considered in everyday

clinical practice. More specifically, by recognising the role of PwP as experts in their own condition, a balance between the need for internal and external attributions of control might prove easier to achieve and ultimately beneficial for overall medication adherence [35].

Limitations and Future Directions

A number of limitations should be considered when interpreting these findings. First, cross-sectional online surveys have the inherent limitation of reliance on self-report data and potential sampling biases (e.g., receiving more responses from more digitally literate, less depressed, more adherent participants; [85]). In addition, the nature of cross-sectional designs does not allow to draw any conclusions on causality and its direction. Therefore, further research is needed adopting a wider range of measures, in-person recruitment methods, and longitudinal designs.

The Other People subscale of the MHLC-C was the only measure to show a low level of internal consistency (Cronbach's $\alpha = .56$). While this should be considered when interpreting the current results, it should also be noted that levels of internal consistency as low as .50 have been deemed acceptable with subscales characterised by a small number of items [70]. In addition, since no medication adherence scale has been validated for Parkinson's to date [61], the development of a new measure of adherence specifically for PwP is strongly supported.

Finally, as medication adherence in PwP appears to be an extremely complex construct unlikely to be explained by a few factors within a single model or perspective, multiple approaches are needed in order to tackle this degree of complexity from a wider range of perspectives. In particular, integrating quantitative

and qualitative evidence may help shed light into subjective factors and issues associated with adherence [86].

Conclusions

To our knowledge, this is the largest cross-sectional study to investigate the predictors of medication adherence in people with Parkinson's. The results showed that perceived control, a construct which can be addressed and changed by interventions, explained a slightly higher amount of variance in adherence compared to medication variables. Only the Internal, Doctors, and Other People dimensions of LOC emerged as significant independent predictors of medication adherence, while depression showed no significant relationship with the outcome variable. These findings highlight a number of potential clinical implications in individuals with Parkinson's, such as the need for targeted psychologically-informed interventions, person-centred approaches to medication management, and standardised measures of adherence specifically validated for this population.

Declaration of Interest

Katherine Deane, UEA, is supported by the National Institute for Health and Care Research (NIHR) Applied Research Collaboration East of England (NIHR ARC EoE) at Cambridge and Peterborough NHS Foundation Trust. The views expressed are those of the author[s] and not necessarily those of the NIHR or the Department of Health and Social Care.

Funding

The authors received no funding from an external source.

Acknowledgements

The authors wish to express their heartfelt thanks to all the participants of the survey as well as all the Parkinson's organisations which facilitated its dissemination: Parkinson's UK, European Parkinson's Disease Association, Parkinson's Ireland, Parkinson's Canada, Parkinson Association of Alberta, Parkinson's New Zealand, Parkinson's New South Wales, Parkinson's Western Australia, Malta Parkinson's, PMD Alliance, Dancing with Parkinson's, Power for Parkinson's, Barbados Parkinson's Trust, Parkinson's International Foundation. Moreover, they would like to thank the several independent PwP groups on social media such as Facebook, Twitter, and patient fora which greatly widened the reach and value of the study.

References

1. Lebouvier T, Chaumette T, Paillusson S, Duyckaerts C, Bruley Des Varannes S, Neunlist M, Derkinderen P. The second brain and Parkinson's disease. Eur J Neurosci. 2009;30:735–741.

2. Kalia L V, Lang AE. Parkinson's disease. Lancet [Internet]. 2015;24:92–98.

3. Simpson J, McMillan H, Reeve D. Reformulating psychological difficulties in people with Parkinson's disease: The potential of a social relational approach to disablism. Parkinsons Dis. 2013;2013.

4. Daley DJ, Deane KHOO, Gray RJ, Clark AB, Pfeil M, Sabanathan K, Worth PF, Myint PK. Adherence therapy improves medication adherence and quality of life in people with Parkinson's disease: a randomised controlled trial. Int J Clin Pract [Internet]. 2014 August 1;68:963–971.

5. McLean G, Hindle J V., Guthrie B, Mercer SW. Co-morbidity and polypharmacy in Parkinson's disease: Insights from a large Scottish primary care database. BMC Neurol. 2017;17:1–8.

6. Malek N, Grosset DG. Medication adherence in patients with Parkinson's disease. CNS Drugs. 2014;29:47–53.

7. Grosset D, Antonini A, Canesi M, Pezzoli G, Lees A, Shaw K, Cubo E, Martinez-Martin P, Rascol O, Negre-Pages L, et al. Adherence to Antiparkinson medication in a Multicenter European study. Mov Disord. 2009;24:826–832.

8. Julius RJ, Novitsky MA, Dubin WR. Medication adherence: A review of the literature and implications for clinical practice. J Psychiatr Pract. 2009;15:34–44.

9. Mukhtar O, Weinman J, Jackson SHD. Intentional non-adherence to medications by older adults. Drugs and Aging. 2014;31:149–157.

10. World Health Organization. Adherence to long-term therapies. Evidence for action. Geneva; 2003.

11. Wright J, Walker J. Medication adherence in Parkinson's. Br J Nurs. 2013;22:686–689.

12. Bainbridge JL, Ruscin JM. Challenges of Treatment Adherence in Older Patients with Parkinson's Disease. Drugs Aging [Internet]. 2009;26:145–155.

13. Marrero RJ, Fumero A, de Miguel A, Peñate W. Psychological factors involved in psychopharmacological medication adherence in mental health patients: A systematic review. Patient Educ Couns. 2020.

14. Daley DJ, Myint PK, Gray RJ, Deane KHOLOO. Systematic review on factors associated with medication non-adherence in Parkinson's disease. Park Relat Disord [Internet]. 2012 December;18:1053–1061.

15. Straka I, Minár M, Gažová A, Valkovič P, Kyselovič J. Clinical aspects of adherence to pharmacotherapy in Parkinson disease: A PRISMA-compliant systematic review. Med (United States) [Internet]. 2018 June 1;97:e10962.

16. Fleisher JE, Stern MB. Medication nonadherence in Parkinson's disease. Curr Neurol Neurosci Rep. 2013;13.

17. Leopold NA, Polansky M, Hurka MR. Drug adherence in Parkinson's disease. Mov Disord. 2004;19:513–517.

18. Richy FF, Pietri G, Moran KA, Senior E, Makaroff LE. Compliance with pharmacotherapy and direct healthcare costs in patients with Parkinson's disease: a retrospective claims database analysis. Appl Health Econ Health Policy [Internet]. 2013 August;11:395–406.

19. Erickson CL, Muramatsu N. Parkinson's disease, depression and medication adherence: Current knowledge and social work practice. J Gerontol Soc Work [Internet]. 2004 August 18;42:3–18.

20. Krousel-Wood M, Joyce C, Holt E, Muntner P, Webber LS, Morisky DE, Frohlich ED, Re RN. Predictors of decline in medication adherence: Results

from the cohort study of medication adherence among older adults. Hypertension. 2011;58:804–810.

21. Yap AF, Thirumoorthy T, Kwan YH. Systematic review of the barriers affecting medication adherence in older adults. Geriatr Gerontol Int. 2016;16:1093–1101.

22. Reijnders JSAM, Ehrt U, Weber WEJ, Aarsland D, Leentjens AFG. A systematic review of prevalence studies of depression in Parkinson's disease. Mov Disord. 2008;23:183–189.

23. Wallston KA, Wallston BS, Smith S, Dobbins CJ. Perceived control and health. Curr Psychol. 1987;6:5–25.

24. Rubenstein LM, Alloy LB, Abramson LY. Perceived Control and Depression. In: Reich JW, Infurna FJ, editors. Perceived Control. New York: Oxford University Press; 2016. pp 229–252.

25. Chipperfield JG, Perry RP, Stewart TL. Perceived Control. 2nd ed. Elsevier Inc.; 2012.

26. Eccles FJR, Simpson J. A review of the demographic, clinical and psychosocial correlates of perceived control in three chronic motor illnesses. Disabil Rehabil [Internet]. 2011;33:1065–1088.

27. Pearlin LI, Schooler C. The Structure of Coping. J Health Soc Behav. 1978;19:2–21.

28. Rotter J. Generalized expectancies for internal versus external control of reinforcement. Psychol Monogr Gen Appl [Internet]. 1966 [cited 2014 August 23];80.

29. Sirois FM. The Control Beliefs Inventory. Carleton University: Unpublished manual; 2003.

30. Bandura A. Self-efficacy mechanism in human agency. Am Psychol. 1982;37:122–147.

31. Dempster M, Howell D, McCorry NK. Illness perceptions and coping in physical health conditions: A meta-analysis. J Psychosom Res [Internet]. 2015;79:506–513.

32. Zarotti N, Simpson J, Fletcher I. 'I have a feeling I can't speak to anybody': A thematic analysis of communication perspectives in people with Huntington's disease. Chronic Illn [Internet]. 2019 [cited 2018 January 15];15:61–73.

33. Zarotti N, Coates E, McGeachan A, Williams I, Beever D, Hackney G, Norman P, Stavroulakis T, White D, White S, et al. Health care professionals' views on psychological factors affecting nutritional behaviour in people with motor neuron disease: A thematic analysis. Br J Health Psychol [Internet]. 2019 November;24:953–969.

34. Verity D, Eccles FJRR, Boland A, Simpson J. Does perceived control mediate the relationship between stigma and well-being for individuals with Parkinson's disease? J Neurol Sci [Internet]. 2020 July 15;414:116841.

35. Náfrádi L, Nakamoto K, Schulz PJ. Is patient empowerment the key to promote adherence? A systematic review of the relationship between self-efficacy, health locus of control and medication adherence. PLoS One. 2017;12:1–23.

36. Cvengros JA, Christensen AJ, Lawton WJ. The role of perceived control and preference for control in adherence to a chronic medical regimen. Ann Behav Med [Internet]. 2004 June;27:155–161.

37. Grosset KA, Bone I, Grosset DG. Suboptimal medication adherence in Parkinson's disease. Mov Disord. 2005;20:1502–1507.

38. Lim KE, Kim SR, Sung YH, Oh S-Y, Kim MS, Chung SJ. Factors influencing self-management in Parkinson's disease: A cross-sectional study. Geriatr Nurs (Minneap) [Internet]. 2020 May;41:254–260.

39. Valldeoriola F, Coronell C, Pont C, Buongiorno MT, Cámara A, Gaig C, Compta Y. Socio-demographic and clinical factors influencing the adherence to treatment in Parkinson's disease: The ADHESON study. Eur J Neurol. 2011;18:980–987.

40. Hindle J V, Watermeyer TJ, Roberts J, Brand A, Hoare Z, Martyr A, Clare L. Goal-orientated cognitive rehabilitation for dementias associated with Parkinson's disease-A pilot randomised controlled trial. Int J Geriatr Psychiatry [Internet]. 2018 May;33:718–728.

41. Advocat J, Enticott J, Vandenberg B, Hassed C, Hester J, Russell G. The effects of a mindfulness-based lifestyle program for adults with Parkinson's

disease: A mixed methods, wait list controlled randomised control study. BMC Neurol [Internet]. 2016 September 8;16:166.

42. Ritter VC, Bonsaksen T. Improvement in quality of life following a multidisciplinary rehabilitation program for patients with Parkinson's disease. J Multidiscip Healthc [Internet]. 2019 March 20;12:219–227.

43. Tyack C, Camic PM. Touchscreen interventions and the well-being of people with dementia and caregivers: A systematic review. Int Psychogeriatrics. 2017;29:1261–1280.

44. Barlow MA, Liu SY, Wrosch C. Chronic illness and loneliness in older adulthood: The role of self-protective control strategies. Heal Psychol. 2015;34:870–879.

45. Jenkinson C, Fitzpatrick R, Peto V, Greenhall R, Hyman N. The PDQ-8: Development and validation of a short-form Parkinson's disease questionnaire. Psychol Heal. 1997;12:805–814.

46. Jenkinson C, Fitzpatrick R. Cross-cultural evaluation of the short form 8-item Parkinson's Disease Questionnaire (PDQ-8): Results from America, Canada, Japan, Italy and Spain. Park Relat Disord. 2007;13:22–28.

47. Yasavage JA, Sheikh JI. 9/Geriatric Depression Scale (GDS) Recent Evidence and Development of a Shorter Version. Clin Gerontol. 1986;5:119–136.

48. Ertan FS, Ertan T, Kiziltan G, Uyguçgil H. Reliability and validity of the Geriatric Depression Scale in depression in Parkinson's disease. J Neurol Neurosurg Psychiatry. 2005;76:1445–1447.

49. Torbey E, Pachana NA, Dissanayaka NNW. Depression rating scales in Parkinson's disease: A critical review updating recent literature. J Affect Disord [Internet]. 2015;184:216–224.

50. Goodarzi Z, Mrklas KJ, Roberts DJ, Jette N, Pringsheim T, Holroyd-Leduc J. Detecting depression in Parkinson disease. Neurology. 2016;87:426–437.

51. Burgener SC, Berger B. Measuring perceived stigma in persons with progressive neurological disease. Dementia [Internet]. 2008 February 1;7:31–53.

52. Wallston KA, Stein MJ, Smith CA. Form C of the MHLC Scales: A Condition-Specific Measure of Locus of Control. J Pers Assess. 1994;63:534–553.

53. Wallston KA. The validity of the Multidimensional Health Locus of Control scales. J Health Psychol. 2005;10:623–631.

54. Gruber-Baldini AL, Ye J, Anderson KE, Shulman LM, AL G-B, Ye J, KE A, LM S, Gruber-Baldini AL, Ye J, et al. Effects of optimism/pessimism and locus of control on disability and quality of life in Parkinson's disease. Parkinsonism Relat Disord [Internet]. 2009 November 5 [cited 2014 July 7];15:665–669.

55. Sirois FM, Davis CG, Morgan MS. "Learning to live with what you can't rise above": Control beliefs, symptom control, and adjustment to tinnitus. Heal Psychol. 2006;25:119–123.

56. Simpson J, Chatzidamianos G, Fletcher I, Perpetuo L, Eccles FJRR. A new scale measuring adaptive perceived control for people with Parkinson's: Initial

construction and further validation. J Neurol Sci [Internet]. 2018 August 15;391:77–83.

57. Schwarzer R, Jerusalem M. Generalized Self-Efficacy scale. In: Weinman J, editor. Measures in health psychology: a user's portfolio. Causal and control beliefs. Windsor: NFER-NELSON; 1995. pp 35–37.

58. Nilsson MH, Hagell P, Iwarsson S. Psychometric properties of the General Self-Efficacy Scale in Parkinson's disease. Acta Neurol Scand [Internet]. 2015 August;132:89–96.

59. Chan AHY, Horne R, Hankins M, Chisari C. The Medication Adherence Report Scale (MARS-5): a measurement tool for eliciting patients' reports of non-adherence. Br J Clin Pharmacol. 2019.

60. Horne R, Weinman J. Self-regulation and self-management in asthma: Exploring the role of illness perceptions and treatment beliefs in explaining non-adherence to preventer medication. Psychol Heal. 2002;17:17–32.

61. Tosin MHS, Stebbins GT, Goetz CG, Santana RF, Leite MAA, Oliveira BGRB. Measuring Medication Adherence in Parkinson's Disease: A Systematic Review of Contributing Components in Rating Scales. Mov Disord Clin Pract. 2020;7:607–615.

62. Mynors G, Jenkinson C, MacNeill V, Balcon R. A pilot evaluation of specialist community pharmacy services for patients with Parkinson's disease. Pharm J. 2007;278:709–712.

63. Vluggen S, Hoving C, Schaper NC, De Vries H. Psychological predictors of adherence to oral hypoglycaemic agents: an application of the ProMAS questionnaire. Psychol Heal [Internet]. 2020;35:387–404.

64. Malhotra N. Completion time and response order effects in web surveys. Public Opin Q. 2008;72:914–934.

65. Leys C, Delacre M, Mora YL, Lakens D, Ley C. How to classify, detect, and manage univariate and multivariate outliers, with emphasis on pre-registration. Int Rev Soc Psychol. 2019;32:1–10.

66. Gill IJ, Mullin S, Simpson J. Are metacognitive processes associated with posttraumatic stress symptom severity following acquired brain injury? Disabil Rehabil [Internet]. 2015 April 10;37:692–700.

67. Arran N, Craufurd D, Simpson J. Illness perceptions, coping styles and psychological distress in adults with Huntington's disease. Psychol Health Med [Internet]. 2014 January [cited 2014 July 3];19:169–79.

68. Straka I, Minar M, Skorvanek M, Grofik M, Danterova K, Benetin J, Kurca E, GaZova A, Bolekova V, Wyman-Chick KA, et al. Adherence to pharmacotherapy in patients with parkinsons disease taking three and more daily doses of medication. Front Neurol. 2019;10:1–8.

69. Field A. Discovering statistics using IBM SPSS Statistics. 5th ed. London: Sage; 2018.

70. Hinton P, McMurray I, Brownlow C. SPSS Explained. Routledge; 2014.

71. Simpson J, Lekwuwa G, Crawford T. Predictors of quality of life in people with Parkinson's disease: Evidence for both domain specific and general relationships. Disabil Rehabil [Internet]. 2014;36:1964–1970.

72. Shin JY, Habermann B. Medication Adherence in People with Parkinson Disease. J Neurosci Nurs. 2016;48:185–194.

73. Shin JY, Habermann B, Pretzer-Aboff I. Challenges and strategies of medication adherence in Parkinson's disease: A qualitative study. Geriatr Nurs (Minneap) [Internet]. 2015;36:192–196.

74. Reich JW, Infurna FJ. Perceived Control: Theory, Research, and Practice in the First 50 Years. New York: Oxford University Press; 2016.

75. Taher M, Bayat ZS, Zandi KN, Ghasemi E, Abredari H, Karimy M, Abedi AR. Correlation between compliance regimens with health locus of control in patients with hypertension. Med J Islam Repub Iran. 2015;29.

76. Lewis SJG. Heterogeneity of Parkinson's disease in the early clinical stages using a data driven approach. J Neurol Neurosurg Psychiatry [Internet]. 2005 March 1;76:343–348.

77. Burish TGT, Carey MPM, Wallston KKA, Stein MJ, Jamison RN, Lyles JN. Health locus of control and chronic disease: An external orientation may be advantageous. J Soc … [Internet]. 1984 December [cited 2014 July 7];2:326–332.

78. Raiz LR, Kilty KM, Henry ML, Ferguson RM. Medication compliance following renal transplantation. Transplantation [Internet]. 1999;68:51–55.

79. Dodel R, Tinelli M, Deuschl G, Petersen G, Oertel W, Ahmerkamp-Böhme J. The economic benefit of timely, adequate, and adherence to Parkinson's disease treatment: the Value of Treatment Project 2. Eur J Neurol [Internet]. 2021 February 8;28:707–716.

80. DiMatteo MR, Lepper HS, Croghan TW. Depression is a risk factor for noncompliance with medical treatment meta-analysis of the effects of anxiety and depression on patient adherence. Arch Intern Med. 2000;160:2101–2107.

81. Greenland JC, Williams-Gray CH, Barker RA. The clinical heterogeneity of Parkinson's disease and its therapeutic implications. Eur J Neurosci. 2019;49:328–338.

82. Giroux ML. Parkinson disease: Managing a complex, progressive disease at all stages. Cleve Clin J Med. 2007;74:313–328.

83. Robinson SA, Lachman ME. Perceived Control and Behavior Change. In: Perceived Control. ; 2016. pp 201–228.

84. Wolinsky FD, Vander Weg MW, Martin R, Unverzagt FW, Willis SL, Marsiske M, Rebok GW, Morris JN, Ball KK, Tennstedt SL. Does cognitive training improve internal locus of control among older adults? Journals Gerontol - Ser B Psychol Sci Soc Sci. 2010;65 B:591–598.

85. Wright KB. Researching Internet-Based Populations: Advantages and Disadvantages of Online Survey Research, Online Questionnaire Authoring Software Packages, and Web Survey Services. J Comput Commun [Internet]. 2005 April 1 [cited 2014 July 9];10:JCMC1034.

86. McLeod J. Qualitative Research in Counselling and Psychotherapy. SAGE; 2012.

Table 1

Demographic Characteristics.

