DOCTOR OF CLINICAL PSYCHOLOGY (DCLINPSY)

Doctorate in Clinical Psychology: Main Research Portfolio

1) “Where do you fit?”: A Meta Ethnography of Family Caregivers Experiences of Caring in Disorders of Consciousness 2) Provision and Barriers of Psychological Support for Psychosis in a Community Mental Health Team: A Care Coordinator Enquiry Audit 3) “That could have been me”: An Interpretative Phenomenological Analysis of Healthcare Professionals Experience of Managing the Professional and Personal Impact of Patient Death in Motor Neurone Disease.

Slay, Natalie

Award date:
2022

Awarding institution:
University of Bath

Research Portfolio Submitted in Part Fulfilment of the requirements for the Degree of Doctorate in Clinical Psychology

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Doctorate in Clinical Psychology

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May 2022

Word counts

Literature review: 5988

Service-related project: 3567

Main research project: 7500

Executive summary: 999

Impact of COVID Statement

The timing of the covid-19 pandemic and the understandable additional pressures it placed on services prevented the implementation of recommendations resulting from my service-related project and thus removed the possibility of re-auditing to evaluate their utility. Consequently, the decision was made alongside the fellow research team to write up the findings with the hope that a future trainee may consider implementing and evaluating recommendations at a later stage.

Thankfully, I had already sought approval for and planned to conduct my main research project interviews online, which was undoubtedly helpful in improving accessibility during the pandemic. However, the stress of the pandemic and the changing landscape may have affected healthcare professionals' willingness to participate in the project, particularly as this related to patient death. Thus, while it did not appear to impede participant recruitment, as I achieved a good sample size for doctoral Interpretative Phenomenological Analysis research, it may have affected the diversity of the sample.

Lastly, the pandemic undoubtedly created an additional stressor on a personal level. For example, at one time, requiring me to complete the multi-faceted roles of a Trainee Clinical Psychologist from one desk with increased detachment from society. In addition, the impact throughout the research process on individuals, including myself, such as unfortunately contracting covid-19, caused delays necessitating flexible and ever-changing timelines.

Contents

Abstracts

Literature Review: “Where do you fit?”: A Meta Ethnography of Family Caregivers Experiences of Caring in Disorders of Consciousness

Family caregivers of those with disorders of consciousness face the difficult task of fulfilling caring responsibilities while at the same time navigating grief and maintaining hope about the prospect of recovery. Existing research and quantitative reviews have documented the significant distress experienced by this group. However, while such findings have been echoed in qualitative research, no attempt has yet been made to synthesise these to provide further conceptual understanding. Therefore, this meta-ethnography using the principles of Noblit and Hare (1988) aimed to address the question: *what are family caregivers' experience of caregiving in disorders of consciousness.* A literature search of five electronic databases identified 302 papers, of which 11 met the inclusion criteria and underwent reciprocal translation and line of argument synthesis. Eight third-order constructs were identified, and a model was produced describing the interaction between these: around the clock caregiving; redefining the relationship; disrupted relationships; modifications to life; living with uncertainty; holding hope; navigating the middle path; wider system pressures. Finally, clinical implications and areas for future research are discussed.

Keywords: caregiving, disorders of consciousness, family caregiver

Service-Related Project: Provision and Barriers of Psychological Support for Psychosis in a Community Mental Health Team: A Care Coordinator Enquiry Audit

Current National Institute for Health and Care Excellence (2014) guidelines for psychosis recommend individual Cognitive Behavioural Therapy (CBTp) should be offered to all and Family Interventions (FI) where appropriate. Despite this, a wealth of research has found significant discrepancies between guidelines and implementation rates, which remain poor. In light of this, and to aid the development of a psychological intervention for psychosis pathway in a Community Mental Health Team, a service evaluation audit was conducted. Completed through Care Coordinator (CCO) enquiry, this audit examined the prevalence of schizophrenia and psychosis based on ICD-10 codes F20-F29 (WHO, 1992), numbers referred and receiving CBTp or FI, reasons for non-referral and strategies for improving referral rates. All 13 CCO working on the services psychosis pathway completed the audit based on their February 2020 caseload. The audit recorded 192 clients meeting the criteria, of which; 0% were referred for FI, 7.3% for CBTp with only 3.1% actual recipients, and 7.3% referred for an alternative form of psychological therapy. The most common non-referral reason was a client not experiencing distress, while training was rated the most helpful means of improving referrals. Potential reasons for low implementation rates and service recommendations are discussed.

Keywords: psychosis, CBT-p, audit, psychological support

Main Research Project: "That could have been me": An Interpretative Phenomenological Analysis of Healthcare Professionals Experience of Managing the Professional and Personal Impact of Patient Death in Motor Neurone Disease

Health care professionals working in motor neurone disease will inevitably encounter patient death. Yet, relative to other terminal conditions, the professional and personal impact of this remains seldom discussed. Using semi-structured interviews, this study aimed to explore 10 health care professionals' experiences of managing the professional and personal impact of patient death in motor neurone disease. Four group experiential themes with 11 sub-themes were identified using an interpretative phenomenological approach: death is part of the job; nuanced challenges in MND; places death on your personal agenda; caring for oneself to care for others. The findings demonstrate an interaction for healthcare professionals between patient death and their relationship to their own mortality, with such reflections increasing with age and most paramount when there were assumed similarities with the patients they were supporting. Participants acknowledged the importance of maintaining a healthy work-life balance and preserving emotional boundaries to manage this and the need for more reflective spaces. Notably, participants also spoke of their work as an enriching experience that shaped their approaches to living. Clinical implications and areas for future research are discussed.

Keywords: health care professionals, motor neurone disease, patient death, death anxiety

“Where do you fit?”: A Meta Ethnography of Family Caregivers Experiences of Caring in Disorders of Consciousness

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Literature Review
May 2022

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Word count (excluding tables and references):
5988

Target journal:
Journal of Qualitative Health Research
(Word limit: 6000 - excluding tables, abstract and references)
Rationale: The journal has a high impact factor and welcomes qualitative review papers, especially those seeking to develop healthcare and improve qualitative research in this context

Introduction

Disorders of consciousness (DoC) signifies the umbrella term encompassing vegetative states (VS) and minimally conscious states (MCS) (Royal College of Physicians [RCP], 2020). Most commonly resulting from a traumatic brain injury or diffuse cerebral hypoxia, in both states, individuals experience periods of wakefulness (Laureys et al., 2004; Monti et al., 2010). However, in VS, there is an absence of awareness of self or others, whereas, although slight, in MCS, individuals display reproducible behavioural evidence of awareness (Giacino et al., 2002). While DoC can be a transient experience, as time progresses, the impact on an individual's cognition and physical health becomes increasingly profound, and the likelihood of recovery decreases to as little as 3% after six months in a VS (Katz et al., 2009; Ashwal et al., 1994). Thus, owing to the severity and pervasiveness of the condition, people in DoC require a demanding schedule of care, often from both formal providers and family members (Goudarzi et al., 2015; Soeterik et al., 2017).

Family members are therefore confronted with a complex and ambiguous scenario of navigating grief and loss while the individual is still alive (Giovannetti et al., 2015; Hamama-Raz et al., 2013), yet at the same time maintaining a sense of hope regarding recovery (Tresch et al.,1991). Consequently, some scholars have likened this experience of ambiguous loss (Boss, 1999) to caring for a loved one with dementia (Soeterik et al., 2018). However, while both are distressing, in dementia, the experience of loss is gradual. In contrast, in DoC, relationship change and loss is sudden and unexpected, involving high degrees of uncertainty, often complicated by family members assuming a caregiving role (Cipolletta et al., 2014). While variation in definitions exists (Kent et al., 2016), family caregivers (FC) typically incorporate an unpaid relative, partner or friend who delivers assistance on tasks for an individual with an acute or chronic condition (Reinhard et al., 2008).

Research has demonstrated the significant burden placed on FC in DoC as they attempt to navigate multiple roles within the health care and family system (Duff, 2006; Gonzalez-Lara et al., 2021). This is often at the cost of personal sacrifice with increasing isolation and a reduction in their own leisure time while experiencing a range of negative emotions, including anxiety, guilt, and blame (Hamama-Raz et al., 2013; Tzidkiahu et al., 1994) and an overall reduction in quality of life (Soeterik et al., 2017). To summarise the current understanding of the psychological needs of this population, Soeterik et al. (2017) conducted a systematic review of 18 quantitative studies which highlighted the significant clinical distress experienced by FC regarding overall wellbeing, burden and grief. However, the authors questioned whether focusing solely on quantitative studies captured the “right variables” (Soeterik et al., 2017, p.1383) to reflect the whole caregiving experience, including negative and positive elements. Moreover, as included studies used generic wellbeing psychometric measures, this may have prevented consideration of the psychological impact of unique aspects of DoC, such as living loss (Crow, 2006), which requires further exploration (Kitzinger & Kitzinger, 2014).