Variable	*N*	%	*M*	*SD*
Age (yrs.)			65.05	9.08
Gender				
Female	732	60.5		
Male	478	39.5		
Language (English)				
Native	1164	96.2		
Non-native	46	3.8		
Country				
Anguilla	1	0.1		
Australia	40	3.3		
Barbados	1	0.1		
Canada	51	4.2		
Guernsey	1	0.1		
Hong Kong	1	0.1		
India	5	0.4		
Ireland	26	2.1		
Malta	1	0.1		
New Zealand	42	3.5		
Nigeria	1	0.1		
Philippines	3	0.2		
South Africa	30	2.5		
United Kingdom	790	65.3		
United States	217	17.9		

Ethnicity				
White (any white background)	1143	94.5		
Asian (any Asian background)	18	1.5		
Prefer not to say	12	1.0		
Mixed/multiple ethic groups	12	1.0		
Other	8	0.7		
Hispanic or Latino/a	7	0.6		
Aboriginal (Australia & New Zealand)	5	.4		
Black, African, or Caribbean	3	0.2		
Arab	1	0.1		
Native American	1	0.1		
Time since diagnosis (yrs.)			6.58	5.30
Physical comorbidity				
Yes	573	47.4		
No	637	52.6		
Taking medication alone				
Yes	1162	96.0		
No	48	4.0		
Doses per day			4.36	1.94
Varying doses (with clinical team approval)				
Yes	291	24.0		
No	919	76.0		
Paying for medication				
Yes	391	32.3		
No	819	67.7		
Medication knowledge (0 = low, 10 = high)			7.23	4.40

Physical problems accessing medication		
Yes	182	15.0
No	1028	85.0
Other medication		
Yes	941	77.8
No	269	22.2
Psychiatric medication		
Yes	438	36.2
No	772	63.8
Psychological support		
Yes	103	8.5
No	1107	91.5
Depression (GDS-15 > 4)		
Depressed	632	52.2
Not depressed	578	47.8
Adherence (MARS-5 < 23)		
Adherent	553	45.7
Not adherent	657	54.3

Note. GDS-15 = Geriatric Depression Scale-15; M = mean; MARS-5 = Medication Adherence Report Scale; SD = standard deviation; yrs = years.

Table 2

Descriptive Statistics for Standardised Measures.

Variable	*M*	*SD*	α
PDQ-8	10.54	6.07	.84
PUKSoPC	51.91	10.08	.89
PMS	19.08	3.73	.81
GDS-15	5.7174	4.10	.87
SCS	26.61	5.18	.86
GSE	29.22	5.39	.92
MHLC-C Internal	21.54	5.88	.73
MHLC-C Chance	16.84	5.63	.73
MHLC-C Doctors	12.79	3.13	.60
MHLC-C Other People	9.98	3.18	.56
MARS-5	21.47	2.99	.72

Note. α = Cronbach's alpha; GDS-15 = Geriatric Depression Scale-15; GSE = General Self-Efficacy Scale; M = mean; MARS-5 = Medication Adherence Report Scale; MHLC-C = Multidimensional Health Locus of Control – Form C; PDQ-8 = Parkinson's Disease Questionnaire-8; PMS = Pearlin Mastery Scale; PUKSoPC = Parkinson's UK Scale of Perceived Control; SCS = Symptom Control Scale; SD = standard deviation; yrs = years.

Table 3

Correlation coefficients for all variables.

		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24
1	GENDER																								
2	AGE	-.091**																							
3	TIME DIAG	.001	.101**																						
4	COMOR	-.019	.154**	-.049																					
5	MEDS ALONE	.104**	-.042	-.123**	-.019																				
6	DAILY DOSES	.002	.023	.405**	-.003	-.104**																			
7	VARY DOSES	.063*	-.033	.179**	.005	.035	.213**																		
8	PAY MEDS	.045	-.300**	-.046	-.093**	.068*	-.089**	.049																	
9	KNOW MEDS	.039	-.004	.009	-.022	.042	.026	.058*	.018																
10	PP MEDS ACCESS	.042	-.081**	.152**	.05	-.104**	.167**	.066*	.006	-.013															
11	OTHER MEDS	-.001	.140**	-.001	.316**	.014	.033	.008	-.009	-.045	.03														
12	PSY MEDS	.109**	-.041	.065*	.085**	-.067*	.047	.067*	.127**	-.039	.111**	.337**													
13	PSY SUPPORT	.089**	-.131**	-.056	.132**	-.059*	.008	.05	.106**	-.041	.079**	.070*	.245**												
14	PUKSoPC	.076**	.105**	.034	-.027	.150**	0	.077**	-.013	.298**	-.100**	-.102**	-.166**	-.086**											
15	PDQ-8	.035	-.106**	.242**	.099**	-.228**	.259**	.037	.016	-.151**	.345**	.151**	.284**	.181**	-.425**										
16	PMS	-.027	-.005	-.102**	-.079**	.162**	-.137**	.004	.018	.147**	-.155**	-.086**	-.142**	-.096**	.526**	-.545**									
17	GDS-15	-.015	-.029	.038	-.001	-.103**	.086**	.02	.01	-.081**	.107**	.051	.140**	.072*	-.352**	.364**	-.353**								

18	SCS	.054	-.090**	-.099**	-.049	.203**	-.149**	.025	.061*	.173**	-.125**	-.092**	-.111**	-.053	.526**	-.395**	.520**	-.296**						
19	GSE	-.003	-.006	-.176**	-.048	.191**	-.153**	-.002	.059*	.141**	-.130**	-.106**	-.181**	-.082**	.519**	-.478**	.569***	-.286**	.471**					
20	MHLC-C_IN	-.061*	-.032	-.021	-.05	.095**	-.069*	0	.118**	.049	-.042	-.046	-.075**	-.039	.233**	-.139**	.291**	-.086**	.475**	.285**				
21	MHLC-C_CH	-.054	.012	-.036	.031	-.036	-.055	-.053	-.006	-.159**	-.007	.008	.014	-.029	-.232**	.130**	-.305**	.115**	-.167**	-.106**	.009			
22	MHLC-C_DR	-.031	.069*	-.124**	.027	-.009	-.086**	-.015	-.034	.014	-.089**	.076**	-.002	.015	.145**	-.075**	.113**	-.086**	.166**	.155**	.147**	.048		
23	MHLC-C_OP	-.049	.008	-.002	.083**	-.100**	.043	.024	-.155**	-.112**	.074*	.017	-.004	.002	-.065*	.184**	-.214**	.110**	-.092**	-.141**	-.106**	.223**	.288**	
24	MARS-5	-.002	.059*	-.231**	.024	.033	-.131**	-.159**	-.099**	.067*	-.165**	.074*	-.054	-.043	.058*	-.160**	.058*	-.03	.054	.068*	-.066*	.05	.235**	.124**

Note. * = $p < .05$; ** = $p < .01$; COMOR = physical comorbidity; DAILY DOSES = number of daily doses; GDS-15 = Geriatric Depression Scale-15; GSE = General Self-Efficacy Scale; KNOW MEDS = knowledge on medication; MARS-5 = Medication Adherence Report Scale; MEDS ALONE = taking medication alone; MHLC-C_CH = Multidimensional Health Locus of Control – Form C, Chance dimension; MHLC-C_DR = Multidimensional Health Locus of Control – Form C, Doctors dimension; MHLC-C_IN = Multidimensional Health Locus of Control – Form C, Internal dimension; MHLC-C_OP = Multidimensional Health Locus of Control – Form C, Other People scale; OTHER MEDS = taking other medication; PAY MEDS= paying for medication; PDQ-8 = Parkinson's Disease Questionnaire-8; PMS = Pearlin Mastery Scale; PP MEDS ACCESS = physical problems accessing medication; PSY MEDS = psychiatric medication; PSY SUPPORT = psychological support; PUKSoPC = Parkinson's UK Scale of Perceived Control; SCS = Symptom Control Scale; TIME DIAG = time since diagnosis.

Table 4

Hierarchical regression model predicting medication adherence with confidence intervals and standard errors based on 1000 bootstrap samples.

	B	95% *CI*	*SE*	β	*R*	R^2	ΔR^2	*p*
Step 1					.059	.004	.004	.040
CONSTANT	20.203	18.960, 21.321	.607					<.001
AGE	0.019	0.003, 0.038	.009	.059				.040
Step 2					.264	.070	.066	<.001
CONSTANT	21.288	20.105, 22.482	.605					<.001
AGE	0.023	0.005, 0.041	.009	.070				.013
TIME DIAG	-0.010	-0.013, -0.007	.001	-.213				<.001
PDQ-8	-0.050	-0.081, -0.022	.015	-.101				<.001
Step 3					.334	.111	.042	<.001
CONSTANT	21.656	20.143, 23.133	.755					<.001
AGE	0.005	-0.012, 0.024	.009	.017				.573
TIME DIAG	-0.008	-0.012, -0.005	.002	-.179				<.001
PDQ-8	-0.037	-0.068, -0.006	.016	-.074				.017
DAILY DOSES	-0.019	-0.118, 0.080	.050	-.012				.694
OTHER MEDS	0.640	0.203, 1.080	.222	.089				.001

KNOW MEDS	0.085	0.008, 0.163	.038	.069				.013
PP MEDS ACCESS	-0.854	-1.405, -.332	.270	-.102				<.001
PAY MEDS	-0.614	-1.012, -0.241	.188	-.096				<.001
VARY DOSES	-0.801	-1.197, -0.393	.204	-.114				<.001
Step 4					.404	.163	.052	<.001
CONSTANT	20.044	17.817, 22.126	1.099					<.001
AGE	0.002	-0.016, 0.020	.009	.005				.867
TIME DIAG	-0.007	-0.010, -0.004	.002	-.154				<.001
PDQ-8	-0.050	-0.084, -0.015	.018	-.101				.005
DAILY DOSES	-0.015	-0.115, 0.081	.049	-.010				.745
OTHER MEDS	0.541	0.125, 0.970	.211	.075				.006
KNOW MEDS	0.090	0.015, 0.164	.038	.073				.009
PP MEDS ACCESS	-0.776	-1.293, -.272	.261	-.093				.001
PAY MEDS	-0.421	-0.812, -0.042	.192	-.066				.021
VARY DOSES	-0.852	-1.242, -0.465	.197	-.122				<.001
PUKSoPC_SUM	0.005	-0.015, 0.026	.011	.018				.616
PMS	-0.006	-0.070, 0.061	.032	-.007				.849

GSE	-0.007	-0.048, 0.034	.021	-.013	.704
MHLC-C_IN	-0.048	-0.078, -0.017	.016	-.095	<.001
MHLC-C_DR	0.169	0.106, 0.233	.033	.177	<.001
MHLC-C_OP	0.081	0.023, 0.141	.030	.086	.004

Note. CI = confidence interval; COMOR = physical comorbidity; DAILY DOSES = number of daily doses; GSE = General Self-Efficacy Scale; KNOW MEDS = knowledge on medication; MHLC-C_DR = Multidimensional Health Locus of Control – Form C, Doctors dimension; MHLC-C_IN = Multidimensional Health Locus of Control – Form C, Internal scale; MHLC-C_OP = Multidimensional Health Locus of Control – Form C, Other People dimension; OTHER MEDS = taking other medication; PAY MEDS= paying for medication; PDQ-8 = Parkinson's Disease Questionnaire-8; PMS = Pearlin Mastery Scale; PP MEDS ACCESS = physical problems accessing medication; PUKSoPC = Parkinson's UK Scale of Perceived Control; SE = standard error; TIME DIAG = time since diagnosis.

Chapter Four

Discussion and Critical Evaluation

The overarching aims of the present thesis portfolio were to identify the scope of research on psychosocial interventions which measured perceived control in PwP, and to assess the extent to which different subconstructs of perceived control predict medication adherence in PwP over and above other known predictors, such as depression and medication variables. Both aims showed the potential to provide opportunities to enhance medication adherence in this population. To this end, a scoping review and an empirical study consisting of a large-scale cross-sectional survey were conducted. The main findings of the papers presented in Chapter Two and Three are summarised below, followed by an extended critical evaluation and recommendations for future research and clinical practice.

Scoping Review

In Chapter Two, the review of psychosocial interventions for PwP addressing perceived control as an outcome identified 12 eligible studies. These tested cognitive, educational, mindfulness-based, and physical interventions. Their outcomes included measures of four subconstructs of perceptions of control: general perceived control (i.e., non-specific, as reported by qualitative studies), locus of control, mastery, and self-efficacy. The most commonly investigated perceived control outcome was self-efficacy, measured using the General Self-Efficacy Scale (GSE; Schwarzer & Jerusalem, 1995), the Chronic Disease Self-Efficacy Scale (CDSES; Lorig et al.,

1996), or the PROMIS Self-Efficacy for Managing Chronic Conditions; (Gruber-Baldini et al., 2017). Locus of control was measured using the Multidimensional Health Locus of Control – Form B (MHLC-B; Wallston et al., 1994). Of these tools, the GSE was the only one specifically validated with individuals with Parkinson's (Nilsson et al., 2015).

Mixed results were reported by the 12 studies of cognitive, educational, and physical interventions with PwP, with a marked discrepancy between quantitative and qualitative methods. The majority of quantitative studies reported non-significant changes in perceived control (Connor et al., 2019; Cucca et al., 2021; Pappa et al., 2017; Prewitt et al., 2017; Sajatovic et al., 2017) or no significant differences compared to treatment as usual (Hindle et al., 2018). In contrast, qualitative studies or the qualitative components in mixed methods investigations reported that following the interventions participants felt increased levels of general (i.e., non-specific) perceived control (Bognar et al., 2017; Soundy et al., 2019; Vandenberg et al., 2019), self-efficacy (Pappa et al., 2017), or mastery (Morris et al., 2021).

One exception to this, was a mixed-method RCT that reported significant quantitative improvements in internal locus of control and increased qualitative feelings of control following a mindfulness-based lifestyle programme with PwP (Advocat et al., 2016; Vandenberg et al., 2019), albeit with a small effect size (Cohen's d = .28) and no significant differences observed at a 6-month follow-up.

Empirical Study

The empirical study, presented in Chapter Three, investigated the predictive value of multiple subconstructs of perceived control on medication adherence in

individuals with Parkinson's, while accounting for other pre-established predictors (e.g., depression and medication variables). An online cross-sectional survey was developed, which consisted of a demographic and clinical questionnaire and standardised measures of depression, different subconstructs of perceived control (mastery, adaptive control, symptom control, self-efficacy, locus of control), and medication adherence. The direction and extent of associations between the variables were investigated.

A 4-block hierarchical regression analysis indicated that 15.3% of variance in medication adherence in a sample of 1210 PwP was predicted by a model consisting of age, time since diagnosis, disease severity, medication variables, and subconstructs of perceived control. The latter, added in the last block, explained a slightly higher amount of variance than medication variables. Among the subconstructs of perceived control, internal and external dimensions of locus of control emerged as significant independent predictors of medication adherence. More specifically, Internal locus of control, as measured by the Internal subscale of the Multidimensional Health Locus of Control – Form C (MHLC-C; Wallston et al., 1994), emerged as a negative predictor of adherence. This suggested that attributing more control over outcomes to themselves made PwP slightly less likely to adhere to medication. On the other hand, higher levels of external perceived control, in the form of the Doctors and Other People subscales, significantly predicted higher levels of adherence. For PwP, this translated into a higher likelihood of being adherent if they attributed more control over outcomes to clinicians or significant others. In addition, in contrast with most of the previous literature, the empirical study found that depression shared no significant relationship with medication adherence in PwP.

Critical Evaluation

This section presents an extended evaluation of the methodology and findings of the thesis portfolio, their implications for relevant psychological theory and practice, and their strengths and limitations. A number of additional areas for future research development are also suggested.

Theoretical and Clinical Implications

The scoping review suggests that the current literature on psychosocial interventions affecting perceptions of control in individuals with Parkinson's is still in its infancy. Even though a wide range of non-pharmacological and non-surgical psychosocial interventions are available (Cutler, 2004), only four types of intervention (cognitive, educational, mindfulness-based, and physical) were found to have evaluated perceived control as an outcome for PwP. Of these, none adopted a psychotherapeutic model, despite the psychological nature of the construct of perceived control (Reich & Infurna, 2016; Wallston et al., 1987) and evidence that psychological therapy can target and improve forms of perceived control in chronic conditions (Cusack et al., 2019; Guo et al., 2017; Robinson & Lachman, 2016; Thompson & Wierson, 2000). It was therefore important that this review was conducted and that this gap was highlighted.

Despite being preliminary due to their small effect size, the positive short-term findings observed with a mindfulness-based lifestyle programme (Advocat et al., 2016; Vandenberg et al., 2019) contribute to the evidence supporting mindfulness-based approaches to target perceived control (Pagnini et al., 2016; Reich & Infurna, 2016). In particular, lower perceived control has been associated with feelings of being

stuck, imprisoned, or without choices – which in turn are often associated with the concept of lacking mindfulness (i.e., 'mindlessness'; Pagnini et al., 2016). Similarly, decreased mindlessness has been related to increased perceptions of having choices (Langer & Ngnoumen, 2017). As the perception of having choices is thought to give rise to controllability (Fatemi & Langer, 2016), the successful implementation of mindfulness-based interventions could be hypothesised to be linked with increased levels of perceived control (Fatemi & Langer, 2016).

The association between mindfulness interventions and perceived control has also important implications for clinical and health psychology practice. First, it suggests that mindfulness-based third wave cognitive behavioural approaches (e.g., mindfulness-based stress reduction or mindfulness-based cognitive therapy; Kabat-Zinn, 2006; Teasdale et al., 2000) may be effective in improving perceived control in PwP – particularly thanks to evidence of their feasibility in people with neurodegenerative diseases (Clare et al., 2018; Simpson et al., 2021; Zarotti et al., 2022), including Parkinson's (Zarotti et al., 2021). In addition, it has been argued that some of the basic processes involved with transitioning from mindlessness to mindfulness, such as increasing awareness of mindsets and changing perspectives around them, are in fact common to several psychotherapeutic models, albeit with different names (e.g., 'insight', 'cognitive restructuring'; Castonguay & Hill, 2007; Pagnini et al., 2016). Thus, increasing mindfulness by addressing these processes shows the potential to underlie positive change in perceived control not only in specific mindfulness-based psychological interventions, but also those based on different orientations such as cognitive and psychodynamic therapy (Pagnini et al., 2016).

The findings of the empirical study highlighted the complex nature of medication adherence in Parkinson's. Demographic, clinical, and psychological variables accounted for a relatively small amount of variance in the outcome variable. This contributes to the evidence that adherence represents a multifaceted construct "influenced at multiple levels beyond patient-related factors, including social and economic, therapy related and health system factors" (Rich et al., 2015; p. 685). Nevertheless, different subconstructs of perceived control predicted medication adherence slightly more than medication variables, even after controlling for demographic and clinical variables. This not only corroborates the initial hypothesis of the empirical study, but also contributes to a rich body of research on the importance of perceived control by providing the first evidence of this type with Parkinson's. More specifically, it is consistent with a review of two decades of health psychology literature highlighting perceived control as the most determinant predictor of medication adherence across studies on conditions other than Parkinson's which adopted wide range of different theoretical frameworks (Holmes et al., 2014).

Less consistent with previous research was the finding that, among the subconstructs of perceived control, only locus of control (LOC) was a significant independent predictor of adherence. More specifically, internal LOC emerging as a negative predictor and external LOC as positive appeared to be in contrast with evidence indicating that higher levels of internal LOC exert a more positive impact on medication adherence than higher external LOC (Náfrádi et al., 2017; Taher et al., 2015). In addition, this seemed to suggest that increasing Internal LOC may in fact undermine adherence, contradicting the finding that interventions which focus on enhancing internal aspects of LOC, such as cognitive training and empowerment programmes, are effective in improving adherence in older populations and people

with chronic conditions (Náfrádi et al., 2017; Wolinsky et al., 2010). However, as mentioned in Chapter Three, increased external causal attributions predicting better adherence may be population-specific (Burish et al., 1984; Raiz et al., 1999) and linked to the complexity of medication profiles. Consistent with the fact that Parkinson's predominantly affects older populations, the sample in the empirical study was characterised by a mean age of 65. As a consequence, the potential impact of cohort differences in beliefs around the role of clinicians and the trust in their advice should be taken into consideration. In particular, evidence has shown that older people tend to display higher levels of trust in their doctors and their recommendations than younger adults, especially when dealing with chronic conditions (Bungay & Cappello, 2009; Butterworth & Campbell, 2014). This enhanced trust has also been associated with higher acceptance of medication regimens irrespective of potential side effects (Hervé et al., 2004). Therefore, the effect of cohort characteristics and beliefs which characterise PwP may at least partially explain why External LOC – and especially its Doctors dimension – emerged as a significant positive predictor of medication adherence in our study.

In addition, most self-report adherence measures currently used with Parkinson's fail to evaluate patients' empowerment and intentional variations in medication behaviours agreed with the clinical team (Tosin et al., 2020), and only reflect how closely PwP adhere to what doctors consider the optimal regimen (Náfrádi et al., 2017). Considering the high complexity and tailored nature of medication profiles in Parkinson's (Kalia & Lang, 2015) – also confirmed by almost a quarter of the participants in our survey reporting intentional and agreed regimen variations – this limitation may lead to a systematic misrepresentation of adherence in PwP. In turn, this could mean that, when adherence is measured on a more person-centred

level, which accounts for autonomy, empowerment, and shared control between patients and clinicians, Internal LOC positively predicts adherence in Parkinson's (Náfrádi et al., 2017) – and particularly a form of 'critical adherence' which reflects increased autonomous and empowered decision-making (Bader et al., 2006). This would be consistent with a survey study in people who underwent renal transplantation which also found that Internal LOC predicted lower levels of adherence and highlighted how "a balance of locus of control that optimizes patients' feelings of empowerment but reinforces respect for and faith in their physician is critical" (Raiz et al., 1999; p. 54).

From a theoretical perspective, the hypothesis that both internal and external LOC predict adherence positively in individuals with Parkinson's is consistent with the Theory of Planned Behaviour (TPB). As mentioned previously, TPB suggests that behavioural intentions (i.e., an individual's motivation to engage in a specific behaviour; Ajzen, 1991; Rhodes & Courneya, 2004) are guided by attitudes towards a behaviour, subjective norms regarding the behaviour, and perceived behavioural control – with the latter consisting of expectations regarding having the ability and resources to perform the behaviour (Ajzen, 1991). According to TPB, internal and external LOC as positive predictors of adherence would reflect PwP's perceptions of behavioural control and motivation to be adherent, irrespective of its specific causal attribution (Ajzen, 2002). In turn, this would be consistent with the finding that perceived behavioural control is among the strongest predictors of medication adherence in people with chronic illness (for a review and a meta-analysis, see Holmes et al., 2014; Rich et al., 2015), and that "examining solely the main effects of the subdimensions [of LOC] may not be sufficient, but looking into the interaction effects

between Internal LOC and External LOC as well as External LOC subdimensions on medical regimen adherence might be more fruitful" (Náfrádi et al., 2017; p. 10).

Further evidence is needed to test this hypothesis, particularly as some of the interventions from studies identified by the scoping review may in time prove effective at increasing LOC and perceived behavioural control in PwP (Náfrádi et al., 2017; Wolinsky et al., 2010). Additional findings on the positive predictive value of both Internal and External LOC would also suggest that interventions such as cognitive training and empowerment programmes (Náfrádi et al., 2017; Wolinsky et al., 2010) are effective in reducing medication adherence in PwP as in other conditions. This may help shed light on the apparent contradiction suggested by the results of the empirical study may in fact be a product our currently limited understanding of the nature of adherence and the ways to assess it effectively in the Parkinson's population (Erickson & Muramatsu, 2004; Straka et al., 2018; Sumbul-Sekerci et al., 2022).

Finally, previous research consistently reported depression to be one of the strongest predictors of medication adherence in PwP (Daley et al., 2012; Erickson & Muramatsu, 2004; Fleisher & Stern, 2013; Richy et al., 2013; Shin & Habermann, 2016; Straka et al., 2018). However, this was not the case in the empirical study, which found no evidence to support a significant relationship between these constructs. As suggested in Chapter Three, this could reflect an overgeneralisation of a finding from research on older populations in general (Krousel-Wood et al., 2011; Yap et al., 2016). This is also compounded by substantial heterogeneity in previous studies, which are characterised by inconsistent measurement of adherence (Straka et al., 2018), including Electronic Medication Packaging (i.e., recording each times a medication bottle is opened; Grosset, 2010; Grosset et al., 2005), older self-report measures based on a small number of dichotomous yes/no questions (e.g., Morisky-Green Test;

Morisky et al., 1986; Straka et al., 2019; Valldeoriola et al., 2011), non-quantitative reports (e.g., in case studies; Erickson & Muramatsu, 2004), and different ways to conceptualise sub-optimal adherence (e.g., medication abuse; Evans et al., 2005). These differences in adherence measurement not only highlight a considerable lack of consistency, but also demonstrate how aspects of medication adherence such as patients' empowerment, motivation, and agreed deviations from regimens have previously been overlooked (Tosin et al., 2020).

In addition, some previous studies also show a number of methodological limitations. For instance, Vallderiola and colleagues (2011) found that depression significantly predicted adherence in PwP based on a logistic regression analysis. However, to perform this they dichotomised their originally continuous data on depression and adherence, which in turn is recognised to increase the risk of obtaining spurious positive results (Altman & Royston, 2006). Another investigation instead found a significant positive association between depression and adherence as a univariate correlation (Straka et al., 2019), but this association did not remain significant when depression was entered in a multiple regression model with other variables.

In conclusion, the high heterogeneity and limitations which characterise the previous evidence, combined with the results from our large-scale study, appear to suggest a strong need to rethink the relationship between depression and medication adherence in individuals with Parkinson's.

Strengths and Limitations

The research presented in this thesis portfolio has a number of strengths and limitations which should be considered along with its findings. A major strength of

the review is that, to our knowledge, it is the first to set out the current scope of research on psychosocial interventions for PwP that have measured perceived control outcomes. Moreover, the scoping methodology itself may be viewed as having both strengths and limitations. Following the guidance of the Joanna Briggs Institute (Peters et al., 2021) enabled this developing body of research to be scoped with the rigour of a systematic and replicable search strategy (Arksey & O'Malley, 2005; Grimshaw, 2010), despite the heterogeneity of conceptualisations and methods used. However, the limited number of studies and the diversity of interventions and outcomes, for which no formal appraisal of quality or risk of bias was appropriate (Peters et al., 2021), limits the conclusions that can be drawn. In addition, a further limitation of the review is the restriction to studies written fully in English. This may have excluded relevant evidence published in a different language and may have limited insights on the external validity of measures and differences in conceptualisations of control and adherence across cultures (Neimann Rasmussen & Montgomery, 2018).

The empirical study is the largest cross-sectional investigation of medication adherence in PwP to date, and the first to test the extent to which multiple subconstructs of perceived control predict medication adherence within a single multifactorial design. These are major strengths of the study, since most previous evidence not only focused on the predictive value of single subconstructs, but also recruited samples of less than half of the participants in our survey (Shin & Habermann, 2016; Straka et al., 2018). Similarly, the size and value of the obtained dataset has the potential to inform future analyses (see Areas for Future Development below). Another strength of the empirical study was the inclusion of Patient and Public Involvement (PPI), whereby five people with Parkinson's kindly agreed to assess the

acceptability and feasibility of the full draft of the survey prior to commencing the data collection. This proved extremely valuable, as important changes were made to fundamental aspects of the survey in response to the feedback received. These included improved flow and readability of the advertising material, specific questions on daily Parkinson's medications to avoid confusion, a progress bar to allow progress monitoring, and additional instructions on some of the measures to make them more tailored for PwP (see Appendices D–L for all survey-related materials).

A potential limitation of the empirical study is the inherent risk of self-selection biases which characterises online methods (Wright, 2005) and could have led to an overrepresentation of participants with specific characteristics (e.g., younger and more digitally literate, less depressed, more adherent). This largely proved not to be the case of our survey, as the final sample showed good levels of demographic diversity, with wide range of participant age (i.e., 26 – 89) and time since diagnosis (i.e., 1 month – 30 years), and nearly equal representation in terms of gender, clinical depression, and adherence. However, other intrinsic limitations of online cross-sectional designs – e.g., the reliance on internet access and self-reported data, the inability to check for potential cognitive impairments, and the lack of statistical insight into causation (Taris et al., 2021) – still affected the present study and should be considered when interpreting its results. In addition, although implemented to ensure the validity and reliability of the measures used within the survey, the exclusion of participants from countries where English was not an official language may have limited the diversity and representativeness of the sample (Field, 2018).

Finally, the lack of a Parkinson-specific measure of medication adherence validated for this population meant that an appropriate general measure had to be selected by carefully considering the available alternatives from existing reviews

(Lavsa et al., 2011; Tosin et al., 2020). In this regard, the MARS-5 was chosen due to its previous use with PwP (Mynors et al., 2007) and strong validity and reliability with populations with long-term conditions (Chan et al., 2019). However, this also carried the limitation, shared by all adherence scales used so far with PwP (Tosin et al., 2020), of not being able to address all the different psychosocial components which underpin adherence (WHO, 2003).

Areas for Future Development

Interventions to modify locus of control may have potential to improve medication adherence in PwP (Cvengros et al., 2004; Náfrádi et al., 2017; Rich et al., 2015; Tucker et al., 2001). However, the limited nature of the literature identified in the scoping review suggests that further high-quality research is needed on psychosocial interventions to affect perceptions of control in PwP, especially as a primary outcome. More specifically, considering that no psychotherapeutic interventions were identified despite evidence that they can improve perceived control in chronic conditions (Cusack et al., 2019; Guo et al., 2017; Robinson & Lachman, 2016; Thompson & Wierson, 2000), future studies should aim to test different models of psychotherapy for this purpose. In addition, since the GSE was the only outcome measure validated for PwP in the studies included in our review, more general measures of perceived control need to be validated with this population and more Parkinson-specific ones such as the Parkinson's UK Scale of Perceived Control (Simpson et al., 2018) need to be developed. Ultimately, as further evidence accrues on interventions, a systematic review, characterised by a narrower research question and a formal appraisal of the quality of the evidence, should be carried out to synthesise their effectiveness on perceptions of control.

The size of the dataset collected in the empirical study means that there is potential for additional analyses concerning perceived control, depression, and medication adherence in PwP. These could include initial or further validations of measures, and comparative analyses across geographical areas and healthcare systems (e.g., UK and US). Moreover, in light of the complexity of medication adherence in Parkinson's, and the differences identified between findings for perceived control outcomes from quantitative and qualitative intervention research, increased use of mixed-method designs may be helpful (Bryman, 2007; McLeod, 2012). In particular, since the validation of a Parkinson-specific adherence measure is currently warranted, additional qualitative research may aid its development by identifying and integrating subjective factors affecting non-adherence which may go potentially overlooked in quantitative designs. This may also include person-centred factors to the measurement of adherence which, as mentioned above, may in turn help shed further light on the role of internal and external locus of control on medication adherence in PwP.

Finally, the fact that less than one in 10 participants (i.e., 8.5%) reported receiving psychological support in our survey suggests that the provision of psychological support for PwP may represent a major problem across several countries worldwide. Moreover, when considering only the participants from the UK, this figure dropped to 4.9% (39 participants out of 790) – just over one third of the 12% rate of general over-65s expected to be able to access IAPT according to the Department of Health (2011). As a consequence, further attention and consideration are needed on this issue from clinical researchers and policy-makers in order to shape future clinical guidance and service provision – perhaps joining similar ongoing calls involving other

neurodegenerative conditions (e.g., Huntington's disease, motor neuron disease, multiple sclerosis; Simpson, Eccles, et al., 2021; Zarotti, Dale, et al., 2022).

Reflections on the Research Process

Coming from a background in clinical research on neurodegenerative conditions, the process of completing this thesis portfolio was perhaps one of the aspects of clinical psychology training which I found most familiar. However, upon reflection, conducting this work also provided a number of novel experiences which have been especially meaningful to me.

The involvement of PwP as lay advisors within the context of PPI proved extremely helpful, not only in terms of shaping and perfecting the research design, but also as a gateway to the wider Parkinson's community. Indeed, I feel this opportunity provided me with invaluable insight into some of the subjective experiences of PwP, which was further enriched by the pleasant exchanges and interactions I had with individuals with Parkinson's, their caregivers, and related associations worldwide during the recruitment process. This research would not have been possible without their support and enthusiasm.

In fact, as this was my first time leading a number of studies specifically focused on this condition, I have been deeply impressed and inspired by the dedication, commitment, and dignity of the Parkinson's community. Looking back, I am sincerely grateful for the opportunity to work with them, and for how they helped me grow as both a researcher and a clinician in the past three years. I genuinely hope my present and future research and clinical activity will be able to recompensate their support for this thesis.

Overall Conclusions

Parkinson's is an incurable neurodegenerative condition which requires highly complex medication regimens to limit the impact of its symptoms. Medication adherence is therefore of great importance for PwP. This thesis portfolio investigated the associations between medication adherence in Parkinson's and psychological factors such as perceived control and depression. A scoping review found that the literature on psychosocial interventions affecting perceived control as an outcome in PwP is still in its infancy and lacking any evidence on specific psychotherapeutic interventions. A large-scale cross-sectional online survey found that subconstructs of perceived control in individuals with Parkinson's exert a larger influence on medication adherence than medication-related factors. In addition, internal and external locus of control appear to play a significant role in adherence. However, a number of condition-specific caveats ought to be considered, such as the need to validate general measures of medication adherence with PwP or, more importantly, develop tools which are specifically designed for this population.

References

Advocat, J., Enticott, J., Vandenberg, B., Hassed, C., Hester, J., & Russell, G. (2016). The effects of a mindfulness-based lifestyle program for adults with Parkinson's disease: A mixed methods, wait list controlled randomised control study. *BMC Neurology*, *16*(1), 166. https://doi.org/10.1186/s12883-016-0685-1

Ahlskog, J. E. (2009). *Parkinson's Disease Treatment Guide for Physicians*. Oxford University Press.

Ajzen, I. (1991). The theory of planned behavior. *Organizational Behavior and*

Human Decision Processes, *50*(2), 179–211.

Ajzen, I. (2002). Perceived behavioral control, self-efficacy, locus of control, and the theory of planned behavior. *Journal of Applied Social Psychology*, *32*(4), 665–683. https://doi.org/10.1111/j.1559-1816.2002.tb00236.x

Alloy, L. B., Wagner, C. A., Black, S. K., Gerstein, R. K., & Abramson, L. Y. (2011). The breakdown of self-enhancing and self-protecting cognitive biases in depression. *Handbook of Self-Enhancement and Self-Protection.*, 358–379.

Altman, D. G., & Royston, P. (2006). The cost of dichotomising continuous variables. *British Medical Journal*, *332*(7549), 1080. https://doi.org/10.1136/bmj.332.7549.1080

Arksey, H., & O'Malley, L. (2005). Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology*, *8*(1), 19–32. https://doi.org/10.1080/1364557032000119616

Bader, A., Kremer, H., Erlich-Trungenberger, I., Rojas, R., Lohmann, M., Deobald, O., Lochmann, R., Altmeyer, P., & Brockmeyer, N. (2006). An adherence typology: Coping, quality of life, and physical symptoms of people living with HIV/AIDS and their adherence to antiretroviral treatment. *Medical Science Monitor*, *12*(12), CR493-500.

Bandura, A. (1982). Self-efficacy mechanism in human agency. *American Psychologist*, *37*(2), 122–147. https://doi.org/10.1037/0003-066X.37.2.122

Barber. (1995). What constitutes good prescribing? *British Medical Journal*, *310*, 923–925.

Barbosa, E. R. (2013). Non-motor symptoms in Parkinson's disease. *Arquivos de Neuro-Psiquiatria*, *71*(4), 203–204. https://doi.org/10.1590/0004-282X20130001

Barlow, M. A., Liu, S. Y., & Wrosch, C. (2015). Chronic illness and loneliness in older adulthood: The role of self-protective control strategies. *Health Psychology*, *34*(8), 870–879. https://doi.org/10.1037/hea0000182

Bognar, S., DeFaria, A. M., O'Dwyer, C., Pankiw, E., Simic Bogler, J., Teixeira, S., Nyhof-Young, J., & Evans, C. (2017). More than just dancing: experiences of people with Parkinson's disease in a therapeutic dance program. *Disability and Rehabilitation*, *39*(11), 1073–1078. https://doi.org/10.1080/09638288.2016.1175037

Brown, R., & Jahanshahi, M. (1995). Depression in Parkinson's disease: a psychosocial viewpoint. In *Advances in neurology* (Vol. 65, pp. 61–84). http://www.ncbi.nlm.nih.gov/pubmed/7872153

Bryman, A. (2007). Barriers to integrating quantitative and qualitative research. *Journal of Mixed Methods Research*, *1*(1), 8–22. https://doi.org/10.1177/2345678906290531

Bungay, H., & Cappello, R. (2009). 'As long as the doctors know what they are doing': trust or ambivalence about patient information among elderly men with prostate cancer? *European Journal of Cancer Care*, *18*(5), 470–476. https://doi.org/10.1111/j.1365-2354.2008.00992.x

Burish, T. G. T., Carey, M. P. M., Wallston, K. K. A., Stein, M. J., Jamison, R. N., & Lyles, J. N. (1984). Health locus of control and chronic disease: An external orientation may be advantageous. *Journal of Social and …*, *2*(4), 326–332. https://doi.org/10.1521/jscp.1984.2.4.326

Butterworth, J. E., & Campbell, J. L. (2014). Older patients and their GPs: shared decision making in enhancing trust. *British Journal of General Practice*, *64*(628), e709–e718. https://doi.org/10.3399/bjgp14X682297

Castonguay, L. G., & Hill, C. E. (2007). *Insight in psychotherapy*.

Chan, A. H. Y., Horne, R., Hankins, M., & Chisari, C. (2019). The Medication Adherence Report Scale (MARS-5): a measurement tool for eliciting patients' reports of non-adherence. *British Journal of Clinical Pharmacology*. https://doi.org/10.1111/bcp.14193

Chaudhuri, K. R., & Schapira, A. H. V. (2006). Non-motor symptoms of PD diagnosis and management. *The Lancet Neurology*, *5*(March), 235–245. http://neurology.thelancet.com

Chen, J. J., & Marsh, L. (2014). Anxiety in Parkinson's disease: Identification and management. *Therapeutic Advances in Neurological Disorders*, *7*(1), 52–59. https://doi.org/10.1177/1756285613495723

Chipperfield, J. G., Perry, R. P., & Stewart, T. L. (2012). Perceived Control. In *Encyclopedia of Human Behavior: Second Edition* (2nd ed.). Elsevier Inc. https://doi.org/10.1016/B978-0-12-375000-6.00109-9

Clare, L., Teale, J. C., Toms, G., Kudlicka, A., Evans, I., Abrahams, S., Goldstein, L. H., Hindle, J. V., Ho, A. K., Jahanshahi, M., Langdon, D., Morris, R., Snowden, J. S., Davies, R., Markova, I., Busse, M., & Thompson-Coon, J. (2018). Cognitive rehabilitation, self-management, psychotherapeutic and caregiver support interventions in progressive neurodegenerative conditions: A scoping review. *NeuroRehabilitation*, *43*(4), 443–471. https://doi.org/10.3233/NRE-172353

Connor, K. I., Cheng, E. M., Barry, F., Siebens, H. C., Lee, M. L., Ganz, D. A., Mittman, B. S., Connor, M. K., Edwards, L. K., McGowan, M. G., & Vickrey, B. G. (2019). Randomized trial of care management to improve Parkinson disease care quality. *Neurology*, *92*(16), E1831–E1842.

https://doi.org/10.1212/WNL.0000000000007324

Corti, O., Lesage, S., & Brice, A. (2011). What genetics tells us about the causes and mechanisms of Parkinson's disease. *Physiological Reviews*, *91*(4), 1161–1218. https://doi.org/10.1152/physrev.00022.2010

Cucca, A., Di Rocco, A., Acosta, I., Beheshti, M., Berberian, M., Bertisch, H. C., Droby, A., Ettinger, T., Hudson, T. E., Inglese, M., Jung, Y. J., Mania, D. F., Quartarone, A., Rizzo, J. R., Sharma, K., Feigin, A., Biagioni, M. C., & Ghilardi, M. F. (2021). Art therapy for Parkinson's disease. *Parkinsonism and Related Disorders*, *84*, 148–154. https://doi.org/10.1016/j.parkreldis.2021.01.013

Cusack, S. E., Coleman, J. A., Rappaport, L. M., & Sheerin, C. (2019). Moderation of improvement in self-efficacy following group psychotherapy for PTSD. In *Psychological Services* (Vol. 16, Issue 4, pp. 657–663). Educational Publishing Foundation. https://doi.org/10.1037/ser0000260

Cutler, D. M. (2004). Behavioral Health Interventions: What Works and Why? In and H. in L. L. National Research Council (US) Panel on Race, Ethnicity (Ed.), *Critical Perspectives on Racial and Ethnic Differences in Health in Late Life.* (pp. 643–676). National Academies Press (US).