Currently, existing qualitative research has documented a more holistic account of FC experiences and needs in DoC (Cipolletta et al., 2014; Giovannetti et al., 2015; Goudarzi et al., 2018; Imani-Goghary & Ghaljeh, 2020; Soeterik et al., 2018). However, there had been no attempt to aggregate these findings until recently, with the publication of Chinner et al. (2021)’s scoping review, which sought to describe the qualitative and quantitative research on FC quality of life. This review utilised the WHOQOL-BREF model (WHOQOL Group, 1998) as a guiding template for their descriptive analyses, highlighting that caregiving impacts significantly across all four domains: physical, psychological, social, and environmental. Furthermore, FC reported some positive aspects, including the reminder of their love and commitment to the individual (Hamama-Raz et al., 2013) and the realisation of their inner strength and coping resources (Chinner et al., 2021). Thus, this study provided valuable insight into the caregiving experience. However, it is not without criticism. Firstly, as the review included literature from various sources but did not include a quality assessment, this may have increased the risk of bias (Grant et al., 2009). Secondly, as the primary aim of a scoping review is to describe rather than synthesise, the findings are arguably limited in providing a more in-depth understanding than possible from reading each study individually (Grant et al., 2009; Sandelowski et al., 1997). Thirdly, by using a deductive approach (Linneberg & Korsgaard, 2019), guided by a prescriptive framework explicitly focused on quality of life, the review may have overlooked important elements in the overall general caregiving experience (Chinner et al., 2021). Thus, there remains a need for a dedicated qualitative synthesis to understand this to support the development of interventions for FC in DoC (Corallo et al., 2015).

To this effect, this review aims to use an interpretative meta-ethnography approach (Noblit & Hare, 1988) which goes beyond synthesising research to facilitate a higher level of understanding (Campbell et al., 2011) to address the question; *what are the experiences of FC caring for people with DoC?*

Method

Design

The method was developed using eMERGE guidelines (France et al., 2019a) designed to aid the standardised reporting of meta-ethnographies. This approach (Noblit & Hare, 1988) was selected as it preserves the interpretative features of primary data (Atkins et al., 2008) by enabling the context of research to be accounted for while moving beyond simply aggregating studies enabling the possible creation of a new conceptual understanding (France et al., 2019). This is achieved by systematically contrasting translations of findings presented in original studies, following Noblit & Hare's (1988) seven steps displayed in Table 1, as used in previous health research (Britten et al., 2002; Pindus et al., 2018; Toye & Barker, 2020). This synthesis adopted an interpretative constructivism approach to acknowledge the possibility of differing yet co-existing views rather than assuming a universal truth (Rubin & Rubin, 2013). Multi-disciplinary review team (described in Table 2) discussions were held throughout the meta-ethnography, offering space to reflect on researcher positioning to diminish possible bias (Holmes, 2020). Appendix A provides more detailed reflexive statements by the authors.

Table 1

Seven stages of meta-ethnography (Noblit & Hare, 1988)

Seven steps of meta-ethnography
1. Getting started
2. Deciding what is relevant to the initial interest
3. Reading the studies
4. Determining how the studies are related
5. Translating the studies into one another
6. Synthesising the translations
7. Expressing the synthesis

Table 2

Multi-disciplinary review team members

Initials	Background
N.S	Trainee Clinical Psychologist with special interest in grief work and qualitative research
A.S	University Lecturer, Clinical Psychologist specialising in older adults and interest in qualitative research
J. P	Occupational Therapist specialising in working with individuals with DoC
H.S	Research Assistant, Masters Student

Search Strategy

As presented in Table 3, a pre-planned search strategy was developed through literature consultation and review team discussions. The comprehensive literature search of five databases (PsychINFO, Embase, MEDLINE, Web of Science and PubMed) was conducted in July 2021, with reference lists of included studies manually scanned for additional relevant papers (see Appendix B for results per database). Throughout, inclusion and exclusion criteria listed in Table 4 were adhered to with no restriction placed on the publication date; however, inclusion was limited to papers published in English. Commentaries, case studies and descriptive articles were excluded due to a lack of interpretative depth (France et al., 2019). Moreover, papers focused on specific interventions or decision making were excluded because of possible differences across cultures and health care systems. Importantly FC was operationalised as non-paid lay caregivers related by blood or friendship (Sarmento et al., 2017). For transparency, each stage was recorded using the Preferred Reporting Items for Systematic Reviews and Meta-analysis (PRISMA; Moher et al., 2009), as displayed in Figure 1.

Table 3

Pre-planned search strategy

Search Terms
((("Disorders of consciousness" OR "Low Awareness State*" OR "Post coma unawareness" OR "Unawareness state" OR "aphallic" OR "Vegetative State*" OR "Minimally conscious state*") AND (Qualitative OR Experience OR Interview OR Grounded theory OR Phenomenology OR Narrative OR Thematic OR IPA)) AND (Caregiv* OR Coping OR Needs)) AND (Famil* OR Spouse* OR Relative OR Caregiver* OR Parent OR Informal Caregiver)

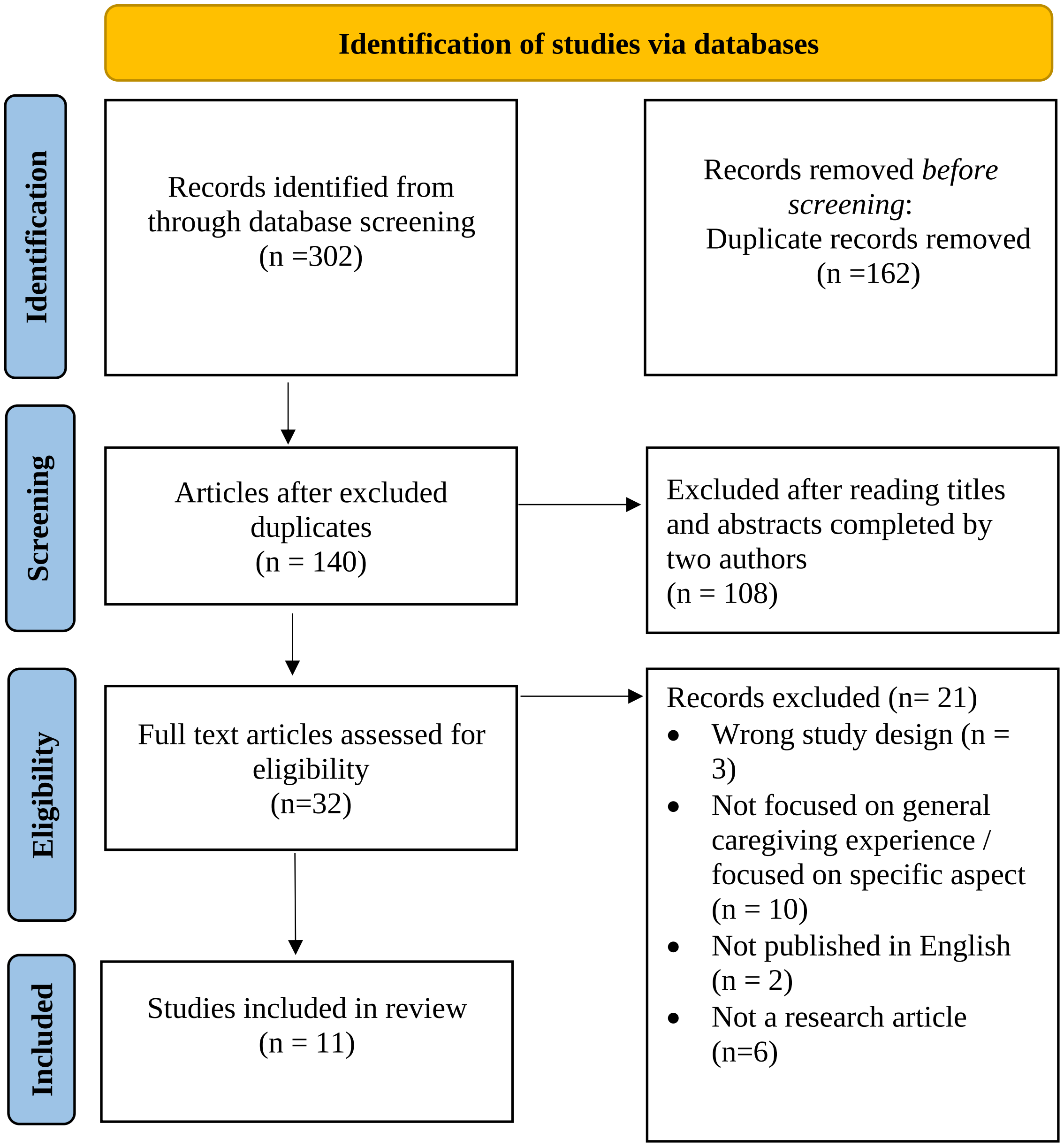
Table 4

Inclusion and exclusion criteria for studies

	Inclusion	Exclusion
Research Design	• Qualitative method of data collection and analysis • Mixed methods (if qualitative data can be extracted)	• Observational studies • Quantitative studies • Case studies
Quality	• Peer reviewed journal	• Reviews or commentaries
Concepts	• Experience or needs of family caregiver of a person with DOC	• The experience is not separated from the experience of caring for those with other illnesses and brain injuries • The focus of the research is on the experience of interventions or decision making, e.g., removal of tube feeding rather than the general phenomenon of being a family caregiver
Sample	• Family caregivers of people with DOC	• Exclusively focused on health care professionals' experiences of DOC

Figure 1

Identification, screening and eligibility of studies included in this review using PRISMA flow chart (Moher et al., 2009)



Selecting primary studies

A total of 302 studies were identified throughout the search process. These were imported to Covidence © to allow for blind review between authors. After removing 140 duplicates, the titles and abstracts of the remaining 160 studies were screened independently by N.S and H.S to determine whether they met the inclusion criteria, with 32 studies undergoing a full-text review, 11 of which were included in this review. At this stage, the final selection of papers was discussed and confirmed with the wider team. Any disagreements between N.S and H.S were resolved through verbal discussion and consideration of inclusion criteria; if consensus was not achieved, A.S was consulted.