Cvengros, J. A., Christensen, A. J., & Lawton, W. J. (2004). The role of perceived control and preference for control in adherence to a chronic medical regimen. *Annals of Behavioral Medicine*, *27*(3), 155–161. https://doi.org/10.1207/s15324796abm2703_3

Daley, D. J., Deane, K. H. O. O., Gray, R. J., Clark, A. B., Pfeil, M., Sabanathan, K., Worth, P. F., & Myint, P. K. (2014). Adherence therapy improves medication adherence and quality of life in people with Parkinson's disease: a randomised controlled trial. *International Journal of Clinical Practice*, *68*(8), 963–971.

https://doi.org/10.1111/ijcp.12439

Daley, David James, Myint, P. K., Gray, R. J., & Deane, K. H. O. L. O. O. (2012). Systematic review on factors associated with medication non-adherence in Parkinson's disease. *Parkinsonism and Related Disorders*, *18*(10), 1053–1061. https://doi.org/10.1016/j.parkreldis.2012.09.004

Dempster, M., Howell, D., & McCorry, N. K. (2015). Illness perceptions and coping in physical health conditions: A meta-analysis. *Journal of Psychosomatic Research*, *79*(6), 506–513. https://doi.org/10.1016/j.jpsychores.2015.10.006

Department of Health. (2011). *Talking therapies: A four-year plan of action*. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_123759

Dorsey, E. R., Constantinescu, R., Thompson, J. P., Biglan, K. M., Holloway, R. G., Kieburtz, K., Marshall, F. J., Ravina, B. M., Schifitto, G., Siderowf, A., & Tanner, C. M. (2007). Projected number of people with Parkinson disease in the most populous nations, 2005 through 2030. *Neurology*, *68*(5), 384–386. https://doi.org/10.1212/01.wnl.0000247740.47667.03

Driver, J. A., Logroscino, G., Gaziano, J. M., & Kurth, T. (2009). Incidence and remaining lifetime risk of Parkinson disease in advanced age. *Neurology*, *72*(5), 432–438.

Eccles, F. J. R., & Simpson, J. (2011). A review of the demographic, clinical and psychosocial correlates of perceived control in three chronic motor illnesses. *Disability and Rehabilitation*, *33*(13–14), 1065–1088. https://doi.org/10.3109/09638288.2010.525287

Emre, M. (2007). Dementia Associated with Parkinsons Disease. *European Neurological Review*, *2*, 46. https://doi.org/10.17925/enr.2007.00.02.46

Emre, M., Aarsland, D., Brown, R., Burn, D. J., Duyckaerts, C., Mizuno, Y., Broe, G. A., Cummings, J., Dickson, D. W., Gauthier, S., Goldman, J., Goetz, C., Korczyn, A., Lees, A., Levy, R., Litvan, I., McKeith, I., Olanow, W., Poewe, W., … Dubois, B. (2007). Clinical diagnostic criteria for dementia associated with Parkinson's disease. *Movement Disorders*, *22*(12), 1689–1707. https://doi.org/10.1002/mds.21507

Erickson, C. L., & Muramatsu, N. (2004). Parkinson's disease, depression and medication adherence: Current knowledge and social work practice. *Journal of Gerontological Social Work*, *42*(3–4), 3–18. https://doi.org/10.1300/J083v42n03_02

Evans, A. H., Lawrence, A. D., Potts, J., Appel, S., & Lees, A. J. (2005). Factors influencing susceptibility to compulsive dopaminergic drug use in Parkinson disease. *Neurology*, *65*(10), 1570–1574. https://doi.org/10.1212/01.wnl.0000184487.72289.f0

Fatemi, S. M., & Langer, E. J. (2016). Perceived Control and Mindfulness. In *Perceived Control* (pp. 131–146). Oxford University Press. https://doi.org/10.1093/acprof:oso/9780190257040.003.0006

Ffytche, D. H., Creese, B., Politis, M., Chaudhuri, K. R., Weintraub, D., Ballard, C., & Aarsland, D. (2017). The psychosis spectrum in Parkinson disease. *Nature Reviews Neurology*, *13*(2), 81–95. https://doi.org/10.1038/nrneurol.2016.200

Field, A. (2018). *Discovering statistics using IBM SPSS Statistics* (5th ed.). Sage.

Fleisher, J. E., & Stern, M. B. (2013). Medication nonadherence in Parkinson's disease. In *Current Neurology and Neuroscience Reports* (Vol. 13, Issue 10). https://doi.org/10.1007/s11910-013-0382-z

Foltynie, T., Brayne, C. E. G., Robbins, T. W., & Barker, R. A. (2004). The cognitive

ability of an incident cohort of Parkinson's patients in the UK. The CamPaIGN study. *Brain*, *127*(3), 550–560. https://doi.org/10.1093/brain/awh067

Gelb, D. J., Oliver, E., & Gilman, S. (1999). Diagnostic Criteria for Parkinson Disease. *Archives of Neurology*, *56*(1), 33. https://doi.org/10.1001/archneur.56.1.33

Goldman, J. G., & Holden, S. (2014). Treatment of Psychosis and Dementia in Parkinson's Disease. *Current Treatment Options in Neurology*, *16*(3), 1–25. https://doi.org/10.1007/s11940-013-0281-2

Goldman, J. G., & Postuma, R. (2014). Premotor and nonmotor features of Parkinson's disease. *Current Opinion in Neurology*, *27*(4), 434–441. https://doi.org/10.1097/WCO.0000000000000112

Grenard, J. L., Munjas, B. A., Adams, J. L., Suttorp, M., Maglione, M., McGlynn, E. A., & Gellad, W. F. (2011). Depression and medication adherence in the treatment of chronic diseases in the United States: A meta-analysis. *Journal of General Internal Medicine*, *26*(10), 1175–1182. https://doi.org/10.1007/s11606-011-1704-y

Grimshaw, J. (2010). A knowledge synthesis chapter. In *Canadian Institutes of Health Research*. http://www.cihr-irsc.gc.ca/e/41382.html

Grosset, D. (2010). Therapy adherence issues in Parkinson's disease. *Journal of the Neurological Sciences*, *289*(1–2), 115–118. https://doi.org/10.1016/j.jns.2009.08.053

Grosset, D., Antonini, A., Canesi, M., Pezzoli, G., Lees, A., Shaw, K., Cubo, E., Martinez-Martin, P., Rascol, O., Negre-Pages, L., Senard, A., Schwarz, J., Strecker, K., Reichmann, H., Storch, A., Löhle, M., Stocchi, F., & Grosset, K. (2009). Adherence to Antiparkinson medication in a Multicenter European study. *Movement Disorders*, *24*(6), 826–832. https://doi.org/10.1002/mds.22112

Grosset, K. A., Bone, I., & Grosset, D. G. (2005). Suboptimal medication adherence in Parkinson's disease. *Movement Disorders*, *20*(11), 1502–1507. https://doi.org/10.1002/mds.20602

Gruber-Baldini, A. L., Velozo, C., Romero, S., & Shulman, L. M. (2017). Validation of the PROMIS® measures of self-efficacy for managing chronic conditions. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation*, *26*(7), 1915–1924. https://doi.org/10.1007/s11136-017-1527-3

Guo, Y. F., Zhang, X., Plummer, V., Lam, L., Cross, W., & Zhang, J. P. (2017). Positive psychotherapy for depression and self-efficacy in undergraduate nursing students: A randomized, controlled trial. *International Journal of Mental Health Nursing*, *26*(4), 375–383. https://doi.org/10.1111/inm.12255

Hervé, C., Mullet, E., & Sorum, P. C. (2004). Age and medication acceptance. *Experimental Aging Research*, *30*(3), 253–273. https://doi.org/10.1080/03610730490447886

Hindle, J. V, Watermeyer, T. J., Roberts, J., Brand, A., Hoare, Z., Martyr, A., & Clare, L. (2018). Goal-orientated cognitive rehabilitation for dementias associated with Parkinson's disease-A pilot randomised controlled trial. *International Journal of Geriatric Psychiatry*, *33*(5), 718–728. https://doi.org/10.1002/gps.4845

Holmes, E. A. F., Hughes, D. A., & Morrison, V. L. (2014). Predicting adherence to medications using health psychology theories: A systematic review of 20 years of empirical research. *Value in Health*, *17*(8), 863–876. https://doi.org/10.1016/j.jval.2014.08.2671

Horne, R. (2000). Assessing perceptions of medication: psychological perspectives. In *Handbook of drug research methodology* (pp. 299–319). United Kingdom

Drug Utilisation Research Group.

Horne, Robert, & Weinman, J. (2002). Self-regulation and self-management in asthma: Exploring the role of illness perceptions and treatment beliefs in explaining non-adherence to preventer medication. *Psychology and Health*, *17*(1), 17–32. https://doi.org/10.1080/08870440290001502

Ishihara, L. S., Cheesbrough, A., Brayne, C., & Schrag, A. (2007). Estimated life expectancy of Parkinson's patients compared with the UK population. *Journal of Neurology, Neurosurgery and Psychiatry*, *78*(12), 1304–1309. https://doi.org/10.1136/jnnp.2006.100107

Jin, H. K., Kim, Y. H., & Rhie, S. J. (2016). Factors affecting medication adherence in elderly people. *Patient Preference and Adherence*, *10*, 2117–2125. https://doi.org/10.2147/PPA.S118121

Kabat-Zinn, J. (2006). Mindfulness-Based Interventions in Context: Past, Present, and Future. *Clinical Psychology: Science and Practice*, *10*(2), 144–156. https://doi.org/10.1093/clipsy.bpg016

Kalia, L. V, & Lang, A. E. (2015). Parkinson's disease. *Lancet*, *24*(1), 92–98. https://doi.org/10.1016/S0140-6736(14)61393-3

Keller, P. A., Lipkus, I. M., & Rimer, B. K. (2002). Depressive Realism and Health Risk Accuracy: The Negative Consequences of Positive Mood. *Journal of Consumer Research*, *29*(1), 57–69. https://doi.org/10.1086/339921

Krousel-Wood, M., Joyce, C., Holt, E., Muntner, P., Webber, L. S., Morisky, D. E., Frohlich, E. D., & Re, R. N. (2011). Predictors of decline in medication adherence: Results from the cohort study of medication adherence among older adults. *Hypertension*, *58*(5), 804–810. https://doi.org/10.1161/HYPERTENSIONAHA.111.176859

Kyngäs, H., Duffy, M. E., & Kroll, T. (2000). Conceptual analysis of compliance. *Journal of Clinical Nursing*, *9*(1), 5–12. https://doi.org/10.1046/j.1365-2702.2000.00309.x

Lam, W. Y., & Fresco, P. (2015). Medication Adherence Measures: An Overview. *BioMed Research International*, *2015*(8), 1–12. https://doi.org/10.1155/2015/217047

Langer, E. J., & Ngnoumen, C. T. (2017). Mindfulness. In *Positive psychology* (pp. 95–111). Routledge.

Lavsa, S. M., Holzworth, A., & Ansani, N. T. (2011). Selection of a validated scale for measuring medication adherence. *Journal of the American Pharmacists Association*, *51*(1), 90–94. https://doi.org/10.1331/JAPhA.2011.09154

Lehane, E., & McCarthy, G. (2009). Medication non-adherence-exploring the conceptual mire. *International Journal of Nursing Practice*, *15*(1), 25–31. https://doi.org/10.1111/j.1440-172X.2008.01722.x

Lehmann, A., Aslani, P., Ahmed, R., Celio, J., Gauchet, A., Bedouch, P., Bugnon, O., Allenet, B., & Schneider, M. P. (2014). Assessing medication adherence: Options to consider. *International Journal of Clinical Pharmacy*, *36*(1), 55–69. https://doi.org/10.1007/s11096-013-9865-x

Leopold, N. A., Polansky, M., & Hurka, M. R. (2004). Drug adherence in Parkinson's disease. *Movement Disorders*, *19*(5), 513–517. https://doi.org/10.1002/mds.20041

Leroi, I., Ahearn, D. J., Andrews, M., Mcdonald, K. R., Byrne, E. J., & Burns, A. (2011). Behavioural disorders, disability and quality of life in Parkinson's disease. *Age and Ageing*, *40*(5), 614–621. https://doi.org/10.1093/ageing/afr078

Litvan, I., Goldman, J. G., Tröster, A. I., Schmand, B. A., Weintraub, D., Petersen, R.

C., Mollenhauer, B., Adler, C. H., Marder, K., Williams-Gray, C. H., Aarsland, D., Kulisevsky, J., Rodriguez-Oroz, M. C., Burn, D. J., Barker, R. A., & Emre, M. (2012). Diagnostic criteria for mild cognitive impairment in Parkinson's disease: Movement Disorder Society Task Force guidelines. *Movement Disorders*, *27*(3), 349–356. https://doi.org/10.1002/mds.24893

Lo, R. (1999). Correlates of expected success at adherence to health regimen of people with IDDM. *Journal of Advanced Nursing*, *30*(2), 418–424. https://doi.org/10.1046/j.1365-2648.1999.01085.x

Lorig, K., Stewart, A., Ritter, P., González, V., & al, et. (1996). Outcome measures for health education and other health care interventions. In *Outcome measures for health education and other health care interventions.* Sage Publications, Inc.

Malek, N., & Grosset, D. G. (2014). Medication adherence in patients with Parkinson's disease. *CNS Drugs*, *29*(1), 47–53. https://doi.org/10.1007/s40263-014-0220-0

Mark, M. (2006). Pathogenesis, diagnosis and treatment. In M. Menza & L. Marsh (Eds.), *Psychiatric issues in Parkinson's disease. A practical guide* (pp. 1–17). Taylor & Francis.

Marks, R., Allegrante, J. P., & Lorig, K. (2005). A Review and Synthesis of Research Evidence for Self-Efficacy-Enhancing Interventions for Reducing Chronic Disability: Implications for Health Education Practice (Part II). *Health Promotion Practice*, *6*(1), 37–43. https://doi.org/10.1177/1524839904266792

Marrero, R. J., Fumero, A., de Miguel, A., & Peñate, W. (2020). Psychological factors involved in psychopharmacological medication adherence in mental health patients: A systematic review. *Patient Education and Counseling*, *2019*. https://doi.org/10.1016/j.pec.2020.04.030

McKeith, I. G., & Burn, D. (2000). Spectrum of Parkinson's disease, Parkinson's dementia, and Lewy body dementia. *Neurologic Clinics*, *18*(4), 865–883. https://doi.org/10.1016/S0733-8619(05)70230-9

McLean, G., Hindle, J. V., Guthrie, B., & Mercer, S. W. (2017). Co-morbidity and polypharmacy in Parkinson's disease: Insights from a large Scottish primary care database. *BMC Neurology*, *17*(1), 1–8. https://doi.org/10.1186/s12883-017-0904-4

McLeod, J. (2012). Qualitative Research in Counselling and Psychotherapy. In *Qualitative Research in Counselling and Psychotherapy*. SAGE. https://doi.org/10.4135/9781849209663

Moore, M. T., & Fresco, D. M. (2012). Depressive realism: A meta-analytic review. *Clinical Psychology Review*, *32*(6), 496–509. https://doi.org/10.1016/j.cpr.2012.05.004

Morisky, D. E., Green, L. W., & Levine, D. M. (1986). Concurrent and Predictive Validity of a Self-reported Measure of Medication Adherence. *Medical Care*, *24*(1).

Morris, M. E., Slade, S. C., Wittwer, J. E., Blackberry, I., Haines, S., Hackney, M. E., & McConvey, V. B. (2021). Online Dance Therapy for People With Parkinson's Disease: Feasibility and Impact on Consumer Engagement. *Neurorehabilitation and Neural Repair*, 15459683211046254. https://doi.org/10.1177/15459683211046254

Mukhtar, O., Weinman, J., & Jackson, S. H. D. (2014). Intentional non-adherence to medications by older adults. *Drugs and Aging*, *31*(3), 149–157. https://doi.org/10.1007/s40266-014-0153-9

Muslimovic, D., Post, B., Speelman, J. D., & Schmand, B. (2005). Cognitive profile

of patients with newly diagnosed Parkinson disease. *Neurology*, *65*(8), 1239–1245. https://doi.org/10.1212/01.wnl.0000180516.69442.95

Mynors, G., Jenkinson, C., MacNeill, V., & Balcon, R. (2007). A pilot evaluation of specialist community pharmacy services for patients with Parkinson's disease. *Pharmaceutical Journal*, *278*(7456), 709–712.

Náfrádi, L., Nakamoto, K., & Schulz, P. J. (2017). Is patient empowerment the key to promote adherence? A systematic review of the relationship between self-efficacy, health locus of control and medication adherence. *PLoS ONE*, *12*(10), 1–23. https://doi.org/10.1371/journal.pone.0186458

Neimann Rasmussen, L., & Montgomery, P. (2018). The prevalence of and factors associated with inclusion of non-English language studies in Campbell systematic reviews: A survey and meta-epidemiological study. *Systematic Reviews*, *7*(1), 1–12. https://doi.org/10.1186/s13643-018-0786-6

Nilsson, M. H., Hagell, P., & Iwarsson, S. (2015). Psychometric properties of the General Self-Efficacy Scale in Parkinson's disease. *Acta Neurologica Scandinavica*, *132*(2), 89–96. https://doi.org/10.1111/ane.12368

Nonnekes, J., Timmer, M. H. M., de Vries, N. M., Rascol, O., Helmich, R. C., & Bloem, B. R. (2016). Unmasking levodopa resistance in Parkinson's disease. *Movement Disorders*, *31*(11), 1602–1609. https://doi.org/10.1002/mds.26712

Pagnini, F., Bercovitz, K., & Langer, E. (2016). Perceived control and mindfulness: Implications for clinical practice. *Journal of Psychotherapy Integration*, *26*(2), 91–102. https://doi.org/10.1037/int0000035

Pappa, K., Doty, T., Taff, S. D., Kniepmann, K., & Foster, E. R. (2017). Self-Management Program Participation and Social Support in Parkinson's Disease: Mixed Methods Evaluation. *Physical and Occupational Therapy in Geriatrics*,

35(2), 81–98. https://doi.org/10.1080/02703181.2017.1288673

Parkinson, J. (1817). *An essay on the shaking palsy*. Sherwood, Neely and Jones.

Pearlin, L. I., & Schooler, C. (1978). The Structure of Coping. *Journal of Health and Social Behavior*, *19*(1), 2–21.

Pence, L., Valrie, C. R., Gil, K. M., Redding-Lallinger, R., & Daeschner, C. (2007). Optimism Predicting Daily Pain Medication Use in Adolescents with Sickle Cell Disease. *Journal of Pain and Symptom Management*, *33*(3), 302–309. https://doi.org/10.1016/j.jpainsymman.2006.08.010

Peters, M. D. J., Marnie, C., Tricco, A. C., Pollock, D., Munn, Z., Alexander, L., McInerney, P., Godfrey, C. M., & Khalil, H. (2021). Updated methodological guidance for the conduct of scoping reviews. *JBI Evidence Implementation*, *19*(1).

Postuma, R. B., Aarsland, D., Barone, P., Burn, D. J., Hawkes, C. H., Oertel, W., & Ziemssen, T. (2012). Identifying prodromal Parkinson's disease: Pre-Motor disorders in Parkinson's disease. *Movement Disorders*, *27*(5), 617–626. https://doi.org/10.1002/mds.24996

Prewitt, C. M., Charpentier, J. C., Brosky, J. A., & Urbscheit, N. L. (2017). Effects of Dance Classes on Cognition, Depression, and Self-Efficacy in Parkinson's Disease. *American Journal of Dance Therapy*, *39*(1), 126–141. https://doi.org/10.1007/s10465-017-9242-8

Raiz, L. R., Kilty, K. M., Henry, M. L., & Ferguson, R. M. (1999). Medication compliance following renal transplantation. *Transplantation*, *68*(1), 51–55. https://doi.org/10.1097/00007890-199907150-00010

Reich, J. W., & Infurna, F. J. (2016). *Perceived Control: Theory, Research, and Practice in the First 50 Years*. Oxford University Press.

Reijnders, J. S. A. M., Ehrt, U., Weber, W. E. J., Aarsland, D., & Leentjens, A. F. G. (2008). A systematic review of prevalence studies of depression in Parkinson's disease. *Movement Disorders*, *23*(2), 183–189. https://doi.org/10.1002/mds.21803

Renouf, S., ffytche, D., Pinto, R., Murray, J., & Lawrence, V. (2018). Visual hallucinations in dementia and Parkinson's disease: A qualitative exploration of patient and caregiver experiences. *International Journal of Geriatric Psychiatry*, *33*(10), 1327–1334. https://doi.org/10.1002/gps.4929

Rhodes, R. E., & Courneya, K. S. (2004). Differentiating motivation and control in the Theory of Planned Behavior. *Psychology, Health and Medicine*, *9*(2), 205–215. https://doi.org/10.1080/13548500410001670726

Rich, A., Brandes, K., Mullan, B., & Hagger, M. S. (2015). Theory of planned behavior and adherence in chronic illness: a meta-analysis. *Journal of Behavioral Medicine*, *38*(4), 673–688. https://doi.org/10.1007/s10865-015-9644-3

Richy, F. F., Pietri, G., Moran, K. A., Senior, E., & Makaroff, L. E. (2013). Compliance with pharmacotherapy and direct healthcare costs in patients with Parkinson's disease: a retrospective claims database analysis. *Applied Health Economics and Health Policy*, *11*(4), 395–406. https://doi.org/10.1007/s40258-013-0033-1

Robinson, S. A., & Lachman, M. E. (2016). Perceived Control and Behavior Change. In *Perceived Control* (pp. 201–228). https://doi.org/10.1093/acprof:oso/9780190257040.003.0009

Rotter, J. (1966). Generalized expectancies for internal versus external control of reinforcement. *Psychological Monographs: General and Applied*, *80*(1).

Rubenstein, L. M., Alloy, L. B., & Abramson, L. Y. (2016). Perceived Control and

Depression. In J. W. Reich & F. J. Infurna (Eds.), *Perceived Control* (pp. 229–252). Oxford University Press. https://doi.org/10.1093/acprof:oso/9780190257040.003.0010

Sajatovic, M., Ridgel, A. L., Walter, E. M., Tatsuoka, C. M., Colón-Zimmermann, K., Ramsey, R. K., Welter, E., Gunzler, S. A., Whitney, C. M., & Walter, B. L. (2017). A randomized trial of individual versus group-format exercise and self-management in individuals with Parkinson's disease and comorbid depression. *Patient Preference and Adherence*, *11*, 965–973. https://doi.org/10.2147/PPA.S135551

Schrag, A., Horsfall, L., Walters, K., Noyce, A., & Petersen, I. (2015). Prediagnostic presentations of Parkinson's disease in primary care: a case-control study. *The Lancet. Neurology*, *14*(1), 57–64. https://doi.org/10.1016/S1474-4422(14)70287-X

Schwarzer, R., & Jerusalem, M. (1995). Generalized Self-Efficacy scale. In J. Weinman (Ed.), *Measures in health psychology: a user's portfolio. Causal and control beliefs.* (pp. 35–37). NFER-NELSON.

Shin, J. Y., & Habermann, B. (2016). Medication Adherence in People with Parkinson Disease. *Journal of Neuroscience Nursing*, *48*(4), 185–194. https://doi.org/10.1097/JNN.0000000000000198

Shin, J. Y., Habermann, B., & Pretzer-Aboff, I. (2015). Challenges and strategies of medication adherence in Parkinson's disease: A qualitative study. *Geriatric Nursing*, *36*(3), 192–196. https://doi.org/10.1016/j.gerinurse.2015.01.003

Simpson, J., Chatzidamianos, G., Fletcher, I., Perpetuo, L., & Eccles, F. J. R. R. (2018). A new scale measuring adaptive perceived control for people with Parkinson's: Initial construction and further validation. *Journal of the*

Neurological Sciences, *391*(June), 77–83. https://doi.org/10.1016/j.jns.2018.05.023

Simpson, J., Eccles, F. J., & Zarotti, N. (2021). *Extended evidence-based guidance on psychological interventions for psychological difficulties in individuals with Huntington's disease, Parkinson's disease, motor neurone disease, and multiple sclerosis*. https://doi.org/https://doi.org/10.5281/zenodo.4593883

Simpson, J., Lekwuwa, G., & Crawford, T. (2013). Illness beliefs and psychological outcome in people with Parkinson's disease - Applied Social Sciences Index and Abstracts (ASSIA) - ProQuest. *Chronic Illness*, *9*(2), 165–176.

Simpson, J., McMillan, H., & Reeve, D. (2013). Reformulating psychological difficulties in people with Parkinson's disease: The potential of a social relational approach to disablism. *Parkinson's Disease*, *2013*. https://doi.org/10.1155/2013/608562

Simpson, J., Zarotti, N., Varey, S., Anestis, E., Holland, C., Murray, C., & Eccles, F. J. R. (2021). 'It's a double whammy': A qualitative study of illness uncertainty in individuals with Parkinson's Disease in the context of COVID-19. *Chronic Illness*, 1–26. https://doi.org/10.1177/17423953211043101

Sirois, F. M. (2003). *The Control Beliefs Inventory*. Unpublished manual.

Skinner, E. A. (1996). A guide to constructs of control. *Journal of Personality and Social Psychology*, *71*(3), 549–570. https://doi.org/10.1007/BF00014299

Soh, S. E., Morris, M. E., & McGinley, J. L. (2011). Determinants of health-related quality of life in Parkinson's disease: A systematic review. *Parkinsonism and Related Disorders*, *17*(1), 1–9. https://doi.org/10.1016/j.parkreldis.2010.08.012

Soundy, A., Collett, J., Lawrie, S., Coe, S., Roberts, H., Hu, M., Bromley, S., Harling, P., Reed, A., Coeberg, J., Carroll, C., & Dawes, H. (2019). A qualitative study

on the impact of first steps-a peer-led educational intervention for people newly diagnosed with Parkinson's disease. *Behavioral Sciences*, *9*(10), 107. https://doi.org/10.3390/bs9100107

Straka, I., Minár, M., Gažová, A., Valkovič, P., & Kyselovič, J. (2018). Clinical aspects of adherence to pharmacotherapy in Parkinson disease: A PRISMA-compliant systematic review. *Medicine (United States)*, *97*(23), e10962. https://doi.org/10.1097/MD.0000000000010962

Straka, I., Minar, M., Skorvanek, M., Grofik, M., Danterova, K., Benetin, J., Kurca, E., GaZova, A., Bolekova, V., Wyman-Chick, K. A., Kyselovic, J., & Valkovic, P. (2019). Adherence to pharmacotherapy in patients with parkinsons disease taking three and more daily doses of medication. *Frontiers in Neurology*, *10*(JUL), 1–8. https://doi.org/10.3389/fneur.2019.00799

Strickland, D., & Bertoni, J. M. (2004). Parkinson's prevalence estimated by a state registry. *Movement Disorders*, *19*(3), 318–323. https://doi.org/10.1002/mds.10619

Sumbul-Sekerci, B., Hanagasi, H. A., Bilgic, B., Tufekcioglu, Z., Gurvit, H., & Emre, M. (2022). Medication management and treatment adherence in Parkinson's disease patients with mild cognitive impairment. *Acta Neurologica Belgica*, *0123456789*. https://doi.org/10.1007/s13760-022-01916-1

Suzukamo, Y., Ohbu, S., Kondo, T., Kohmoto, J., & Fukuhara, S. (2006). Psychological adjustment has a greater effect on health-related quality of life than on severity of disease in Parkinson's disease. *Movement Disorders*, *21*(6), 761–766. https://doi.org/10.1002/mds.20817

Taher, M., Bayat, Z. S., Zandi, K. N., Ghasemi, E., Abredari, H., Karimy, M., & Abedi, A. R. (2015). Correlation between compliance regimens with health locus

of control in patients with hypertension. *Medical Journal of the Islamic Republic of Iran*, *29*.

Taris, T. W., Kessler, S. R., & Kelloway, E. K. (2021). Strategies addressing the limitations of cross-sectional designs in occupational health psychology: What they are good for (and what not). *Work and Stress*, *35*(1), 1–5. https://doi.org/10.1080/02678373.2021.1888561

Teasdale, J. D., Segal, Z. V., Williams, J. M. G., Ridgewaya, V. A., Soulsby, J. M., & Lau, M. A. (2000). Prevention of relapse/recurrence in major depression by mindfulness-based cognitive therapy. *Journal of Consulting and Clinical Psychology*, *68*(4), 615–623. https://doi.org/10.1037/0022-006X.68.4.615

Thompson, S. C., & Wierson, M. (2000). Enhancing perceived control in psychotherapy. In *Handbook of psychological change: Psychotherapy processes & practices for the 21st century.* (pp. 177–197). John Wiley & Sons, Inc.

Tosin, M. H. S., Stebbins, G. T., Goetz, C. G., Santana, R. F., Leite, M. A. A., & Oliveira, B. G. R. B. (2020). Measuring Medication Adherence in Parkinson's Disease: A Systematic Review of Contributing Components in Rating Scales. *Movement Disorders Clinical Practice*, *7*(6), 607–615. https://doi.org/10.1002/mdc3.13006

Truong, D. D., Bhidayasiri, R., & Wolters, E. (2008). Management of non-motor symptoms in advanced Parkinson disease. *Journal of the Neurological Sciences*, *266*(1–2), 216–228. https://doi.org/10.1016/j.jns.2007.08.015

Tucker, C. M., Petersen, S., Herman, K. C., Fennell, R. S., Bowling, B., Pedersen, T., & Vosmik, J. R. (2001). Self-regulation predictors of medication adherence among ethnically different pediatric patients with renal transplants. *Journal of Pediatric Psychology*, *26*(8), 455–464. https://doi.org/10.1093/jpepsy/26.8.455

Tyack, C., & Camic, P. M. (2017). Touchscreen interventions and the well-being of people with dementia and caregivers: A systematic review. *International Psychogeriatrics*, *29*(8), 1261–1280. https://doi.org/10.1017/S1041610217000667

Valldeoriola, F., Coronell, C., Pont, C., Buongiorno, M. T., Cámara, A., Gaig, C., & Compta, Y. (2011). Socio-demographic and clinical factors influencing the adherence to treatment in Parkinson's disease: The ADHESON study. *European Journal of Neurology*, *18*(7), 980–987. https://doi.org/10.1111/j.1468-1331.2010.03320.x

Vandenberg, B. E., Advocat, J., Hassed, C., Hester, J., Enticott, J., & Russell, G. (2019). Mindfulness-based lifestyle programs for the self-management of Parkinson's disease in Australia. *Health Promotion International*, *34*(4), 668–676. https://doi.org/10.1093/heapro/day021

Verity, D., Eccles, F. J. R. R., Boland, A., & Simpson, J. (2020). Does perceived control mediate the relationship between stigma and well-being for individuals with Parkinson's disease? *Journal of the Neurological Sciences*, *414*(December 2019), 116841. https://doi.org/10.1016/j.jns.2020.116841

Von Campenhausen, S., Bornschein, B., Wick, R., Bötzel, K., Sampaio, C., Poewe, W., Oertel, W., Siebert, U., Berger, K., & Dodel, R. (2005). Prevalence and incidence of Parkinson's disease in Europe. *European Neuropsychopharmacology*, *15*(4), 473–490. https://doi.org/10.1016/j.euroneuro.2005.04.007

Walker, J. (2001). *Control and the Psychology of Health: Theory, Measurement, and Applications*. Open University.

Wallston, K. A., Stein, M. J., & Smith, C. A. (1994). Form C of the MHLC Scales: A

Condition-Specific Measure of Locus of Control. *Journal of Personality Assessment*, *63*(3), 534–553. https://doi.org/10.1207/s15327752jpa6303_10

Wallston, K. A., Wallston, B. S., Smith, S., & Dobbins, C. J. (1987). Perceived control and health. *Current Psychology*, *6*(1), 5–25. https://doi.org/10.1007/BF02686633

Weintraub, D., & Burn, D. J. (2011). Parkinson's disease: the quintessential neuropsychiatric disorder. *Movement Disorders : Official Journal of the Movement Disorder Society*, *26*(6), 1022–1031. https://doi.org/10.1002/mds.23664

Willis, A. W., Schootman, M., Kung, N., & Racette, B. A. (2013). Epidemiology and neuropsychiatric manifestations of Young Onset Parkinson's Disease in the United States. *Parkinsonism and Related Disorders*, *19*(2), 202–206. https://doi.org/10.1016/j.parkreldis.2012.09.014

Wolinsky, F. D., Vander Weg, M. W., Martin, R., Unverzagt, F. W., Willis, S. L., Marsiske, M., Rebok, G. W., Morris, J. N., Ball, K. K., & Tennstedt, S. L. (2010). Does cognitive training improve internal locus of control among older adults? *Journals of Gerontology - Series B Psychological Sciences and Social Sciences*, *65 B*(5), 591–598. https://doi.org/10.1093/geronb/gbp117

World Health Organization. (2003). *Adherence to long-term therapies. Evidence for action.*

Wright, J., & Walker, J. (2013). Medication adherence in Parkinson's. *British Journal of Nursing*, *22*(12), 686–689. https://doi.org/10.12968/bjon.2013.22.12.686

Yap, A. F., Thirumoorthy, T., & Kwan, Y. H. (2016). Systematic review of the barriers affecting medication adherence in older adults. *Geriatrics and Gerontology International*, *16*(10), 1093–1101. https://doi.org/10.1111/ggi.12616

Yasavage, J. A., & Sheikh, J. I. (1986). 9/Geriatric Depression Scale (GDS) Recent

Evidence and Development of a Shorter Version. *Clinical Gerontologist*, *5*(1–2), 119–136. https://doi.org/10.1300/J018v05n01

Zarotti, N., Coates, E., McGeachan, A., Williams, I., Beever, D., Hackney, G., Norman, P., Stavroulakis, T., White, D., White, S., Halliday, V., McDermott, C., Al-Chalabi, A., Archer, R., Baird, W., Boddy, M., Bradburn, M., Cade, J., Cooper, C., … Young, T. (2019). Health care professionals' views on psychological factors affecting nutritional behaviour in people with motor neuron disease: A thematic analysis. *British Journal of Health Psychology*, *24*(4), 953–969. https://doi.org/10.1111/bjhp.12388

Zarotti, N., Dale, M., Eccles, F. J. R., & Simpson, J. (2022). More than Just a Brain Disorder: A Five-Point Manifesto for Psychological Care for People with Huntington's Disease. *Journal of Personalized Medicine*, *12*(1), 64. https://doi.org/10.3390/jpm12010064

Zarotti, N., Eccles, F., Broyd, A., Longinotti, C., Mobley, A., & Simpson, J. (2022). Third wave cognitive behavioural therapies for people with multiple sclerosis: a scoping review. *Disability and Rehabilitation*, 1–16. https://doi.org/10.1080/09638288.2022.2069292

Zarotti, N., Eccles, F. J. R., Foley, J. A., Paget, A., Gunn, S., Leroi, I., & Simpson, J. (2021). Psychological interventions for people with Parkinson's disease in the early 2020s: Where do we stand? *Psychology and Psychotherapy: Theory, Research and Practice*, *94*(3), 760–797. https://doi.org/10.1111/papt.12321

Zarotti, N., Simpson, J., & Fletcher, I. (2019). 'I have a feeling I can't speak to anybody': A thematic analysis of communication perspectives in people with Huntington's disease. *Chronic Illness*, *15*(1), 61–73. https://doi.org/10.1177/1742395317733793

Zhang, Z. X., & Roman, G. C. (1993). Worldwide occurrence of Parkinson's disease: An updated review. *Neuroepidemiology*, *12*(4), 195–208. https://doi.org/10.1159/000110318

Appendix A

Author Guidelines for *Disability and Rehabilitation*

Instructions for authors

Thank you for choosing to submit your paper to us. These instructions will ensure we have everything required so your paper can move through peer review, production and publication smoothly. Please take the time to read and follow them as closely as possible, as doing so will ensure your paper matches the journal's requirements.

AUTHOR SERVICES
Supporting Taylor & Francis authors

For general guidance on every stage of the publication process, please visit our Author Services website.

EDITING SERVICES
Supporting Taylor & Francis authors

For editing support, including translation and language polishing, explore our Editing Services website

SCHOLARONE MANUSCRIPTS™

This journal uses ScholarOne Manuscripts (previously Manuscript Central) to peer review manuscript submissions. Please read the guide for ScholarOne authors before making a submission. Complete guidelines for preparing and submitting your manuscript to this journal are provided below.

Contents

    - Style guidelines
    - Formatting and templates
    - References
    - Editing Services
    - Checklist
- Using third-party material in your paper
- Declaration of interest statement
- Clinical Trials Registry
- Complying with ethics of experimentation
- Consent
- Health and safety
- Submitting your paper
- Data Sharing Policy
- Publication charges
- Copyright options
- Complying with funding agencies
- My Authored Works

About the journal

Disability and Rehabilitation is an international, peer reviewed journal, publishing high-quality, original research. Please see the journal's Aims & Scope for information about its focus and peer-review policy.

From 2018, this journal will be online only, and will no longer provide print copies.

Please note that this journal only publishes manuscripts in English.

Disability and Rehabilitation accepts the following types of article: Reviews, Research Papers, Case Studies, Perspectives on Rehabilitation, Reports on Rehabilitation in Practice, Education and Training, and Correspondence. Systematic Reviews including meta-syntheses of qualitative research should be submitted as Reviews. All other types of Reviews will normally be considered as Perspectives in Rehabilitation.

Special Issues and specific sections on contemporary themes of interest to the Journal's readership are published. Please contact the Editor for more information.

Open Access

You have the option to publish open access in this journal via our Open Select publishing program. Publishing open access means that your article will be free to access online immediately on publication, increasing the visibility, readership and impact of your research. Articles published Open Select with Taylor & Francis typically receive 95% more citations* and over 7 times as many downloads** compared to those that are not published Open Select.

Your research funder or your institution may require you to publish your article open access. Visit our Author Services website to find out more about open access policies and how you can comply with these.

You will be asked to pay an article publishing charge (APC) to make your article open access and this cost can often be covered by your institution or funder. Use our APC finder to view the APC for this journal.

Please visit our Author Services website if you would like more information about our Open Select Program.

*Citations received up to 9th June 2021 for articles published in 2016-2020 in journals listed in Web of Science®. Data obtained on 9th June 2021, from Digital Science's Dimensions platform, available at https://app.dimensions.ai
**Usage in 2018-2020 for articles published in 2016-2020.