Data Extraction

A data table was collaboratively developed and piloted by N.S and H.S. As shown in Table 6, this recorded author name(s); year published; title; journal; country; aim; participant group and number; qualitative methodology, data collection type and main findings.

Quality Appraisal

An adapted version (Duggleby et al., 2010) of the 10 item CASP checklist (Critical Appraisal Skills Programme, 2018) was adopted to assess the quality of included studies. The checklist evaluates ten areas; a clear statement of aims, appropriate methodology, research design and recruitment strategy, appropriate data collection, consideration of researcher relationship and ethical issues, data analysis, dissemination of findings, and adding value. Each item was assigned a score on a three-point Likert scale, with one assigned to topics that were poorly addressed to a score of three if extensive justification was provided, enabling a total possible score of 30 as displayed in Table 6. The quality assessment was undertaken by N.S and H.S and discussed with other reviewers, with a breakdown of itemised scores in Appendix C. The decision was made a priori to include all studies irrespective of quality because a lack of reporting is not equivocal to poorly conducted research, and possible removal of conceptually rich accounts may limit understanding (Majid & Vanstone, 2018; France et al., 2019b). Notably, of included studies, most weaknesses resided in poor reporting of the researcher relationship (Melia, 2010).

Data Analysis

Data analysis began with the in-depth repeated reading of included primary studies to identify conceptually rich constructs aligned to the research question. At this stage, data were categorised in line with Schutz (1971) as presented below in Table 5.

Table 5

Descriptions of construct levels (Schutz, 1971)

Construct	Definition
First-order constructs	Representing participants' responses expressed through quotes
Second-order constructs	Reflecting the original researcher's interpretation of first-order constructs
Third-order constructs	Symbolising reviewers' abstraction and interpretation of second-order constructs

Each study was coded across the full primary study to identify first and second-order concepts, which were placed in an excel grid alongside notes on contextual information about the study (Britten et al., 2002; France et al., 2019b; Malpass et al., 2009). Across studies, similarities and differences in concepts were compared to consider how they were related, with shared concepts clustered under conceptual category labels, an illustrative example of which is displayed in Appendix D (Atkins et al., 2008; Erasmus, 2014). These titles reflected descriptive labels (Sattar, 2021) and were iteratively developed and refined within discussions with the review team to ensure this was executed in a meaningful way (Toye et al., 2014). The most recently published paper (Gonzalez-Lara et al., 2021) became the index article (Campbell et al., 2011; Fleming et al., 2013), with the remaining studies translated in date order. The reciprocal translation was conducted iteratively using a written narrative (Atkins et al., 2008; Campbell et al., 2011). In doing so, concepts from the index paper were compared to study 2 and 3, and so on, an example of which is presented in Appendix E. At this stage, third-order constructs were created by the first author and subsequently discussed in-depth with the research team and refined accordingly. While minor inconsistencies across studies were noted, the research team agreed these did not warrant a separate refutational synthesis (Noblit & Hare, 1988). Instead, it was agreed that building this into a line of argument synthesis would be more appropriate, whereby themes are presented as a storyline to provide a conceptual level of understanding beyond the aggregate of individual studies, aided by a visual representation, displayed in Figure 2 (France et al., 2019a). While selecting the most recent paper as the index study is relatively common practice, the ordering of papers for synthesising has not yet been empirically investigated (Sattar et al., 2021). Thus, to enhance the value of the synthesis and retain the value of contextual information, once the initial stage was complete studies were grouped by country of origin and synthesis was cross-checked across these (France et al., 2019b).

Results

In total, 150 FC were included in the identified studies presented in Table 6, with two papers also comprising a small sample of professional caregivers (n=8). Across studies, there was variation in place of residence (home, long-term residential, hospital), diagnosis (VS or MSC), time after injury (2 months - 27years) and relationship to the patient (spouse, child, sibling). Through the reciprocal synthesis, eight third-order constructs were identified, as listed in Table 7. These over-arching themes enabled a new level of interpretation as represented in the conceptual model (Figure 2) and written narrative, which utilises a line-of-argument synthesis to consider the inter-relationship between themes (Noblit & Hare, 1988).

Table 7

Eight third-order constructs identified through reciprocal synthesis

Constructs	Papers
Around the clock caregiving	All
Redefining the relationship	1,2,3,6,7,8,9,10,11
Disrupted relationships	1,2,3,4,5,7,8,9,10
Modifications to life	All
Living with uncertainty	1,2,3,4,5,6,7,8,10,11
Holding hope	2,3,4,5,7,9
Navigating the middle path	1,2,3,4,5,6,7,8,10,11
Wider system pressures	1,2,3,4,6,7,8,10

Table 6

Data extraction table outlining features of included studies

ID	Author/ Year	Title	Journal	Country	Aim	Participant group and size	Qualitative Method	Data Collection Method	Main Findings	CASP Score
1	Gonzalez-Lara et al. (2021)	The multiplicity of caregiving burden: a qualitative analysis of families with prolonged disorders of consciousness	Brain Injury	Canada	To better understand the experiences of family members of patients with DoC with specific focus on the multiplicity of competing roles	Mixed FC (n=12)	Constructivist grounded theory	Semi-structured interviews	6 main themes: caregiver as central role; unpaid health provider; advocate; broader family system; financial supporter; wider community	25
2	Imani-Goghary & Ghaljeh (2021)	The experience of family caregivers caring for a patient with chronic disorders of consciousness:	Inter-national Journal of Palliative Nursing	Iran	To describe the experiences of FC of patients in DoC	Mixed FC (n=15)	Content analysis	Semi-structured interviews	2 overarching themes: challenging care; mental turmoil	21

		a qualitative content analysis								
3	Gooshki et al. (2019)	The experience and reactions reported by family caregivers of vegetative patients: Qualitative Content Analysis	International Journal of Ayurvedic Medicine	Iran	To explain FC experiences of the patient care process for patients in DoC	Mixed FC (n=8)	Qualitative content analysis	Semi-structured interviews	5 main themes: internal conflict/ paradox; family reaction; communication with patient; family relationship; difficulty in care	24
4	Goudarzi et al. (2018)	The Resilient Care of Patients with Vegetative State at Home: a Grounded Theory	Journal of Caring Sciences	Iran	To explore the process of taking care of patients in vegetative state	Mixed caregivers (n=22) family (n=17) professionals (n=5)	Grounded theory	Unstructured interviews	4 main themes: erosive care; erosive expenditures; seeking solver education; lasting hope	25
5	Lovstad et al. (2018)	“It gets better. It can´t be worse than what we have been through.” Family accounts of the	Brain Injury	Norway	To explore family life and caring when a family member is in an MCS	Mixed FC (n=5)	Thematic analysis	Focus group semi-structured interviews	3 overarching themes: family unity under pressure; acknowledging the	25

		minimally conscious state							severity; moving on towards normal life	
6	Soeterik et al. (2018)	“Neither a wife nor a widow”: an interpretative phenomenological analysis of the experiences of female family caregivers in disorders of consciousness	Neuropsychological Rehabilitation	United Kingdom	Explore how female family members make sense of a DoC and negotiate their caring relationship with the injured person	Female FC (n=9)	Interpretative Phenomenological Analysis	Semi-structured interviews	4 overarching themes: loss without a name; relationship without a title; symbiotic relating; frozen futures	27
7	Giovannetti et al. (2015)	Informal caregivers of patients with disorders of consciousness: Experience of ambiguous loss	Brain Injury	Italy	To better understand the lived experience of caregivers of relative with a DoC and key psychological process involved	FC (n=20)	Grounded theory	Semi-structured interviews	4 major themes: another person with a past in common; losing and finding myself; old and new ways of being in a relationship; dealing with concerns	25

8	Goudarzi et al. (2015)	Multiple Victims: The Result of Caring Patients in Vegetative State	Iran Red Crescent Medical Journal	Iran	To explore the effects of caring for vegetative patients on families and caregivers at home	Mixed caregivers (n=16) family (n=13) professionals (n=3)	Content analysis	Unstructured interviews & observations	3 main themes: lost main caregiver; affected caring partner; affected family	24
9	Cipolletta et al. (2014)	ita tua, mors mea: The experience of family caregivers of patients in a vegetative state	Journal of Health Psychology	Italy	To explore the voice of family caregivers and their experience an emotional paradox between life and death	Mixed family caregivers (n=24)	Interpretative Phenomenological Analysis	Semi-structured interviews	6 main themes: reactions to VS occurrence; assistance experience; end of life preferences; family relationships; resources	26
10	Covelli et al. (2014)	A Qualitative Study on Perceptions of Changes Reported by Caregivers of Patients in Vegetative State and Minimally Conscious State: The	The Scientific World Journal	Italy	To understand how women informal caregivers of DoC patients describe, represent, and	Female Informal Caregivers (n=15)	Thematic analysis	Unstructured interviews	6 main themes: changes in life perception; pragmatic changes in everyday life; changes in individual	22

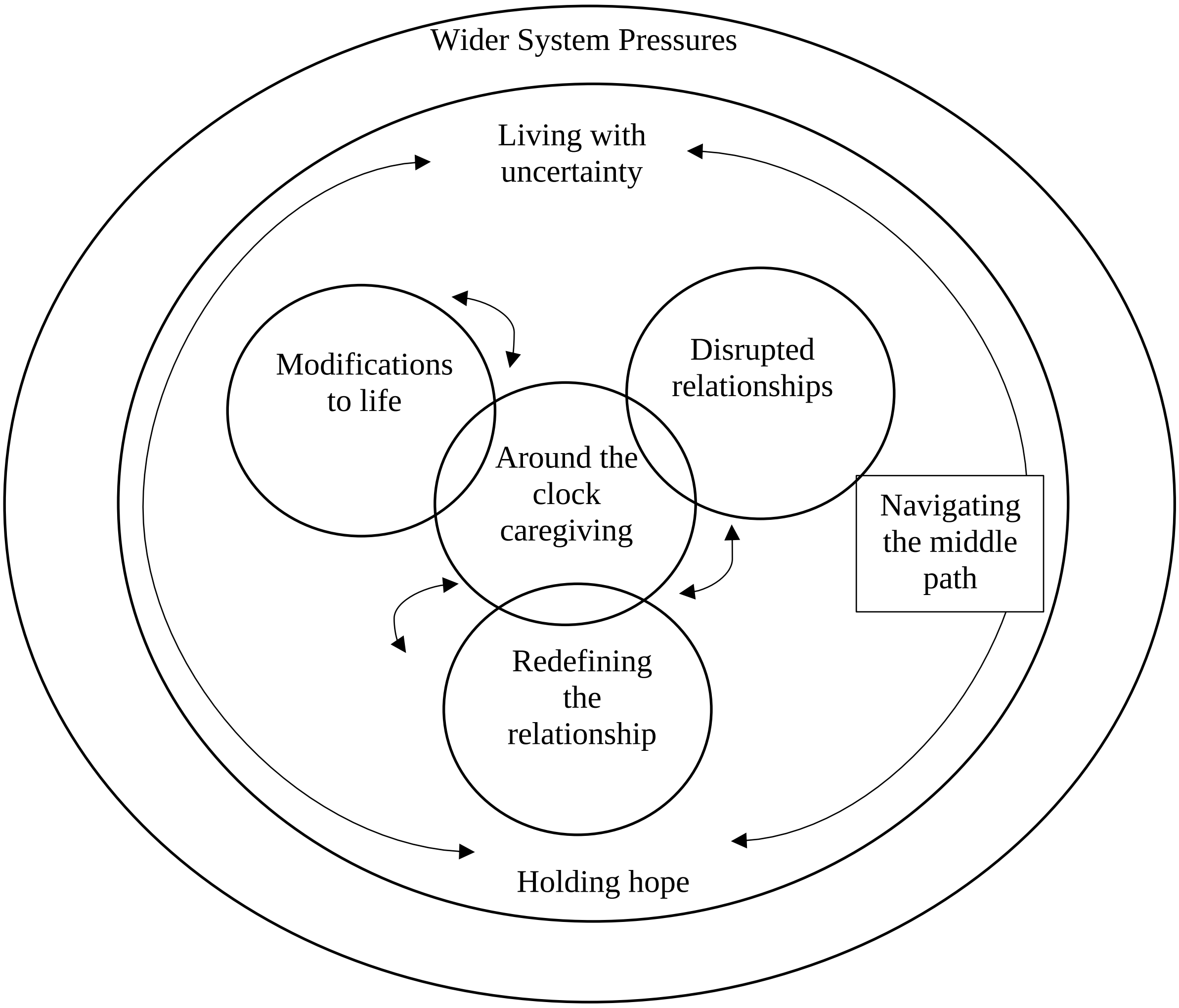
		‘‘Time Gap Experience’			experience the DOC and life changes				perceptions; changes in interpersonal relationships; expressed needs; perceptions about the future	
11	Hamama-Raz et al. (2013)	From Hope to Despair, and Back: Being the Wife of a Patient in a Persistent Vegetative State	Qualitative Health Research	Israel	To understand the implications and the meaning of PVS among wives providing the caregiving role	Wives of those in DOC (n=12)	Content analysis	Semi-structured interviews	2 central core themes: the power of values, responsibility, commitment and love and; the hidden pain	28

Line of argument synthesis

Central to all themes is the concept of 'around the clock caregiving' acknowledging the all-consuming nature of the FC role. Fulfilling this, often in sudden circumstances, triggers significant changes to other life areas reflected in the three overlapping constructs: 'redefining the relationship,' 'modifications to life', and 'disrupted relationships'. FC grapple to make sense of and define this change in relationship with their loved one while experiencing fractures in other relationships and life areas they feel cannot support and appreciate their unique circumstances. The interaction between these constructs is dynamic instead of linear, oscillating at different time points depending on individual circumstances, within the backdrop of 'living with uncertainty'. FC face daily uncertainty surrounding their loved one's prognosis, degree of awareness, and the condition's trajectory. This is perpetuated by medical instability and mixed and inconsistent messages from professionals. At times, combined with 'wider system pressures', this uncertainty can become intolerable, causing FC to align more strongly with their caregiving role. Consequently, this further cements the belief they are best placed to fulfil the caregiving role, often disrupting their own lives and relationships with others, and triggering further modifications. To manage the inherent uncertainty, FC acknowledge the importance of 'holding hope' through employing coping strategies to help them 'navigate the middle path', such as concentrating on minor improvements and not thinking of the future. This supports FC in regaining equilibrium between fulfilling the caregiving role and the surrounding concepts while navigating DOC's ambiguous paradox and uncertainty.

Figure 2

Conceptual model of FC experiences in DoC



Around the clock caregiving

Caregiving was cited as a central multi-faceted role, encapsulating but not limited to the provision of physical care, advocacy, and decision making (Gonzalez-Lara et al., 2021; Goudarzi et al., 2015; Soeterik et al., 2018). The unique needs of those with DoC necessitate specialist tasks in which FC often feel unskilled and require additional education (Gooshki et al., 2019; Goudarzi et al., 2018). The caregiving role was described as all-consuming, acknowledging the pervasive and around the clock nature of responsibilities to a totally dependent family member while struggling to balance other commitments (Imani-Goghary & Ghaljeh, 2021). As quoted in Giovannetti et al. (2015), "I don't have a life for myself anymore, days and nights pass taking care of Laura" (p. 476).

This experience was likened to caring for a newborn (Covelli et al., 2014; Goudarzi et al., 2015), as even in the absence of providing direct care, a constant vigilance of their loved one's condition and the thoughts and worries related to this remain (Giovenetti et al., 2015). Illustrating this, a participant in Imani-Goghary and Ghaljeh (2021) stated, "I don't have a good sleep during night, because I should check her condition" (p.304). This experience is intensified by an absence of verbal communication requiring FC to be their surrogate voice to ensure appropriate care (Lovstad et al., 2018; Soeterik et al., 2018). Often the role was assumed by a primary caregiver, with varying degrees of support from wider networks (Gonzalez-Lara et al., 2021; Goudarzi et al., 2018). A decision, motivated for some, by a moral obligation (Goudarzi et al., 2018; Lovstad et al., 2018); for others, the belief they are best placed (Giovenetti et al., 2015) and concerns over who else could provide care in their absence (Gonzalez-Lara et al., 2021). Even when a loved one resided in a facility or hospital, FC reiterated the all-consuming nature of their role. Many acknowledged that the healthcare system does not always meet needs (Gonzalez-Lara et al., 2021) or experience a lack of trust in their caregiving (Cipolletta et al., 2014; Gonzalez-Lara et al., 2021). These experiences further fuel FC belief that they possess unique knowledge and intuition to provide the best standard of care (Giovenneti et al., 2015; Gooshki et al., 2019); as described by a participant in Cipolletta et al. (2016) "he needs me, not other people. They [nurses] get him up, but I shave him and wash him. I care for him like no one else. He's never cared for in the way you hope" (p. 1201). However, placing oneself in this position is a double-edged sword, as while offering a meaningful experience, the responsibility is equally burdensome (Hamama-Raz et al., 2013).