Peer review

Taylor & Francis is committed to peer-review integrity and upholding the highest standards of review. For submissions to *Disability and Rehabilitation* authors are given the option to remain anonymous during

the peer-review process. Authors will be able to indicate whether their paper is 'Anonymous' or 'Not Anonymous' during submission, and should pay particular attention to the below:

- Authors who wish to remain **anonymous** should prepare a complete text with information identifying the author(s) removed. This should be uploaded as the "Main Document" and will be sent to the referees. A separate title page should be included providing the full affiliations of all authors. Any acknowledgements and the Declaration of Interest statement must be included but should be worded mindful that these sections will be made available to referees.
- Authors who wish to be **identified** should include the name(s) and affiliation(s) of author(s) on the first page of the manuscript. The complete text should be uploaded as the "Main Document".

Once your paper has been assessed for suitability by the editor, it will be peer-reviewed by independent, anonymous expert referees. If you have shared an earlier version of your Author's Original Manuscript on a preprint server, please be aware that anonymity cannot be guaranteed. Further information on our preprints policy and citation requirements can be found on our Preprints Author Services page. Find out more about what to expect during peer review and read our guidance on publishing ethics.

Preparing your paper

All authors submitting to medicine, biomedicine, health sciences, allied and public health journals should conform to the Uniform Requirements for Manuscripts Submitted to Biomedical Journals, prepared by the International Committee of Medical Journal Editors (ICMJE).

We also refer authors to the community standards explicit in the American Psychological Association's (APA) Ethical Principles of Psychologists and Code of Conduct.

We encourage authors to be aware of standardised reporting guidelines

below when preparing their manuscripts:

- Case reports - CARE
- Diagnostic accuracy - STARD
- Observational studies - STROBE
- Randomized controlled trial - CONSORT
- Systematic reviews, meta-analyses - PRISMA

Whilst the use of such guidelines is supported, due to the multi-disciplinary nature of the Journal, it is not compulsory.

Structure

Your paper should be compiled in the following order: title page; abstract; keywords; main text, introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s); figures; figure captions (as a list).

In the main text, an introductory section should state the purpose of the paper and give a brief account of previous work. New techniques and modifications should be described concisely but in sufficient detail to permit their evaluation. Standard methods should simply be referenced. Experimental results should be presented in the most appropriate form, with sufficient explanation to assist their interpretation; their discussion should form a distinct section.

Tables and figures should be referred to in text as follows: figure 1, table 1, i.e. lower case. The place at which a table or figure is to be inserted in the printed text should be indicated clearly on a manuscript. Each table and/or figure must have a title that explains its purpose without reference to the text.

The title page should include the full names and affiliations of all authors involved in the preparation of the manuscript. The corresponding author should be clearly designated, with full contact information provided for this person.

Word count

Please include a word count for your paper. There is no word limit for papers submitted to this journal, but succinct and well-constructed papers are preferred.

Style guidelines

Please refer to these style guidelines when preparing your paper, rather than any published articles or a sample copy.

Please use any spelling consistently throughout your manuscript.

Please use double quotation marks, except where "a quotation is 'within' a quotation". Please note that long quotations should be indented without quotation marks.

For tables and figures, the usual statistical conventions should be used.

Drugs should be referred to by generic names. Trade names of substances, their sources, and details of manufacturers of scientific instruments should be given only if the information is important to the evaluation of the experimental data.

Alt Text

This journal is now including Alt Text (alternative text), a short piece of text that can be attached to your figure to convey to readers the nature or contents of the image. It is typically used by systems such as pronouncing screen readers to make the object accessible to people that cannot read or see the object, due to a visual impairment or print disability. Alt text will also be displayed in place of an image, if said image file cannot be loaded. Alt Text can also provide better image context/descriptions to search engine crawlers, helping them to index an image properly. To include Alt Text in your article, please follow our Guidelines.

Formatting and templates

Papers may be submitted in any standard format, including Word and LaTeX. Figures should be saved separately from the text. To assist you in preparing your paper, we provide formatting template(s).

Word templates are available for this journal. Please save the template to your hard drive, ready for use.

A LaTeX template is available for this journal. Please save the template to your hard drive, ready for use.

If you are not able to use the templates via the links (or if you have any other template queries) please contact us here.

References

Please use this reference guide when preparing your paper. An EndNote output style is also available to assist you.

Taylor & Francis Editing Services

To help you improve your manuscript and prepare it for submission, Taylor & Francis provides a range of editing services. Choose from options such as English Language Editing, which will ensure that your article is free of spelling and grammar errors, Translation, and Artwork Preparation. For more information, including pricing, visit this website.

Checklist: what to include

1. **Author details**. Please ensure everyone meeting the International Committee of Medical Journal Editors (ICJME) requirements for authorship is included as an author of your paper. Please ensure all listed authors meet the Taylor & Francis authorship criteria. All authors of a manuscript should include their full name and affiliation on the cover page of the manuscript. Where available, please also include ORCiDs and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the article PDF

(depending on the journal) and the online article. Authors' affiliations are the affiliations where the research was conducted. If any of the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after your paper is accepted. Read more on authorship.

2. A structured **abstract** of no more than 200 words. A structured abstract should cover (in the following order): the *purpose* of the article, its *materials and methods* (the design and methodological procedures used), the *results* and conclusions (including their relevance to the study of disability and rehabilitation). Read tips on writing your abstract.
3. You can opt to include a **video abstract** with your article. Find out how these can help your work reach a wider audience, and what to think about when filming.
4. 5-8 **keywords**. Read making your article more discoverable, including information on choosing a title and search engine optimization.
5. A feature of this journal is a boxed insert on **Implications for Rehabilitation**. This should include between two to four main bullet points drawing out the implications for rehabilitation for your paper. This should be uploaded as a separate document. Below are examples:

   Example 1: Leprosy

   - Leprosy is a disabling disease which not only impacts physically but restricts quality of life often through stigmatisation.
   - Reconstructive surgery is a technique available to this group.
   - In a relatively small sample this study shows participation and social functioning improved after surgery.

   Example 2: Multiple Sclerosis

   - Exercise is an effective means of improving health and well-being experienced by people with multiple sclerosis (MS).
   - People with MS have complex reasons for choosing to exercise or not.

    - Individual structured programmes are most likely to be successful in encouraging exercise in this cohort.
6. **Acknowledgement**. Please supply all details required by your funding and grant-awarding bodies as follows: *For single agency grants*: This work was supported by the under Grant . *For multiple agency grants*: This work was supported by the under Grant ; under Grant ; and under Grant .
7. **Declaration of Interest**. This is to acknowledge any financial or non-financial interest that has arisen from the direct applications of your research. If there are no relevant competing interests to declare please state this within the article, for example: *The authors report there are no competing interests to declare*. Further guidance on what is a conflict of interest and how to disclose it.
8. **Data availability statement.** If there is a data set associated with the paper, please provide information about where the data supporting the results or analyses presented in the paper can be found. Where applicable, this should include the hyperlink, DOI or other persistent identifier associated with the data set(s). Templates are also available to support authors.
9. **Data deposition.** If you choose to share or make the data underlying the study open, please deposit your data in a recognized data repository prior to or at the time of submission. You will be asked to provide the DOI, pre-reserved DOI, or other persistent identifier for the data set.
10. **Supplemental online material.** Supplemental material can be a video, dataset, fileset, sound file or anything which supports (and is pertinent to) your paper. We publish supplemental material online via Figshare. Find out more about supplemental material and how to submit it with your article.
11. **Figures.** Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour). Figures should be saved as TIFF, PostScript or EPS files.
12. **Tables.** Tables should present new information rather than duplicating what is in the text. Readers should be able to interpret the

table without reference to the text. Please supply editable files.

13. **Equations**. If you are submitting your manuscript as a Word document, please ensure that equations are editable. More information about mathematical symbols and equations.
14. **Units.** Please use SI units (non-italicized).

Using third-party material in your paper

You must obtain the necessary permission to reuse third-party material in your article. The use of short extracts of text and some other types of material is usually permitted, on a limited basis, for the purposes of criticism and review without securing formal permission. If you wish to include any material in your paper for which you do not hold copyright, and which is not covered by this informal agreement, you will need to obtain written permission from the copyright owner prior to submission. More information on requesting permission to reproduce work(s) under copyright.

Declaration of Interest Statement

Please include a declaration of interest statement, using the subheading "Declaration of interest." If you have no interests to declare, please state this (suggested wording: *The authors report no conflicts of interest*). For all NIH/Wellcome-funded papers, the grant number(s) must be included in the disclosure of interest statement. Read more on declaring conflicts of interest.

Clinical Trials Registry

In order to be published in Disability and Rehabilitation , all clinical trials must have been registered in a public repository, ideally at the beginning of the research process (prior to participant recruitment). Trial registration numbers should be included in the abstract, with full details in the methods section. Clinical trials should be registered prospectively – i.e. before participant recruitment. The clinical trial registry should be publicly

accessible (at no charge), open to all prospective registrants, and managed by a not-for-profit organization. For a list of registries that meet these requirements, please visit the WHO International Clinical Trials Registry Platform (ICTRP). The registration of all clinical trials facilitates the sharing of information among clinicians, researchers, and patients, enhances public confidence in research, and is in accordance with the ICMJE guidelines.

Complying with ethics of experimentation

Please ensure that all research reported in submitted papers has been conducted in an ethical and responsible manner, and is in full compliance with all relevant codes of experimentation and legislation. All papers which report *in vivo* experiments or clinical trials on humans or animals must include a written statement in the Methods section. This should explain that all work was conducted with the formal approval of the local human subject or animal care committees (institutional and national), and that clinical trials have been registered as legislation requires. Authors who do not have formal ethics review committees should include a statement that their study follows the principles of the Declaration of Helsinki.

Please ensure that all research reported in submitted papers has been conducted in an ethical and responsible manner, and is in full compliance with all relevant codes of experimentation and legislation. All original research papers involving humans, animals, plants, biological material, protected or non-public datasets, collections or sites, must include a written statement in the Methods section, confirming ethical approval has been obtained from the appropriate local ethics committee or Institutional Review Board and that where relevant, informed consent has been obtained. For animal studies, approval must have been obtained from the local or institutional animal use and care committee. All research studies on humans (individuals, samples, or data) must have been performed in accordance with the principles stated in the Declaration of Helsinki. In settings where ethics approval for non-interventional studies (e.g. surveys) is not required, authors must include a statement to explain this.

In settings where there are no ethics committees in place to provide ethical approval, authors are advised to contact the Editor to discuss further. Detailed guidance on ethics considerations and mandatory declarations can be found in our Editorial Policies section on Research Ethics.

Consent

All authors are required to follow the ICMJE requirements and Taylor & Francis Editorial Policies on privacy and informed consent from patients and study participants. Authors must include a statement to confirm that any patient, service user, or participant (or that person's parent or legal guardian) in any type of qualitative or quantitative research, has given informed consent to participate in the research. For submissions where patients or participants can be potentially identified (e.g. a clinical case report detailing their medical history, identifiable images or media content, etc), authors must include a statement to confirm that they have obtained written informed consent to publish the details from the affected individual (or their parents/guardians if the participant in not an adult or unable to give informed consent; or next of kin if the participant is deceased). The process of obtaining consent to publish should include sharing the article with the individual (or whoever is consenting on their behalf), so that they are fully aware of the content of the article before it is published. Authors should familiarise themselves with our policy on participant/patient privacy and informed consent. They may also use the Consent to Publish Form, which can be downloaded from the same Author Services page.

Health and safety

Please confirm that all mandatory laboratory health and safety procedures have been complied with in the course of conducting any experimental work reported in your paper. Please ensure your paper contains all appropriate warnings on any hazards that may be involved in carrying out the experiments or procedures you have described, or that may be involved in instructions, materials, or formulae.

Please include all relevant safety precautions; and cite any accepted standard or code of practice. Authors working in animal science may find it useful to consult the International Association of Veterinary Editors' Consensus Author Guidelines on Animal Ethics and Welfare and Guidelines for the Treatment of Animals in Behavioural Research and Teaching. When a product has not yet been approved by an appropriate regulatory body for the use described in your paper, please specify this, or that the product is still investigational.

Submitting your paper

This journal uses ScholarOne to manage the peer-review process. If you haven't submitted a paper to this journal before, you will need to create an account in the submission centre. Please read the guidelines above and then submit your paper in the relevant Author Centre, where you will find user guides and a helpdesk. By submitting your paper to *Disability and Rehabilitation* you are agreeing to originality checks during the peer-review and production processes.

The Editor of *Disability and Rehabilitation* will respond to appeals from authors relating to papers which have been rejected. The author(s) should email the Editor outlining their concerns and making a case for why their paper should not have been rejected. The Editor may choose to accept the appeal and secure a further review, or to not uphold the appeal. In case of the latter, the Editor of *Disability and Rehabilitation: Assistive Technology* will be consulted.

On acceptance, we recommend that you keep a copy of your Accepted Manuscript. Find out more about sharing your work.

Data Sharing Policy

This journal applies the Taylor & Francis Basic Data Sharing Policy. Authors are encouraged to share or make open the data supporting the results or analyses presented in their paper where this does not violate the protection of human subjects or other valid privacy or security

concerns.

Authors are encouraged to deposit the dataset(s) in a recognized data repository that can mint a persistent digital identifier, preferably a digital object identifier (DOI) and recognizes a long-term preservation plan. If you are uncertain about where to deposit your data, please see this information regarding repositories.

Authors are further encouraged to cite any data sets referenced in the article and provide a Data Availability Statement.

At the point of submission, you will be asked if there is a data set associated with the paper. If you reply yes, you will be asked to provide the DOI, pre-registered DOI, hyperlink, or other persistent identifier associated with the data set(s). If you have selected to provide a pre-registered DOI, please be prepared to share the reviewer URL associated with your data deposit, upon request by reviewers.

Where one or multiple data sets are associated with a manuscript, these are not formally peer reviewed as a part of the journal submission process. It is the author's responsibility to ensure the soundness of data. Any errors in the data rest solely with the producers of the data set(s).

Publication charges

There are no submission fees, publication fees or page charges for this journal.

Color figures will be reproduced in color in your online article free of charge.

Copyright options

Copyright allows you to protect your original material, and stop others from using your work without your permission. Taylor & Francis offers a number of different license and reuse options, including Creative Commons licenses when publishing open access. Read more on

publishing agreements.

Complying with funding agencies

We will deposit all National Institutes of Health or Wellcome Trust-funded papers into PubMedCentral on behalf of authors, meeting the requirements of their respective open access (OA) policies. If this applies to you, please tell our production team when you receive your article proofs, so we can do this for you. Check funders' OA policy mandates here. Find out more about sharing your work.

My Authored Works

On publication, you will be able to view, download and check your article's metrics (downloads, citations and Altmetric data) via My Authored Works on Taylor & Francis Online. This is where you can access every article you have published with us, as well as your free eprints link, so you can quickly and easily share your work with friends and colleagues.

We are committed to promoting and increasing the visibility of your article. Here are some tips and ideas on how you can work with us to promote your research.

Queries

Should you have any queries, please visit our Author Services website or contact us here.

Updated 12-11-2021

Appendix B

PRISMA-ScR Checklist

Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	1
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	4-6
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	7
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	N/A
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	7-8
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	8
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	Table 1-2
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	8
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	9

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	9-10
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	N/A
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	9
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	9-10; Figure 1
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	9-13
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	N/A
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	9-13
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	9-13
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	14-17
Limitations	20	Discuss the limitations of the scoping review process.	17
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	18
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	N/A

JBI = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.
* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.
† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.
§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMAScR): Checklist and Explanation. Ann Intern Med. 2018;169:467–473. doi: 10.7326/M18-0850.

Appendix C

FMH Ethics Approval for Empirical Study

Faculty of Medicine and Health Sciences Research Ethics Committee

University of East Anglia

Dr Nicolo Zarotti
Norwich Medical School
University of East Anglia
Norwich Research Park
Norwich
NR4 7TJ

NORWICH MEDICAL SCHOOL
Bob Champion Research & Educati
Building
Rosalind Franklin Road
University of East Anglia
Norwich Research Park
Norwich NR4 7UQ

Email: fmh.ethics@uea.ac.uk
www.med.uea.ac.uk

18th December 2020

Dear Dr Zarotti

Title: The role of perceived control in the relationship between depression and medication adherence in people with Parkinson's disease

Reference: 2020/21-045

Thank you for your email of 4th December 2020 notifying us of the amendments you would like to make to your above proposal. These have been considered and I can confirm that your amendments have been approved.

Please can you ensure that any further amendments to either the protocol or documents submitted are notified to us in advance, and that any adverse events which occur during your project are reported to the Committee.

Approval by the FMH Research Ethics Committee should not be taken as evidence that your study is compliant with GDPR and the Data Protection Act 2018. If you need guidance on how to make your study GDPR compliant, please contact your institution's Data Protection Officer.

Please can you arrange to send us a report once your project is completed.

Yours sincerely

Dr Jackie Buck
Chair
FMH Research Ethics Committee

COVID-19: The FMH Research Ethics Committee procedures remain as normal. Please note that our decisions as to the ethics of your application take no account of changes in Government measures and UEA guidelines relating to the coronavirus pandemic and all approvals granted are, of course, subject to these.

Appendix D

Survey Advertising Material

Volunteers Needed to Help us Find Out How Mood and Feelings of Control Affect Taking Medication for Parkinson's

Hello! We are a Research Team at the University of East Anglia (UK) and we are looking for volunteers to take part in a research project on how feelings of control and mood in people with Parkinson's may affect taking medication for Parkinson's. We hope this will help us make taking medications easier for people with Parkinson's in the future. If you choose to take part, you will be asked to complete an anonymous online survey which will last around 35-45 minutes. To participate you need to be:

- 18 or older
- Fluent in English
- Living in an English-speaking country
- Diagnosed with Parkinson's, and
- Taking medication(s) for Parkinson's

Are You Interested?

If so, please click the link below for further information about the project and the option to take part:

[LINK]

Appendix E

Survey Information Sheet

[Included at the beginning of the online survey, as first landing page link]

The relationship between feelings of control, low mood, and medication adherence in people with Parkinson's

Hello! We are a Research Team at the University of East Anglia (UK), and we are looking for volunteers with Parkinson's to help us find out about whether depression and feelings of control affect the ways in which medication is taken. If you choose to take part, you will be asked to complete a survey which will last approximately 35 to 45 minutes. However, before you decide, it is important for you to understand what the project is about and what it would involve. Please take time to read through this information carefully. You may also discuss it with your family or friends if you wish. In case anything is not clear, please do not hesitate to contact us through the details provided at the end of this page.

This information sheet is also available as a paper copy from the Chief Investigator of the project, Dr Nicolò Zarotti (contact details listed below).

What is the study about, and why are you carrying it out?

Being able and feeling motivated to take medications is a very important aspect of treating Parkinson's disease, especially because better adherence to medications normally means better control of symptoms and quality of life in general. At the

moment, we are not sure which aspect of our sense of control helps the most with difficulties with taking medications.

Why have I been approached?

You have been approached because you are 18 or older, fluent in English, live in an English-speaking country, have a diagnosis of Parkinson's and take medications for Parkinson's.

Do I have to take part?

No. It's completely up to you to decide whether or not to take part in this study. Not taking part will have no negative repercussions on your treatment.

Will I be able to withdraw after participating?

No, as the responses you provide will be saved without your name or any way to identify you, we will not be able to identify your information to remove it once you finish and submit the survey. However, you can stop and leave the website at any time before completing it. Incomplete surveys will not be stored.

What will I be asked to do if I take part?

If you decide to take part, you will be asked to complete an online survey consisting of a number of questionnaires asking you questions about how Parkinson's affects your mental wellbeing and how you take your medications. The survey will take approximately 35-45 minutes, although you can stop and save it at any time and return to finish it later.

Are there any benefits to taking part?

Although you may find it interesting to take part in this research, there are no direct benefits to you in participating. However, by taking part you will be contributing to our understanding of the factors affecting medication adherence in people with Parkinson's. This may in turn help make medication adherence easier in the future for people with Parkinson's and similar conditions.

Will my data be confidential?

The information you provide is confidential and anonymous. The data collected for this study will stored securely and privately on a password-protected University of East Anglia online server (OneDrive), based in the UK. The files will be encrypted, that is no one other than the Research Team will be able to access them, and your information will be managed in line with General Data Protection Regulation (GDPR, 2018). If you have any questions about how your data will be handled in this research project, in the first instance please contact the Chief Investigator, Dr Nicolò Zarotti (n.zarotti@uea.ac.uk).