Redefining the relationship

FC grappled with navigating the sudden and complex change in their relationship with their loved ones in a DoC (Soeterik et al., 2018). Mourning a relationship (Gonzalez-Lara et al., 2021) while maintaining their loved ones' sense of personhood (Lovstad et al., 2018) presents daily and future challenges (Soeterik et al., 2018). Many FC had created shared goals and imagined futures with their loved ones and were thus left mourning what might have been (Hamma-Raz et al., 2013). This was often intensified with each passing year due to the ambiguous paradox of their loved one's physical presence yet the inability to grow in a two-sided relationship and form new memories. This ambiguity presented challenges for FC in defining their relationship, which does not align with conventional societal relationship paradigms, as many considered their loved ones neither living nor dead (Hamama-Raz et al., 2013; Soeterik et al., 2018), as reflected in the quote below:

> I'm quite worried about society in a sense, its like, you know, am I, am I single? Do I still have a partner, yes I have a partner, but he's, I haven't spoken to in 9 months, that whole where do you fit? (Soeterik et al., 2018, p.1399)

While FC continued to express resounding love and commitment, the nature of this had for many transformed (Covelli et al., 2014; Hamma-Raz et al., 2013; Soeterik et al., 2018). Those previously in romantic relationships expressed a shift to a parent-child as described in Covelli et al. (2014): "I see him as my fourth child. To me he's a little child, even when I talk to him. I call him 'little one', 'hi my little one', because he is like a helpless child" (p.5). Consequently, FC grapple with redefining ways of maintaining their bond, which often involved gestures to honour their relationships, preserving their loved one's sense of personhood (Lovstad et al., 2018), and increased reliance on proximity, as explained in Giovannetti et al. (2015) "maybe we touch and caress him even too much… we feel a need for it" (p.477).

Disrupted relationships

FC expressed disruptions in other significant relationships (Goudarzi et al., 2015) and throughout family structures (Goudarzi et al., 2018) because of differing perspectives, outlooks, and approaches (Cipolletta et al., 2014), as explained by a participant in Lovstad et al. (2018); "in the beginning, in a way, I felt that you [parents] wanted me to be there more often than I actually felt like, and more than what I felt was ok for me" (p.1662). Moreover, FC acknowledged that it was easy for their relationship with their loved one in DoC to be prioritised above all others, as described in Gonzalez-Lara et al. (2021) "I had to remember . . . that we were also parents to three other children" (p. 203).

As each FC navigated their own experience, some utilised family relationships and wider networks as crucial sources of support and were committed to maintaining these (Gonzalez-Lara et al., 2021; Gooshki et al., 2019 Hamma-Raz et al., 2013). However, many expressed retreating from or changes in relationships with wider friendship groups and family who could not comprehend their unique circumstances and needs, instead opting to seek new connections with people going through their shared experience (Covelli et al., 2014) as described in Giovennetti et al. (2015), “I made new friends, met new people that are in the same situation that understand my needs and my problems... and I prefer these friendships” (p.477).

Modifications to life

Fulfilling the caregiving role was often in tension with other life areas, and therefore FC frequently faced “being pulled in a lot of different directions” (Gonzalez-Lara et al., 2021, p. 202). As such, FC described renegotiating professional and educational obligations and aspirations (Giovenetti et al., 2015; Goudarzi et al., 2018; Gonzalez-Lara et al., 2021), often reducing or ceasing paid employment. Such decisions were typically in conflict with the financial burden of caregiving (Covelli et al., 2014) yet could be eased by accommodating employers (Gonzalez-Lara et al., 2021). In addition, FC often assumed responsibilities once undertaken by the individual in the DoC, requiring further modifications to daily living (Gonzalez-Lara et al., 2021). Many shared challenges in prioritising their own needs and overall well-being to pursue interests, social engagements, and leisure time, as those in the DOC “come first and then me” (Giovennetti et al., 2015, p.477). Thus, they described feelings of isolation as if their life had been paused (Gooshki et al., 2019), as captured by Goudarzi et al. (2018) “I cannot handle my personal affairs because I do not have time anymore. I haven't been able to go anywhere for five years” (p.167).

However, while the theme of change and sacrifice was paramount, at the same time, the obligation to fulfil the caregiving role was, for some, the motivating factor for prioritising their own needs and offered FC a sense of normalcy (Lovstad et al., 2018) and grounding amongst the uncertainty (Soeterik et al., 2018).

Living with uncertainty

Unlike death's clarity and finite nature (Soeterik et al., 2018), FC in DoC describe facing a constant state of uncertainty that generates feelings of sadness, confusion, and loneliness (Imani-Goghary & Ghaljeh, 2021; Hamama-Raz et al., 2013). This uncertainty encapsulates their loved one's prognosis, degree of awareness, and the possibility of recovery (Gooshki et al., 2019). Although for some, as time progresses uncertainty becomes easier to tolerate, for many, it is not a linear process (Goudarzi et al., 2015) as they face ongoing hope threatening situations (Goudarzi et al., 2018). These include the medical instability in the condition (Soeterik et al., 2019) and the mixed and inconsistent messages from healthcare professionals (Cipolletta et al., 2014; Goudarzi et al., 2018, which are often in paradox with FC conclusions based on the physical presence of their loved one (Lovstad et al., 2018) as captured in Gooshki et al. (2019); “doctors and nurses said the recovery probability is weak…perhaps he never recovers, but I saw him, he was breathing, his heart was beating well” (p.165).

Moreover, the uncertainty and changing parameters perpetuate challenges in FC making sense of other life areas, such as defining their relationship and making future plans (Soeterik et al., 2018; Gonzalez-Lara et al., 2021), as described below:

> I don't quite know what I'm dealing with, and I guess it's the not knowing where it's heading as well, I guess that's very hard too I think that um, you know is this going to go on for a year, two years, three years, twenty years? (Soeterik et al., 2018, p.1400)

Holding hope

A handful of FC remained hopeful of recovery, as shared by a participant in Hamama-Raz et al. (2013) “the balance between hope and acceptance is greater that he will wake up” (p.236). Yet, with time many acknowledged they no longer hope for dramatic positive changes as they fear the possible ramifications if their loved ones were aware of their state (Cipoletta et al., 2016; Gooshki et al., 2019; Hamama-Raz et al., 2013). Nevertheless, hope balanced with realism remains a central feature depicted in other ways (Lovstad et al., 2018), such as for improvements in communication (Lovstad et al., 2018), surpassing medical conclusions (Lovstad et al., 2018) and reducing their loved one's suffering (Gooshki et al., 2019). For some, hope was focused on wanting an end to the situation, on offering certainty over uncertainty; as depicted by a participant in Cipolletta et al. (2014), “it would be better both for her and for me (…) it would have been better to cry for her death” (p.1201). However, they feel ambivalent about the means of achieving this

(Hamama-Raz et al., 2013). Irrespective of the form of hope, it remained a powerful driver in helping FC to fulfil the caregiving role, as illustrated in the below quote.

> I have to be hopeful to the end. I am trying to keep my family hopeful. I try to live with the hope so that I can take good care of home. Nobody knows the results of this world' affairs so it's better to be hopeful. (Goudarzi et al., 2018, p. 168)

Navigating the middle path

To enable FC to fulfil their role and navigate a middle path between managing uncertainty and maintaining hope, they reported drawing upon various strategies and resources. For instance, as the future was considered frightening, FC instead opted to focus on present day-to-day responsibilities (Covelli et al., 2014; Giovennetti et al., 2015) as outlined in Covelli et al. (2014); “I think about tomorrow. About the future, never. Yes, the thought of saying 'tomorrow' scares me. You know, if I didn't do it like that, I don't think I could live” (p.6).

FC focused on appreciating small signs of improvement through this present-focused lens, which they felt would often go unnoticed by professionals. For example, FC described choosing to, at times, repress or avoid possibly conflicting information (Lovstad et al., 2018), with some participants even describing not going “to the ward at the morning because the doctor was there” (Gooshki et al., 2019, p.165). Doing so helped protect their loved one's sense of personhood, reaffirming them as social beings and family members, which helped FC maintain hope (Lovstad et al., 2018) as illustrated below:

> I don't think she will ever walk or get out of the wheelchair. But maybe use her arms a little bit more. Maybe be able to draw a little bit. I look at the small stuff, no matter how tiny it is, and think that we're moving forward (Lovstad et al., 2018, p. 1665)

To help navigate this path, FC drew upon an inner strength many didn't realise they had (Covelli et al., 2014; Giovenetti et al., 2015; Hamma-Raz et al., 2013), which for some was heightened by a belief in spirituality or higher power (Gonzalez-Lara et al., 2021; Goudarzi et al., 2018). Notably, FC position on this path between uncertainty and maintaining hope was fluid depending upon the current context, possible hope threatening conditions, and their capacity to draw upon the described strategies.

Wider system pressures

FC described the financial pressures associated with ongoing expenses for equipment, nutrition, and therapeutic methods (Covelli et al., 2014; Imani-Goghary & Ghaljeh, 2021); “preparing the equipment and medications for these patients makes caregiving so difficult. The cost is too high. So far, 70–80 million Rials have been spent on equipment…we can’t afford it” (Imani-Goghary & Ghaljeh, 2021, p.304). Yet despite bounding costs, FC often could often not witness the therapeutic benefit of such interventions, which could be disheartening (Covelli et al., 2014). In addition, FC faced legal decisions which were difficult to navigate without expertise, thus requiring additional funding (Gonzalez-Lara et al., 2021). The expectation of meeting these costs was often challenged by the need for FC to cease or reduce work to fulfil the caregiving role and perpetuated by ongoing uncertainty regarding possible future costs (Gooshki et al., 2019). Consequently, participants reported that such costs “paralyze the family” (Goudarzi et al. 2015, p.5).

Discussion

This meta-ethnography aimed to synthesise available qualitative literature to explore and provide a conceptual understanding of FC experiences of caring for those with DoC. Eleven studies were included, with eight overarching themes identified as presented in Table 7.

Against a backdrop of pervasive uncertainty, this meta-ethnography illustrates how FC fulfil the caregiving role, balance competing demands, and at the same time, face the complex task of making sense of how to integrate these elements into their knowledge of life and their loved one before the injury (Gonzalez-Lara et al., 2021). This process resembles meaning-making, whereby individuals aim to reduce the discrepancy between their confronted circumstances and their existing belief system (Neimeyer, 2006). As such, FC employ their own interpretative framework (Edgar et al., 2015) to navigate a loss that is hard to label and does not fall within societally conventional terms. This experience resonates with ambiguous loss (Boss, 1999); however, in DoC, the ongoing threat of medical instability and conflicting views continuously shifts loss and adjustment parameters (Soeterik et al., 2018), causing instability and disconnection in the dynamic overlapping circles in Figure 2.

The dual-process model of coping with loss (Stroebe & Schut, 1999) offers one framework for interpreting this response by proposing that individuals oscillate in manageable doses between focusing on the relationship loss (loss-orientation) and involving tasks of everyday life and distractions (restoration-orientation). Thus, FC may assume a restorative position by concentrating on caregiving and disconnecting from other life areas when overwhelmed by ambiguity. However, as this model focuses on loss resulting from death, it arguably overlooks the unique paradox in DoC of the body's physical presence yet inability to grow in a two-sided relationship (Soeterik et al., 2018). Acknowledging this, Yehene et al. (2021) outline a process-based model for non-death loss that emphasises 'open systems' in conditions such as DoC. Unlike in death, there are ongoing interactions, which, despite one-sided, create new interpersonal information that FC must process and assimilate with their interpretative framework to make sense of who the person is, was, and will be in the future and the impact of the relationship in each stage (Yehene et al., 2021). Clinicians must, therefore, iteratively support FC as they navigate re-defining their relationship in response to ongoing, at times conflicting, incoming information (Yehene et al., 2021). Thus, while this model is still in its infancy, it is concordant with participant accounts in this review and has important clinical implications warranting further empirical investigation in the DoC population.

Relative to views held by medical professionals, FC tended to appraise their loved one's condition and the likelihood of recovery more positively and engaged in strategies to protect this view amongst uncertainty to hold a position of hope. Edgar et al. (2015) postulates this discrepancy may be because of differing interpretative frameworks. While professionals draw upon their scientific background, FC focus on protecting their loved one's sense of personhood (Lovstad et al., 2018). This nuance is important for clinicians to consider when facilitating conversations with FC to avoid possible therapeutic rupture (Lovstad et al., 2018; Schembs et al., 2018).

The strategies for navigating this middle path were diverse, incorporating emotion, problem, and avoidance-focused approaches (Lazarus & Folkman, 1987). While FC did not differentiate between the utility of these, quantitative research has documented how avoidant, and emotion-focused means of coping are associated with higher rates of depression, anxiety and prolonged grief reactions compared to problem-focused coping (Covelli et al., 2015; Cruzado & Elvira de la Morena, 2013). Commonly, FC reported focusing on small gains and disregarding conflicting negative professional evaluations (Jox et al., 2015; Schembs et al., 2018). Although the adoption of denial and hope may offer temporary protection, scholars have warned that rigidity within these can lead to possible longer-term maladaptive consequences (Cramer, 1991; Jox et al., 2015; Schembs et al., 2018). Illustrating this, Yehene et al. (2019) found FC in DoC engaging in unrealistic optimism (Freud, 1982) by not adjusting expectations for improvement despite evidence to the contrary experienced significantly greater yearning, preoccupation, and emotional distress than FC utilising dispositional optimism (Scheier & Carver, 1992). The latter reflects FC, who can adjust expectations in light of unattainable goals and replace these with a realistic one with scholars postulating this process provides FC with a renewed sense of purpose and gives space for hope to become more self-orientated. As such, therapeutic interventions should seek to understand the nuance of hope, coping, and optimism for each FC and perhaps support fostering a position of dispositional optimism (Yehene et al., 2019), yet how to achieve this requires further research.

Consistent with general caregiving literature, FC cited disruptions in relationships with wider networks and feelings of isolation, which have been documented to heighten burden and negatively impact overall wellbeing (Manskow et al., 2015; Soeterik et al., 2019). As a result, FC often sought new connections with others going through their shared experience. In other conditions, the benefits of family peer support groups are well documented in establishing shared identity, mutuality of support, reciprocal learning, and opportunities for personal growth (Shilling et al., 2013). However, while some FC in DoC cite receiving peer support (Chinnor et al., 2021), the delivery and utility of this have yet to be formally investigated. While the relatively low prevalence of DoC compared with other conditions (RCP, 2020) could account for this research gap. Given the availability of online family therapeutic support (Friedman et al., 2018), this warrants further exploration.

Strengths & Limitations

In this review, the umbrella term of DoC was employed, representing a heterogeneous category of conditions displaying varying degrees of behavioural responsiveness (RCP, 2020). While reflective of primary studies mixed-diagnosis participant groups, this must be considered when interpreting the goodness of fit of the conceptual model in figure 2. In MCS, while slight, the presence of reproducible behaviours not present in VS may be the impetus for holding hope and enabling FC to employ strategies for navigating the middle path (Magnani et al., 2020). However, presently the limited evidence exploring the impact of diagnostic category on caregiving and wellbeing is mixed and therefore necessitates further consideration (Corallo et al., 2018; Magnani et al., 2020; Romaniello et al., 2015)

Studies conducted in Italy and Iran are disproportionately represented in this review. This is important given notable differences in health care system funding and facilities alongside variations in how illness and disability are culturally perceived (Goudarzi et al., 2018), which create variation in FC experiences (Gonzalez-Lara et al., 2021). Interestingly, in this meta-ethnography, although studies conducted in Iran (Gooshki et al., 2019; Goudarzi et al., 2018; Goudarzi et al., 2015; Imani-Goghary & Ghaljeh, 2020) placed greater emphasis on wider system pressures which may be accounted for by methodological focus (Anderson, 2010) the essence of the themes were supported in findings from other countries. Thus, the review has demonstrated important themes that appear to transcend across countries. The credibility of which is enhanced by the decision to preserve primary studies' context (Atkins et al., 2008) by subsequently cross-checking the synthesis across studies grouped by country of origin, and thus, lends support to the benefits of such an approach for future meta-ethnographies (France et al., 2019b). Notably, however, this meta-ethnography excluded papers focusing on the experience of interventions and decision-making due to known political and cultural differences surrounding such aspects across countries (Yehene et al., 2019) instead focusing on the universal caregiving experience. Moreover, while outside of the scope of this meta-ethnography, in future, it could be beneficial to systemically explore the synthesis relative to other contextual factors such as time since diagnosis, place of residence and level of caring responsibility assumed (Lovstad, 2015; Steppacher & Kissler, 2018). Yet, the ability to do so may be limited by poor reporting of contextual information in primary studies (Estabrooks et al., 1994).

An important strength of this meta-ethnography is the transparency of completed stages and underpinning decisions, enabling readers to make judicious conclusions regarding transferability (Henriksen et al., 2021). In addition, the adoption of a review team with differing professional backgrounds facilitated consideration of alternative perspectives and reflexivity within an interpretative constructivism approach (Rubin & Rubin, 2013).

Table 8

Clinical implications and recommendations based on meta-ethnography findings

Clinical Implications
• There should be ongoing monitoring of FC wellbeing and adjustment by skilled health care professionals, possibly facilitated by standardised tools validated in the population.
• Interventions should focus on role restoration, maintaining a balance of occupations, and developing helpful coping strategies, the delivery of which should be responsive to the presence of an ‘open system’.
• Services should consider the feasibility and availability of peer support, especially considering the increased use of technology resulting from the COVID-19 pandemic.
• There should be partnership working with FC to acknowledge, record, and if appropriate, investigate behavioural responses that they witness
• There should be an open dialogue between health care professionals and FC, respectful of personhood, especially during the delivery of formal test results, to balance educating and supporting FC emotional adjustment.
• In partnership with FC and as directed by their needs, whether they be practical, emotional, financial, or otherwise, agencies where they exist should support the FC to build a life around and beyond their FC role.

Conclusion

This meta-ethnography, and notably the conceptual model presented in Figure 2, provides an understanding of FC experiences in DoC. On the one hand, this research has highlighted the universal nature of caregiving across health conditions while also emphasising the unique features of DoC. Thus, clinicians supporting FC should be mindful of the recommendations listed in Table 8, namely, the nature of uncertainty and the role of open systems in meaning-making and coping (Yehene et al., 2019; Yehene et al., 2021). Moreover, ongoing research in the areas highlighted throughout the discussion is required to enhance the clinical application of support for FC in DoC.