However, if you have any further questions or complaints about how your data are used, you can also contact:

Professor Niall Broomfield

Head of the Department of Clinical Psychology

and Psychological Therapies (CPPT) at the University of East Anglia

Tel: +44 (0)1603 59 1217

Email: N.Broomfield@uea.ac.uk

What will happen to the results?

The anonymised results will be summarised and reported in a doctoral thesis as part of the Doctorate in Clinical Psychology Programme at the University of East Anglia (UK). The anonymised result database may be used by other researchers, who will ask permission of the UEA research team to access the data. In addition, the results are expected to be submitted for publication in academic or professional journals, and may be shared as part of lay reports, web pages, press releases, conferences, and training material.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the Research Team members at any time to receive further details on relevant Parkinson's and mental health support groups. Some of these are also listed at the end of this form.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Medicine and Health Research Ethics Committee at the University of East Anglia (UK).

Yes, I would like to take part in the research – what do I need to do now?

Thank you very much! To take part in the research simply click on the arrow at the end of this page.

I am not sure about taking part – where can I get further information?

We are very happy to answer any questions you may have. To get in touch, please refer to our contact details below.

No, I do not wish to take part in the consultation – what do I need to do now?

There is nothing more to do. You may simply close your browser window. However, as we are advertising this project via multiple associations, you may hear about it again from another route. If you still wish not to participate, please feel free to ignore any other messages about the survey.

I would like to participate, but I would also like further information on relevant support groups in case I feel distressed

Here is a list of a number of Parkinson's and mental health resources and support groups you may reach out for in case you feel distressed at any point:

Europe:

- Parkinson's UK
    - Website: www.parkinsons.org.uk
    - Helpline: 0808 800 0303 (opening times: Monday-Friday: 9am-7pm, Saturday: 10am-2pm; closed Sundays/bank holidays)
- Parkinson's Association of Ireland: www.parkinsons.ie
- European Parkinson's Disease Association: www.epda.eu.com

- Depression UK: www.depressionuk.org
- Mental Health Foundation: www.mentalhealth.org.uk

Africa:

- Parkinson's Africa: www.parkinsonsafrica.com

North America

- American Parkinson Disease Association: www.apdaparkinson.org
- Parkinson's Foundation: www.parkinson.org
- Michael J. Fox Foundation: www.michaeljfox.org
- Parkinson Canada: www.parkinson.ca
- Anxiety and Depression Organization of America: www.adaa.org

Australasia:

- Parkinson's Australia: www.parkinsons.org.au
- Parkinson's New Zealand: www.parkinsons.org.nz
- Beyond Blue: www.beyondblue.org.au

We hope these can be helpful. Should you have any further questions, please feel free to get in touch with the Research Team via the contact details below.

How to contact us

If you have any questions about the study, or wish to receive a lay summary of its aims and purpose, please feel free to contact the following members of the Research Team at any time:

- Dr Nicolò Zarotti

  Chief Investigator

  Email: n.zarotti@uea.ac.uk

- Dr Katherine Deane

  Research Supervisor

  Email: K.Deane@uea.ac.uk

- Dr Cat Ford

  Research Supervisor

  Email: Catherine.Ford@uea.ac.uk

Thank you for taking the time to read this information sheet. If you agree to take part in the study, please click on the arrow below to continue.

Appendix F

Lay Summary

Treatment for Parkinson's often involves taking a lot of medications. Keeping up with medications can be very difficult for people with Parkinson's and their families. This can become harder when difficulties like feeling depressed or feeling you are not in control get in the way.

Indeed, feeling in control can be an important defence against depression and helpful for managing medications for Parkinson's. There are many different aspects to our sense of control, such as how people manage their health and their symptoms, how well they feel when they have to do something, how many choices they have with their medications, and how free they feel when with other people.

At the moment, we are not sure which aspect of our sense of control helps the most against difficulties with taking medications. Understanding this is important because there are talking therapies to improve the different aspects of your sense of control, and lack of control has been recently highlighted as an important aspect to make talking therapy effective for people with Parkinson's in particular.

Appendix G

Consent Form

[Included in the online survey as clickable statements in lieu of tick boxes, participants were not be able to proceed unless they clicked on all statements]

We are asking if you would like to take part in a research project exploring relationships between feelings of control, depression, and medication adherence in people with Parkinson's. Before you consent to taking part, we ask that you read the Participant Information Sheet and agree with each statement below by clicking on it. If you have any questions or queries before confirming your consent, please feel free to contact the Chief Investigator, Dr Nicolò Zarotti (n.zarotti@uea.ac.uk), at any time.

Please read the following statements and click on each of them to confirm you agree:

1. I confirm that I have read the Participant Information Sheet and fully understand what is expected of me within this study.

2. I am aware that I can ask questions about the survey by emailing the Research Team.

3. I understand that I can withdraw from this research by closing the browser window at any time before I click on the word 'submit' on the last page,

although if I finish and click on the word 'submit' it will no longer be possible to withdraw.

4. I understand that the information from my participation is anonymous, will be combined with other participants' responses, and may be published.

5. I understand that the Chief Investigator will share and discuss anonymous information from my participation with the Research Supervisors and other members of the Research Team.

6. I consent to information from my anonymised data being used in further research, reports, conferences, and training events.

7. I understand that any information I give will remain strictly confidential and anonymous, and will be stored by the Research Team on online password-protected servers at the University of East Anglia.

8. I consent to take part in the above study.

Thank you for confirming your consent to participate. To continue with the study, please click on the arrow below.

Appendix H

Unmet Criteria Page

[Landing page in case any of the Criteria Check questions was answered negatively]

We are really grateful to you for wishing to participate in our study. Unfortunately, it looks like you do not meet all the eligibility criteria we are looking for at this time.

If you have a diagnosis of Parkinson's, but are currently not taking any medications, you may also refer to the following resources in case you wish to receive further support:

Europe:

- Parkinson's UK
    - Website: www.parkinsons.org.uk

    - Helpline: 0808 800 0303 (opening times: Monday-Friday: 9am-7pm, Saturday: 10am-2pm; closed Sundays/bank holidays)

- Parkinson's Association of Ireland: www.parkinsons.ie
- European Parkinson's Disease Association: www.epda.eu.com

Africa:

- Parkinson's Africa: www.parkinsonsafrica.com

North America

- American Parkinson Disease Association: www.apdaparkinson.org
- Parkinson's Foundation: www.parkinson.org
- Michael J. Fox Foundation: www.michaeljfox.org
- Parkinson Canada: www.parkinson.ca

Australasia:

- Parkinson's Australia: www.parkinsons.org.au
- Parkinson's New Zealand: www.parkinsons.org.nz

If you do not have a diagnosis of Parkinson's, but are struggling with depression and wish to receive support, please refer to the following organisations:

- Depression UK: www.depressionuk.org
- Mental Health Foundation: www.mentalhealth.org.uk

- World Health Organization – Depression: www.who.int/health-topics/depression
- Anxiety and Depression Organization of America: www.adaa.org
- Beyond Blue: www.beyondblue.org.au

If you have any further questions, please feel free to contact the following members of the Research Team at any time:

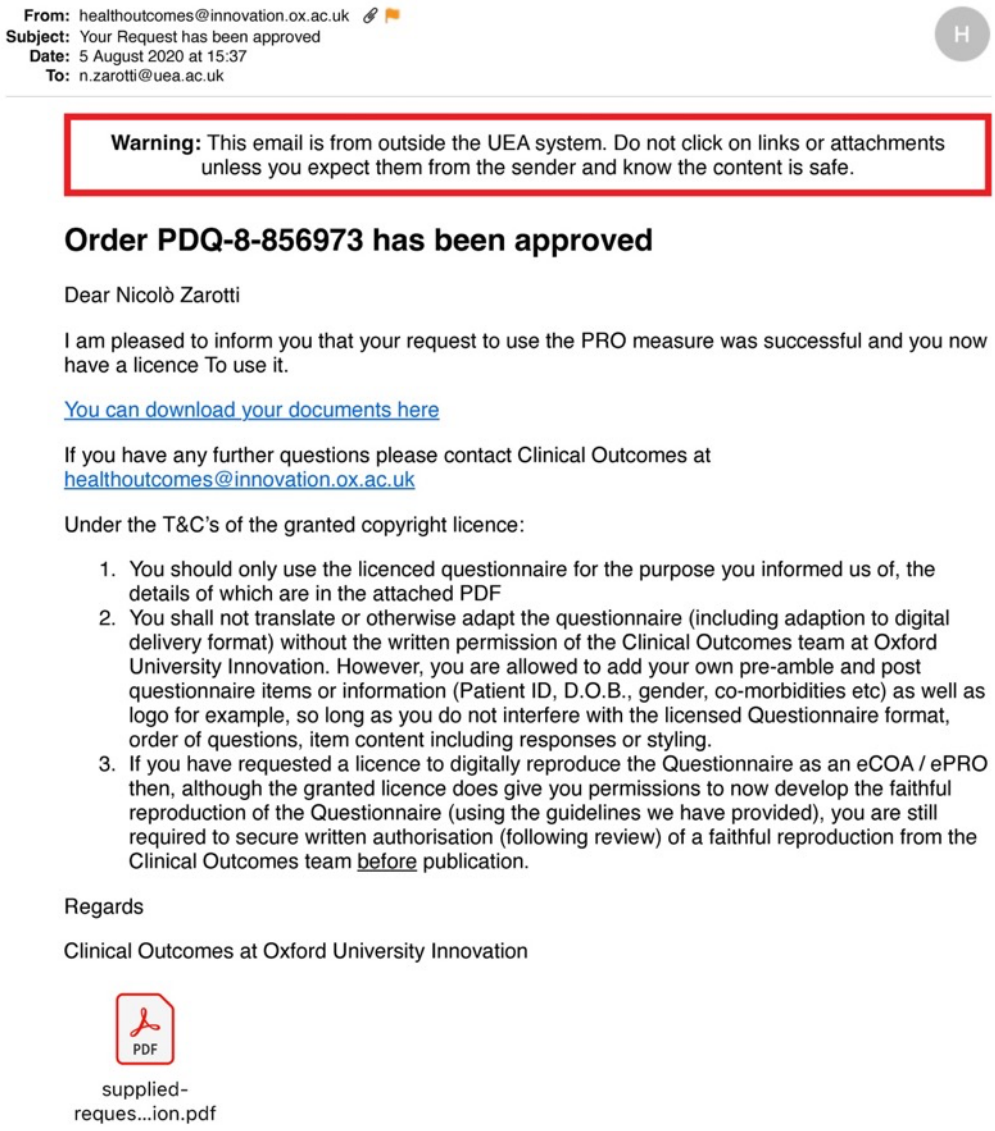
- Dr Nicolò Zarotti
  Chief Investigator
  Email: n.zarotti@uea.ac.uk
- Dr Katherine Deane
  Project Supervisor
  Email: K.Deane@uea.ac.uk
- Dr Cat Ford
  Research Supervisor
  Email: Catherine.Ford@uea.ac.uk

Appendix I

Standardised Measures

Parkinson's Disease Questionnaire - 8 (PDQ-8; Jenkinson et al., 1997)

Copyright owned by Oxford University Innovation Limited 1998. An official license, available for free for non-commercial studies, was been obtained for the survey.



From: healthoutcomes@innovation.ox.ac.uk
Subject: Your Request has been approved
Date: 5 August 2020 at 15:37
To: n.zarotti@uea.ac.uk

H

Warning: This email is from outside the UEA system. Do not click on links or attachments unless you expect them from the sender and know the content is safe.

Order PDQ-8-856973 has been approved

Dear Nicolò Zarotti

I am pleased to inform you that your request to use the PRO measure was successful and you now have a licence To use it.

You can download your documents here

If you have any further questions please contact Clinical Outcomes at healthoutcomes@innovation.ox.ac.uk

Under the T&C's of the granted copyright licence:

1. You should only use the licenced questionnaire for the purpose you informed us of, the details of which are in the attached PDF
2. You shall not translate or otherwise adapt the questionnaire (including adaption to digital delivery format) without the written permission of the Clinical Outcomes team at Oxford University Innovation. However, you are allowed to add your own pre-amble and post questionnaire items or information (Patient ID, D.O.B., gender, co-morbidities etc) as well as logo for example, so long as you do not interfere with the licensed Questionnaire format, order of questions, item content including responses or styling.
3. If you have requested a licence to digitally reproduce the Questionnaire as an eCOA / ePRO then, although the granted licence does give you permissions to now develop the faithful reproduction of the Questionnaire (using the guidelines we have provided), you are still required to secure written authorisation (following review) of a faithful reproduction from the Clinical Outcomes team before publication.

Regards

Clinical Outcomes at Oxford University Innovation

PDF

supplied-reques...ion.pdf

Geriatric Depression Scale – Short Form (GDS-15; Yasavage & Sheikh, 1986)

Please choose the best answer for how you felt over the past week:

	Answer	Score
Are you basically satisfied with your life?	Yes/No	
Have you dropped many of your activities and interests?	Yes/No	
Do you feel that your life is empty?	Yes/No	
Do you often get bored?	Yes/No	
Are you in good spirits most of the time?	Yes/No	
Are you afraid that something bad is going to happen to you?	Yes/No	
Do you feel happy most of the time?	Yes/No	
Do you often feel helpless?	Yes/No	
Do you prefer to stay at home, rather than going out and doing new things?	Yes/No	
Do you feel you have more problems with memory than most people?	Yes/No	
Do you think it is wonderful to be alive?	Yes/No	
Do you feel pretty worthless the way you are now?	Yes/No	
Do you feel full of energy?	Yes/No	
Do you feel that your situation is hopeless?	Yes/No	

Do you think that most people are better off than you are?	Yes/No
	TOTAL

Note. Higher scores indicate higher levels of depression. Cut off for depression: 4/5.

Medication Adherence Report Scale (MARS-5; Chan et al., 2019; Horne & Weinman, 2002)

The following statements refer to your Parkinson's medication. Please read them carefully, and choose how often each applies to you.

	Always	Often	Sometimes	Rarely	Never
I take less than instructed	1	2	3	4	5
I stop taking it for a while	1	2	3	4	5
I miss out a dose	1	2	3	4	5
I alter the dose	1	2	3	4	5
I forget to take it	1	2	3	4	5

Note. Range = 5 – 25, higher scores indicate higher levels of adherence. Cut-off for non-adherence: < 23.

Pearlin Mastery Scale (Pearlin & Schooler, 1978)

How strongly do you agree or disagree that:

	Strongly disagree	Disagree	Agree	Strongly agree
There is really no way I can solve some of the problems I have.	4	3	2	1
Sometimes I feel that I'm being pushed around in life.	4	3	2	1
I have little control over the things that happen to me.	4	3	2	1
I can do just about anything I really set my mind to.	1	2	3	4
I often feel helpless in dealing with the problems of life.	4	3	2	1
What happens to me in the future mostly depends on me.	1	2	3	4
There is little I can do to change many of the important things in my life.	4	3	2	1

Note. Range = 5 – 25, higher scores indicate higher levels of adherence.

Multidimensional Health Locus of Control – Form C (MHLC-C; Wallston, Stein, & Smith, 1994)

Each item below is a belief statement about Parkinson's with which you may agree or disagree. For each statement we would like you to select the extent to which you agree or disagree. This is a measure of your personal beliefs, so there are no right or wrong answers. As we are aware that Parkinson's itself sadly cannot improve, we would like you to consider the following items as related to the management of your condition, and whether it can get better or worse.

	Strongly disagree	Moderately disagree	Disagree	Agree	Moderately agree	Strongly agree
If my condition worsens, it is my own behaviour which determines how soon I will feel better again.	1	2	3	4	5	6
As to my condition, what will be will be	1	2	3	4	5	6
If I see my doctor regularly, I am less likely to have problems with my condition	1	2	3	4	5	6
Most things that affect my condition happen to me by chance.	1	2	3	4	5	6
Whenever my condition worsens, I	1	2	3	4	5	6

should consult a medically trained professional						
I am directly responsible for my condition getting better or worse.	1	2	3	4	5	6
Other people play a big role in whether the management of my condition improves, stays the same, or gets worse.	1	2	3	4	5	6
Whatever goes wrong with my condition is my own fault	1	2	3	4	5	6
Luck plays a big part in determining how my condition improves	1	2	3	4	5	6
In order for my condition to improve, it is up to other people to see that the right things happen	1	2	3	4	5	6
Whatever improvement occurs with my condition is largely a matter of good fortune	1	2	3	4	5	6
The main thing which affects my condition is what I myself do	1	2	3	4	5	6

I deserve the credit when my condition improves and the blame when it gets worse	1	2	3	4	5	6
Following doctor's orders to the letter is the best way to keep my condition from getting any worse	1	2	3	4	5	6
If my condition worsens, it's a matter of fate	1	2	3	4	5	6
If I am lucky, my condition will get better	1	2	3	4	5	6
If my condition takes a turn for the worse, it is because I have not been taking proper care of myself	1	2	3	4	5	6
The type of help I receive from other people determines how soon my condition improves	1	2	3	4	5	6

Note. Higher scores indicate higher predominance of relative attributional style.

Symptom Control Subscale from CBI (Sirois, 2003)

Please read each statement carefully and answer according to how much you agree with each statement.

	Strongly disagree	Disagree	Mildly disagree	Mildly agree	Agree	Strongly agree
I can take control of my health by managing my day-to-day symptoms	1	2	3	4	5	6
If I make the effort, I can manage my illness	1	2	3	4	5	6
There are things that I can do to make my health problem easier to deal with	1	2	3	4	5	6
I believe that I can do more to control my symptoms	1	2	3	4	5	6
If I do the right things, I can make my symptoms more manageable	1	2	3	4	5	6
Regardless of circumstances, there are things I can do to improve my health	1	2	3	4	5	6

Note. Higher scores indicate higher perceptions of control.

Parkinson's UK Scale of Perceived Control (PUKSoPC; Simpson et al., 2018)

Please think about how much each of the following statements applies to you and click on the appropriate option.

	Not at all	Only a little	Somewhat	Quite a lot	Very much
I try to focus on the positives in life	1	2	3	4	5
I know how to manage my stress levels	1	2	3	4	5
I know how to manage when I'm feeling down	1	2	3	4	5
I know what helps me manage my physical symptoms as much as possible	1	2	3	4	5
I know where to go to find out more information about Parkinson's if I need it	1	2	3	4	5
I know about the different treatment options for Parkinson's	1	2	3	4	5
I try to engage in social activities with friends and family when I can	1	2	3	4	5
I try to take part in activities that are good for my physical health	1	2	3	4	5
I try to take part in activities that are good for my mental wellbeing	1	2	3	4	5

I have ways to help me remember to do things	1	2	3	4	5
I ensure my plans are flexible so I can adapt them if I need to	1	2	3	4	5
I set myself targets for things I would like to do	1	2	3	4	5
I share my expertise in Parkinson's with others whenever I can	1	2	3	4	5
I help my family and friends to learn more about Parkinson's	1	2	3	4	5
I am involved with a national organisation (e.g., Parkinson's UK)	1	2	3	4	5

Note. Higher scores indicate higher perceived adaptive control.

General Self-Efficacy Scale (GSE; Schwarzer & Jerusalem, 1995)

Below are a number of statements about yourself. Please select how true you believe they are.

	Not true at all	Hardly true	Moderately true	Exactly true
I can always manage to solve difficult problems if I try hard enough	1	2	3	4
If someone opposes me, I can find the means and ways to get what I want	1	2	3	4
It is easy for me to stick to my aims and accomplish my goals	1	2	3	4
I am confident that I could deal effectively with unexpected events	1	2	3	4
Thanks to my resourcefulness, I know how to handle unforeseen situations	1	2	3	4
I can solve most problems if I invest the necessary effort	1	2	3	4
I can remain calm when facing difficulties because I can rely on my coping abilities	1	2	3	4
When I am confronted with a problem, I can usually find several solutions	1	2	3	4
If I am in trouble, I can usually think of a solution	1	2	3	4

I can usually handle whatever comes my way	1	2	3	4

Note. Higher scores indicate higher perceived self-efficacy.