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Provision and Barriers of Psychological Support for Psychosis in a Community Mental Health Team: A Care Coordinator Enquiry Audit

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May 2022

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Word count (excluding tables and references)
3567

Target journal:
Journal of Mental Health
(Word limit: 4000 - excluding tables, abstract and references)
Rationale: The journal has a high impact factor and has previously published audits in the psychosis field

Introduction

Psychological interventions are a central component of the holistic care package offered to individuals with psychosis and schizophrenia (National Institute for Health and Care Excellence [NICE], 2014). As part of this first-line approach, in conjunction with antipsychotic medication, guidelines posit offering Cognitive Behavioural Therapy for Psychosis (CBTp) to all and Family Interventions (FI) for clients either living with family or in close contact (NICE, 2014). Importantly, CBTp and FI should be delivered over a minimum of 16 and 10 sessions respectively (NICE, 2014) to support improved functioning and reduce distress by helping individuals re-evaluate their beliefs and build supportive networks. Despite this, low implementation rates prevail, with findings suggesting fewer than 10% of individuals are offered an evidence-based approach, highlighting the discrepancy between recommendations and the reality of service provision (The Royal College of Psychiatrists [RCP], 2018; The Schizophrenia Commission, 2012).

Historically, cuts to mental health services resulted in a large proportion of support for those with psychosis typically delivered in early intervention services being absorbed by Community Mental Health Teams (CMHT) which negatively impacted on the quality and efficacy of treatment provided (McGorry, 2015). In light of this, waiting and access time standards for Early Intervention in Psychosis (EIP) services were introduced for those experiencing their first episode or presentation with targets requiring 50% to have commenced treatment within a two-week window after referral (NICE, 2014). Intervention delivery for subsequent episodes of psychosis or need for ongoing support typically occurs within CMHT (NICE, 2014) where guidelines recommend the provision of CBTp and FI as previously described (NICE, 2014). However, CMHT are typically less well-resourced to provide such support, so implementation in these services remains challenging (Tsiachristas et al., 2016).

In an attempt to establish the current provision of psychological interventions for psychosis in CMHT, studies have explored this at service, trust and national levels (Lewis et al., 2012; Haddock et al., 2014; Colling et al., 2017). A systematic review by Ince et al. (2016) identified 11 studies examining rates of implementation, ranging from 4-100% for CBTp and 0-53% for FI. This variability, while in part, may be genuinely reflective of differences in service provision across different areas, is also likely to be influenced by the methodological approach adopted. For example, operationalisation of terms used to determine implementation, including “referred”, “offered” and “delivered” are not universal, with lower implementation rates prevailing in studies adopting a more rigorous approach towards classification (Haddock et al., 2014). Moreover, differing approaches to data collection have been taken, with some authors adopting an objective stance relying on auditing case note systems (Haddock et al., 2014; Pawel et al., 2012) and others a subjective approach through staff enquiry (Gough et al., 2007; Macpherson et al., 2007). Consequently, the former is limited by the availability and reliability of the information recorded (RCP, 2018) while the latter may be affected by the accuracy of staff reporting with both leading to a possible over or under-estimation of provision. It is, therefore, essential that chosen methods for investigating implementation rates are rigorous and underpinned by a clear rationale (Bucci et al., 2016).

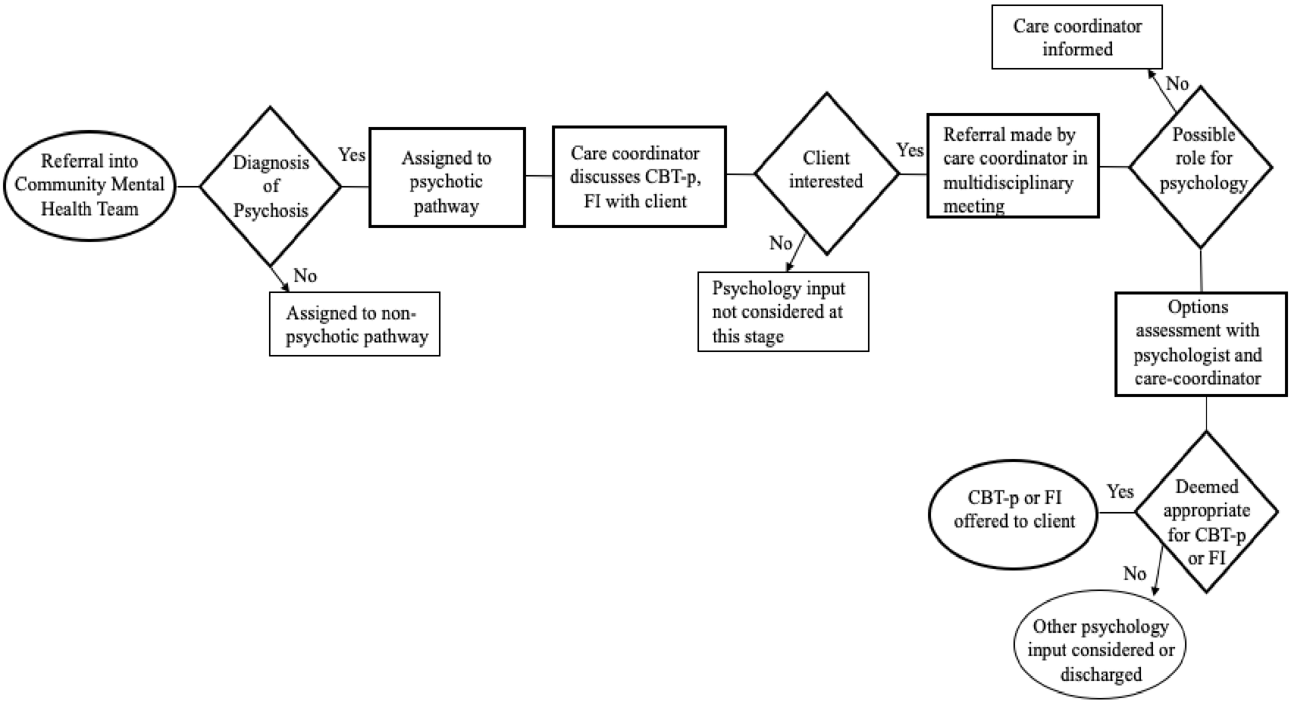
An understanding of barriers to implementation is essential which authors posit occur at three main interacting levels; organisational, individual staff and service recipients (Berry & Haddock, 2008; Bucci et al., 2016). Consequently, staff attitudes, experiences and training, combined with an organisation’s ethos and clients views have been the subject of studies to evaluate the introduction of improvement strategies, targeting these as distinct areas or a blended approach (Rowland, 2004). Whilst staff training in psychological interventions has been shown to improve clinicians’ attitudes towards working with individuals with psychosis (McLeod et al., 2002) and their families (Sin et al., 2014) this does not directly translate into more significant implementation. Illustrating this, Jolley et al. (2013) found that, while training helped Care Coordinators (CCO) competency in delivering NICE recommended CBTp, once they returned to services finding protected time for therapeutic interventions alongside managing their caseloads was difficult. Consequently, many of the CCO sought alternative positions that allowed time to conduct therapy and in so doing created a dilemma by depleting those available to fulfil a vital role in service provision. It is, therefore, essential that recommendations and improvement strategies are multifaceted and seek the views of CCO to ensure they can be supported in current roles.

Service Context

The service evaluated is a CMHT based in South-West England. The multidisciplinary team provides a needs-led service supporting clients with a range of mental health difficulties, divided into "psychotic" and "non-psychotic" pathways. On entering the CMHT, clients are assigned a CCO who guides their journey through the service, for example, by referral for psychological support as outlined in Figure 1.

Figure 1

Clients journey through the CMHT to referral for psychological support as supported by their CCO



Consultation with key stakeholders, namely the Team Manager, CCOs and Clinical Psychologists, enabled the assessment of potential audit topics to enhance psychological support provision. A recent service reconfiguration created a lead Clinical Psychologist role specialising in psychosis and acute care who was championing the establishment of a psychological intervention for psychosis pathway to ensure compliance with NICE (2014) guidelines. Stakeholders felt an audit would significantly contribute to support this pathway as establishing the current level of need, implementation rate, alongside barriers preventing this, and potential strategies to address them would enable the best allocation of available resources. Consequently, this study with trust approval (Appendix G) sought to carry out a local, service-based evaluation by investigating:

- Prevalence of clients with a diagnosis of psychosis on current caseload, to whom the NICE guidelines for psychosis and schizophrenia would apply
- The proportion of clients with a diagnosis referred for and recipients of CBTp, FI, as well as any other psychological therapy
- Reasons for non-referral for CBTp
- Strategies for improving CCO confidence in referring clients

Method

Audit Tool Development and Procedure

An 8-item audit tool mapping onto NICE (2014) recommended guidelines was devised through consultation between the author (Trainee Clinical Psychologist) and a Clinical Psychologist, CCO, Team Manager and a Trust Quality Improvement Representative (See Appendix H). Initially, this was designed as an electronic case note audit tool but was revised during the consultation to a CCO enquiry approach following concerns about a lack of systematic recording of psychological interventions for psychosis data found in a previous trust audit. The finalised tool, therefore, was devised for completion by CCO working on the psychotic pathway, either in paper or online format, with support from the Trainee Clinical Psychologist who then collated the responses.