Appendix L

Full Survey

Participant Information Sheet

The relationship between feelings of control, low mood, and medication adherence in people with Parkinson's

Hello!

We are a Research Team at the University of East Anglia (UK), and we are looking for volunteers with Parkinson's to help us find out about whether depression and feelings of control affect the ways in which medication is taken. If you choose to take part, you will be asked to complete a survey which will last approximately 35 to 45 minutes. However, before you decide, it is important for you to understand what the project is about and what it would involve. Please take time to read through this information carefully. You may also discuss it with your family or friends if you wish. In case anything is not clear, please do not hesitate to contact us through the details provided at the end of this page.
This information sheet is also available as a paper copy from the Chief Investigator of the project, Dr Nicolò Zarotti (contact details listed below).

What is the study about, and why are you carrying it out?

Being able and feeling motivated to take medications is a very important aspect of treating Parkinson's disease, especially because better adherence to medications normally means better control of symptoms and quality of life in general. At the moment, we are not sure which aspect of our sense of control helps the most with difficulties with taking medications.

Why have I been approached?

You have been approached because you are 18 or older, fluent in English, live in an English-speaking country, have a diagnosis of Parkinson's and take medications for Parkinson's.

Do I have to take part?

No. It's completely up to you to decide whether or not to take part in this study. Not taking part will have no negative repercussions on your treatment.

Will I be able to withdraw after participating?

No, as the responses you provide will be saved without your name or any way to identify you, we will not be able to identify your information to remove it once you finish and submit the survey. However, you can stop and leave the website at any time before completing it. Incomplete surveys will not be stored.

What will I be asked to do if I take part?

If you decide to take part, you will be asked to complete an online survey consisting of a number of questionnaires asking you questions about how Parkinson's affects your mental wellbeing and how you take your medications. The survey will take approximately 35-45 minutes, although you can stop and save it at any time and return to finish it later.

Are there any benefits to taking part?

Although you may find it interesting to take part in this research, there are no direct benefits to you in participating. However, by taking part you will be contributing to our understanding of the factors affecting medication adherence in people with Parkinson's. This may in turn help make medication adherence easier in the future for people with Parkinson's and similar conditions.

Will my data be confidential?

The information you provide is confidential and anonymous. The data collected for this study will stored securely and privately on a password-protected University of East Anglia online server (OneDrive), based in the UK. The files will be encrypted, that is no one other than the Research Team will be able to access them, and your information will be managed in line with General Data Protection Regulation (GDPR, 2018).

If you have any questions about how your data will be handled in this research project, in the first instance please contact the Chief Investigator, Dr Nicolò Zarotti (n.zarotti@uea.ac.uk). However, if you have any further questions or complaints about how your data are used, you can also contact:

Professor Niall Broomfield
Head of the Department of Clinical Psychology
and Psychological Therapies (CPPT) at the University of East Anglia
Tel: +44 (0)1603 59 1217
Email: N.Broomfield@uea.ac.uk

What will happen to the results?

The anonymised results will be summarised and reported in a doctoral thesis as part of the Doctorate in Clinical Psychology Programme at the University of East Anglia (UK). The anonymised result database may be used by other researchers, who will ask permission of the UEA research team to access the data. In addition, the results are expected to be submitted for publication in academic or professional journals, and may be shared as part of lay reports, web pages, press releases, conferences, and training material.

Are there any risks?

There are no risks anticipated with participating in this study. However, if you experience any distress following participation you are encouraged to inform the Research Team members at any time to receive further details on relevant Parkinson's and mental health support groups. Some of these are also listed at the end of this form.

Who has reviewed the project?

This study has been reviewed and approved by the Faculty of Medicine and Health Research Ethics Committee at the University of East Anglia (UK).

Yes, I would like to take part in the research – what do I need to do now?

Thank you very much! To take part in the research simply click on the arrow at the end of this page.

I am not sure about taking part – where can I get further information?

We are very happy to answer any questions you may have. To get in touch, please refer to our contact details below.

No, I do not wish to take part in the consultation – what do I need to do now?

There is nothing more to do. You may simply close your browser window. However, as we are advertising this project via multiple associations, you may hear about it again from another route. If you still wish not to participate, please feel free to ignore any other messages about the survey.

I would like to participate, but I would also like further information on relevant support groups in case I feel distressed

Here is a list of a number of Parkinson's and mental health resources and support groups you may reach out for in case you feel distressed at any point:

Europe

Parkinson's UK
Website: www.parkinsons.org.uk
Helpline: 0808 800 0303

Parkinson's Association of Ireland: www.parkinsons.ie

European Parkinson's Disease Association: www.epda.eu.com

Depression UK: www.depressionuk.org

Mental Health Foundation: www.mentalhealth.org.uk

Africa:

Parkinson's Africa: www.parkinsonsafrica.com

North America

American Parkinson Disease Association: www.apdaparkinson.org

Parkinson's Foundation: www.parkinson.org

Michael J. Fox Foundation: www.michaeljfox.org

Parkinson & Movement Disorder Alliance: www.pmdalliance.org

Parkinson Canada: www.parkinson.ca

Anxiety and Depression Organization of America: www.adaa.org

India

Parkinson's Disease and Movement Disorder Society: www.parkinsonssocietyindia.com

Australasia:

Parkinson's Australia: www.parkinsons.org.au

Parkinson's NSW: www.parkinsonsnsw.org.au

Parkinson's New Zealand: www.parkinsons.org.nz

Beyond Blue: www.beyondblue.org.au

We hope these can be helpful. Should you have any further questions, please feel free to get in touch with the Research Team via the contact details below.

How to contact us

If you have any questions about the study, or wish to receive a lay summary of its aims and purpose, please feel free to contact the following members of the Research Team at any time:

Dr Nicolò Zarotti
Chief Investigator
Email: n.zarotti@uea.ac.uk

Dr Katherine Deane
Research Supervisor
Email: k.deane@uea.ac.uk

Dr Cat Ford
Research Supervisor
Email: catherine.ford@uea.ac.uk

Thank you for taking the time to read this information sheet. If you agree to take part in the study, please click on the arrow below to continue.

Consent Form

Consent Form

We are asking if you would like to take part in a research project exploring relationships between feelings of control, depression, and medication adherence in people with Parkinson's.

Before you consent to taking part, we ask that you read the Participant Information Sheet and agree with each statement below by clicking on it.

If you have any questions or queries before confirming your consent, please feel free to contact the Chief Investigator, Dr Nicolò Zarotti (n.zarotti@uea.ac.uk), at any time.

Please read the following statements and click on each of them to confirm you agree:

- ☐ I confirm that I have read the Participant Information Sheet and fully understand what is expected of me within this study.

- [ ] I am aware that I can ask questions about the survey by emailing the Research Team.
- [ ] I understand that I can withdraw from this research by closing the browser window at any time before I click on the word 'submit' on the last page, although if I finish and click on the word 'submit' it will no longer be possible to withdraw.
- [ ] I understand that the information from my participation is anonymous, will be combined with other participants' responses, and may be published.
- [ ] I understand that the Chief Investigator will share and discuss anonymous information from my participation with the Research Supervisors and other members of the Research Team.
- [ ] I consent to information from my anonymised data being used in further research, reports, conferences, and training events.
- [ ] I understand that any information I give will remain strictly confidential and anonymous, and will be stored by the Research Team on online password-protected servers at the University of East Anglia.
- [ ] I consent to take part in the above study.

Thank you for confirming your consent to participate. To continue with the study, please click on the arrow below.

Criteria Check

Are you 18 or older?

- ○ Yes
- ○ No

Are you fluent in English?

- ○ Yes
- ○ No

Do you live in a country where English is the official language?

- ○ Yes
- ○ No

Do you currently have a diagnosis of Parkinson's?

- ○ Yes
- ○ No

Are you currently taking medications for Parkinson's?

- ○ Yes
- ○ No

Demographic and Clinical Variables

How would you describe your gender?

- ○ Male
- ○ Female
- ○ Transgender
- ○ Other
- ○ Prefer not to say

How old are you?

What is your nationality?

Is English your first language?

- Yes
- No

What country do you live in?

How would you describe your ethnic origin?

- Aboriginal (Australia & New Zealand)
- Arab
- Asian (any Asian background)
- Black, African, or Caribbean
- Hispanic or Latino/a
- Mixed/multiple ethic groups
- Native American
- White (any white background)
- Other
- Prefer not to say

If other, please specify:

How long ago were you diagnosed with Parkinson's?

Do you have any other physical health condition in addition to Parkinson's?

- Yes
- No

If yes, which one(s)?

How long ago did you start taking your Parkinson's medications?

Do you take your Parkinson's medications on your own?

- Yes
- No

Does anybody help you to take your Parkinson's medications sometimes?

- Yes
- No

How many times a day do you take your medications (pills, pumps, etc) to manage your Parkinson's?

Do you ever vary the number of doses you take per day?

- ○ Yes – with the approval of my clinical team
- ○ Yes – without the approval of my clinical team
- ○ No

Which of the following forms do you take your Parkinson's medicine in? You can select more than one choice.

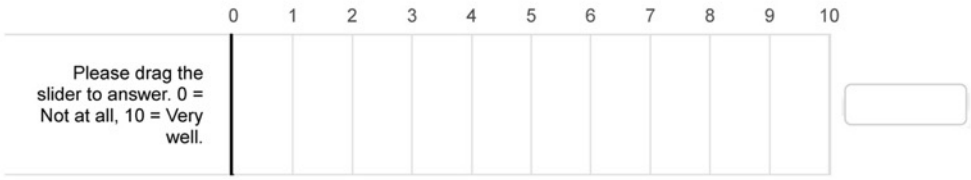
- ☐ Pills
- ☐ Liquid syrups (taken by mouth)
- ☐ Patches (stuck on skin)
- ☐ Injections (rescue apomorphine)
- ☐ Pumps linked to an injection site (for apomorphine)

Which of the following Parkinson's medications are you currently taking? You can select more than one choice.

- ☐ Amantadine (Symmetrel®)
- ☐ Apomorphine
- ☐ Benserazide (Madopar®)
- ☐ Carbidopa (Simenet®)
- ☐ Co-careldopa + Entalcapone (Stalevo®)
- ☐ Duodopa®
- ☐ Entalcapone (Comtess®)
- ☐ Pramipexole (Mirapexin®)
- ☐ Rasagiline (Azilect®)
- ☐ Ropinirole (Requip®)
- ☐ Safinamide (Xadago®)
- ☐ Selegiline (Elderpryl® or Zelapar®)
- ☐ Tolcapone (Tasmar®)

If your medication is not listed above, please write it here:

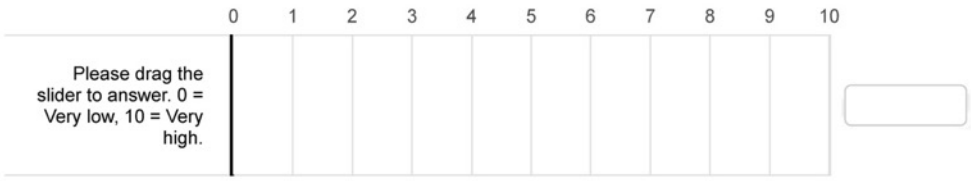
How well do you know the purpose of each of your Parkinson's medications?



Do you have to pay for your Parkinson's medication?

- Yes
- No

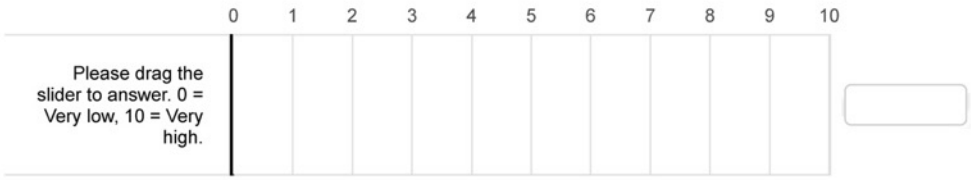
How would you rate your current ability to afford your Parkinson's medication?



Have you experienced any issues physically accessing your Parkinson's medication (e.g., due to limited mobility)?

- ○ Yes
- ○ No

How would you rate the current impact of these physical issues on your ability to access your Parkinson's medication?



When was your last medication review with your neurologist or specialist nurse?

In addition to your Parkinson's medicines, do you take any other medicines?

- ○ No
- ○ Yes – 1 to 3 other medicines every day
- ○ Yes – 4 to 6 other medicines every day
- ○ Yes – 7 or more other medicines every day

Are you currently taking any medications for depression, anxiety, or any other mental health difficulties?

- ○ Yes
- ○ No

If yes, which ones?

Are you currently receiving psychological support for depression, anxiety, or any other mental health difficulties?

- Yes
- No

If yes, in what form?

PDQ-8

Due to having Parkinson's disease, how often during the last month have you…

	Never	Occasionally	Sometimes	Often	Always or cannot do at all
Had difficulty getting around in public?					
Had difficulty dressing yourself?					
Felt depressed?					
Had problems with your close personal relationships?					
Had problems with your concentration, e.g. when reading or watching TV?					
Felt unable to communicate with people properly?					
Had painful muscle cramps or spasms?					
Felt embarrassed in public due to having Parkinson's disease?					

GDS-15

Please choose the best answer for how you felt over the past week:

	Yes	No
Are you basically satisfied with your life?	○	○
Have you dropped many of your activities and interests?	○	○
Do you feel that your life is empty?	○	○
Do you often get bored?	○	○
Are you in good spirits most of the time?	○	○
Are you afraid that something bad is going to happen to you?	○	○
Do you feel happy most of the time?	○	○
Do you often feel helpless?	○	○
Do you prefer to stay at home, rather than going out and doing new things?	○	○
Do you feel you have more problems with memory than most people?	○	○
Do you think it is wonderful to be alive?	○	○
Do you feel pretty worthless the way you are now?	○	○
Do you feel full of energy?	○	○
Do you feel that your situation is hopeless?	○	○
Do you think that most people are better off than you are?	○	○

MARS-5

The following statements refer to your Parkinson's medication. Please read them carefully, and choose how often each applies to you.

	Always	Often	Sometimes	Rarely	Never
I take less than instructed	○	○	○	○	○
I stop taking it for a while	○	○	○	○	○
I miss out a dose	○	○	○	○	○
I alter the dose	○	○	○	○	○
I forget to take it	○	○	○	○	○

PMS

How strongly do you agree or disagree that:

	Strongly disagree	Disagree	Agree	Strongly agree
There is really no way I can solve some of the problems I have.	○	○	○	○
Sometimes I feel that I'm being pushed around in life.	○	○	○	○
I have little control over the things that happen to me.	○	○	○	○
I can do just about anything I really set my mind to.	○	○	○	○
I often feel helpless in dealing with the problems of life.	○	○	○	○
What happens to me in the future mostly depends on me.	○	○	○	○
There is little I can do to change many of the important things in my life.	○	○	○	○

MHLC-C

Each item below is a belief statement about the management of your Parkinson's with which you may agree or disagree. For each statement we would like you to select the extent to which you agree or disagree.

This is a measure of your personal beliefs, so there are no right or wrong answers.

	Strongly disagree	Moderately disagree	Slightly Disagree	Slightly Agree	Moderately agree	Strongly agree
If the management of my Parkinson's worsens, it is my own behaviour which determines how soon I will feel better again.	○	○	○	○	○	○
As to the management of my Parkinson's, what will be will be	○	○	○	○	○	○
If I see my doctor regularly, I am less likely to have problems with how I manage my Parkinson's	○	○	○	○	○	○
Most things that affect how I manage my Parkinson's happen to me by chance	○	○	○	○	○	○
Whenever the management of my Parkinson's worsens, I should consult a medically trained professional	○	○	○	○	○	○

I am directly responsible for the management of my Parkinson's getting better or worse	○	○	○	○	○	○
	Strongly disagree	Moderately disagree	Slightly Disagree	Slightly Agree	Moderately agree	Strongly agree
Other people play a big role in whether the management of my Parkinson's improves, stays the same, or gets worse	○	○	○	○	○	○
Whatever goes wrong with how I manage my Parkinson's is my own fault	○	○	○	○	○	○
Luck plays a big part in determining how the management of my Parkinson's improves	○	○	○	○	○	○
In order for the management of my Parkinson's to improve, it is up to other people to see that the right things happen	○	○	○	○	○	○
Whatever improvement occurs with how I manage my Parkinson's is largely a matter of good fortune	○	○	○	○	○	○
The main thing which affects how I manage my Parkinson's is what I myself do	○	○	○	○	○	○
	Strongly disagree	Moderately disagree	Slightly Disagree	Slightly Agree	Moderately agree	Strongly agree
I deserve the credit when the management of my Parkinson's improves and the blame when it gets worse	○	○	○	○	○	○
Following doctor's orders to the letter is the best way to keep the management of my Parkinson's from getting any worse	○	○	○	○	○	○
If the management of my Parkinson's worsens, it's a matter of fate	○	○	○	○	○	○
If I am lucky, the management of my Parkinson's will get better	○	○	○	○	○	○
If the management of my Parkinson's takes a turn for the worse, it is because I have not been taking proper care of myself	○	○	○	○	○	○
The type of help I receive from other people determines how soon the management of my Parkinson's improves	○	○	○	○	○	○

SCS

Please read each statement carefully and answer according to how much you agree with each statement.

	Strongly disagree	Disagree	Mildly disagree	Mildly agree	Agree	Strongly agree
I can take control of my health by managing my day-to-day symptoms	○	○	○	○	○	○
If I make the effort, I can manage my illness	○	○	○	○	○	○
There are things that I can do to make my health problem easier to deal with	○	○	○	○	○	○
I believe that I can do more to control my symptoms	○	○	○	○	○	○
If I do the right things, I can make my symptoms more manageable	○	○	○	○	○	○
Regardless of circumstances, there are things I can do to improve my health	○	○	○	○	○	○

PUKSoPC

Please think about how much each of the following statements applies to you and click on the appropriate option.

	Not at all	Only a little	Somewhat	Quite a lot	Very much
I try to focus on the positives in life	○	○	○	○	○
I know how to manage my stress levels	○	○	○	○	○
I know how to manage when I'm feeling down	○	○	○	○	○
I know what helps me manage my physical symptoms as much as possible	○	○	○	○	○
I know where to go to find out more information about Parkinson's if I need it	○	○	○	○	○
	Not at all	Only a little	Somewhat	Quite a lot	Very much
I know about the different treatment options for Parkinson's	○	○	○	○	○

I try to engage in social activities with friends and family when I can	○	○	○	○	○
I try to take part in activities that are good for my physical health	○	○	○	○	○
I try to take part in activities that are good for my mental wellbeing	○	○	○	○	○
I have ways to help me remember to do things	○	○	○	○	○
	Not at all	Only a little	Somewhat	Quite a lot	Very much
I ensure my plans are flexible so I can adapt them if I need to	○	○	○	○	○
I set myself targets for things I would like to do	○	○	○	○	○
I share my expertise in Parkinson's with others whenever I can	○	○	○	○	○
I help my family and friends to learn more about Parkinson's	○	○	○	○	○
I am involved with a national organisation (e.g. Parkinson's UK)	○	○	○	○	○

GSE

Below are a number of statements about yourself. Please select how true you believe they are.

	Not true at all	Hardly true	Moderately true	Exactly true
I can always manage to solve difficult problems if I try hard enough	○	○	○	○
If someone opposes me, I can find the means and ways to get what I want	○	○	○	○
It is easy for me to stick to my aims and accomplish my goals	○	○	○	○
I am confident that I could deal effectively with unexpected events	○	○	○	○
Thanks to my resourcefulness, I know how to handle unforeseen situations	○	○	○	○
I can solve most problems if I invest the necessary effort	○	○	○	○
I can remain calm when facing difficulties because I can rely on my coping abilities	○	○	○	○
When I am confronted with a problem, I can usually find several solutions	○	○	○	○

If I am in trouble, I can usually think of a solution	○	○	○	○
I can usually handle whatever comes my way	○	○	○	○