CCO were instructed to complete the audit based on their caseload as of February 2020, to identify the number of clients with a diagnosis of schizophrenia or psychosis based on ICD-10 codes F20-F29 (WHO, 1992) as recorded on electronic case notes or, when no code was available, clinic letters from psychiatrists. Following this, CCO were instructed to provide information as to whether individuals had been formally referred for CBTp, FI or other psychological therapy. Where referrals had not been made, CCO were asked to select one of the following reasons: client choice, client lacks capacity to engage, intervention not indicated, limited knowledge around client’s suitability for intervention, limited knowledge on the provision of psychological support, not discussed or other, with an option to specify.

For those who had been referred, CCO were asked to indicate how many had received a minimum of two sessions and whether any clients had dropped out. The Trainee Clinical Psychologist cross-referenced these numbers with psychology records to ascertain the number of sessions attended by each service user relative to NICE guidelines.

Lastly, CCO were asked to highlight strategies that may help them feel more confident in referring clients for psychological support, with the option to select as many as apply from: training, information, evidence of effectiveness, psychology consultation, improved referral routes or other, with free text for elaboration.

Three randomly selected caseloads were checked for inter-rater reliability in terms of percentage agreement between CCO coding and that completed by the Trainee Clinical Psychologist using both the electronic case note system and psychology records. The reliability for diagnosis coding and the number receiving psychological support were both 100%. In comparison, those referred for psychology support was 96.2%. Due to the lack of systematic recording, it was not possible to code the reason for non-referral.

Public & Patient Involvement

Following audit completion, a consultation was held with a personal experience representative who gave their views on the findings and suggested potential areas for improvement. This feedback was combined with further ideas generated from discussions with the consultation group to construct a full list of recommendations which were disseminated to the service alongside the audit findings.

Results

At the time of the project 13 CCO comprising of Recovery Workers and Community Psychiatric Nurses were working on the psychotic pathway. The proportion of clients on their caseloads meeting diagnostic criteria ranged from 8-94%, with an average of 57%. This meant a total of 192 clients meeting diagnostic criteria were identified.

Referred

Of these 192 clients, none were referred for FI, 14 (7.3%) for CBTp, and 14 (7.3%) for an alternative form of psychological therapy, including support for anxiety, low self-esteem and post-traumatic stress disorder. Thus, 164 clients had not been referred for any psychological support while in the service. Given that CBTp should be offered to all, CCO selected reasons as to why 178 clients had not been referred for this intervention, as presented in Table 1.

Table 1

Reasons reported by CCO as to why clients (n=178) had not been referred for CBTp

Reason	Number (%)
Client choice	28 (16%)
Client lacks capacity to engage	34 (19%)
Limited knowledge around client’s suitability for intervention	27 (15%)
Intervention not indicated as client not experiencing distress	61 (34%)
Not discussed- no further reason provided	28 (16%)

Received

Of the 14 clients referred for alternative psychological support, 11 (78.6%) received a minimum of two sessions. For those referred for CBTp, 6 (42.9%) of these had received a minimum of two sessions, one client dropped out after one session and the rest were deemed not appropriate following psychological assessment. Thus, of the overall sample, only 3.1% received CBTp.

A Clinical Psychologist provided CBTp for all six clients four of whom were still engaging in the intervention with the number of sessions ranging from 2-11. Therefore, at the time of the audit, no one had received the NICE-recommended number of 16 CBTp therapy sessions.

Factors Influencing Referrals

The strategies CCO identified as helping improve psychological intervention referrals and their respective frequencies are listed in Table 2.

Table 2

Strategies for improving CCO confidence in referring clients for psychological interventions and frequency of response given

Strategy	Number (%)
Training	9 (69%)
Information	8 (62%)
Evidence of effectiveness	4 (31%)
Psychology consultation	3 (23%)
Improved referral route	4 (31%)

In this question, 46% of CCO used the option to provide free text to further elaborate on their responses. In support of 69% of CCO identifying training as helpful, the quotes listed in Table 3 suggest this would be particularly beneficial if focused on clarifying the effectiveness of the intervention and client's suitability particularly for those who are older or in an acute phase. Moreover, 31% reported an improved referral route would be beneficial, with free text responses indicating that the current process for some was intimidating, mainly as CCO felt unsure about the information required as illustrated in the quote in Table 3.

Table 3

CCO free text response quotes regarding improving referrals

Strategy	Quote
Training	"It would be helpful to know more about the effectiveness of CBTp as this would help me sell it to clients." "A lot of my caseload are older, and I don't know if they would have the capacity to engage, and whether they would want to now so, I would like to know more about interventions for this group." "Most of my clients are really unwell, and I am not sure if they could commit to coming every week and engage with it."
Improved referral route	"I find having to present referrals in the multidisciplinary meeting intimidating because I don't know how much information is required, it would be better if this was clearer."

Discussion

In light of the services intention to establish a psychological intervention for psychosis pathway, the present CCO enquiry audit aimed to explore the current need and provision of psychological support for psychosis, reasons for non-referral and strategies to improve this. The findings of this audit revealed poor compliance with NICE recommended guidelines for psychological interventions for psychosis; as of those meeting diagnostic criteria, no one was referred for or received FI while 7.3% were referred for CBTp, but only 3.1% were ultimately recipients. Whilst low, these implementation rates fall within the range reported in Ince et al. (2016) systematic review and are consistent with studies quoting rates below 10% (Haddock et al., 2014). The results of this study highlight several areas throughout a client's journey in a CMHT that may be helpful to address to improve implementation.

Interestingly, despite the presence of “psychotic” or “non-psychotic” care pathways to which CCO and clients are assigned, caseloads did not wholly reflect this, with one containing only 8% of clients meeting diagnostic criteria, with the remaining caseload comprising clients with depression and anxiety. This contradicts best practice guidelines that recommend pathways to ensure care delivery in line with key recommendations (NICE, 2014) which research has shown to improve multidisciplinary working and patient satisfaction in a range of other conditions (Campbell et al., 1998). It is, therefore, possible, CCO with only a small caseload of clients with psychosis could be less familiar with the relevant psychological interventions and guidelines that CBTp should be offered to all, which may have impacted referral numbers. Ongoing reviewing of caseloads would, therefore, be important to allow appropriate targeting of limited resources, such as training opportunities for CCO, to ensure optimum benefit and reallocation of clients accordingly.

The most commonly cited reason for non-referral was that the client was not experiencing distress. While the ultimate aim of CBTp is to reduce distress and improve functioning, it would be interesting to understand whether CCO came to this decision through joint discussion or judgement made on the client’s behalf. Understanding this is important as CBTp is a multifaceted intervention, so an absence of outward distress does not preclude a component being beneficial, for example having the opportunity to create a shared understanding and normalising of their experiences (Brabann et al., 2016). Moreover, there is increasing evidence to support the treatment of casual mechanisms involved in non-affective psychosis such as worry, low self-esteem and anxious avoidance which are pertinent in this population and clients report wanting to address (Freeman et al., 2019). Thus, irrespective of whether clients appear outwardly distressed or not, they should be assessed for, and if appropriate, offered a personalised treatment which encompasses these casual mechanisms (Freeman et al., 2019). In light of the preceding, it is possible that the figure of 16% not discussing a referral is greater. However, since the inter-rater reliability process did not allow coding for non-referral reasons as discussions were sparsely documented on the electronic system, this could not be explored further. Thus, one recommendation from this audit is to ensure that, as part of policy, on entering the pathway all CCO must document a conversation about a referral for psychological support and client views, with this data being regularly audited to enable monitoring. Moreover, while outside the remit of the present audit, it would be helpful to understand further how CCO concluded the absence or presence of distress, perhaps through qualitative exploration.

Lacking the capacity to engage was the second most frequently cited reason for non-referral. From the illustrative CCO quotes, the rationale for selecting this option appears to be two-fold. Firstly, encompassing clients who CCO considered in an acute phase of their psychosis which could involve an inpatient admission. However, NICE (2014) guidelines emphasise that psychological interventions can be both started or continued in an acute phase and, within an inpatient setting, where they are effective in producing positive and enduring clinical outcomes (Paterson et al., 2018). Hence, this should not be creating a barrier to referral, and it would seem vital to clarify evidence of effectiveness and suitability of interventions for these groups in training. Secondly, capacity judgements appeared to be related to age which raises concerns, as estimates suggest 20% of those with psychosis are over the age of 65 (Public Health England, 2018). For this population, evidence suggests their primary form of treatment is often medication (Healthcare Commission, 2009) despite the advocation of a combined approach with psychological interventions (NICE, 2014). Reasons non-referral in this population have been explored, with findings suggesting barriers such as staff attitudes, myths about therapy in older age, resource issues and adaptations for age-specific needs (Berry et al., 2020) which resonate in the quotes from the present audit. In terms of recommendations, it would seem helpful to ensure relevant training includes available therapy adaptations for the older population to ensure any memory or concentration difficulties are not a barrier to access. Although not the focus of the present audit, it would be interesting to explore further the demographics of the clients to see whether these age-related barriers are reflected in referral and delivery rates.

In terms of helping to improve referrals for psychological interventions, training and information were the most common options selected with quotes suggesting a need for a greater understanding of the structure, suitability and effectiveness of the interventions to help guide discussions with clients. One option would be to increase the provision of more formal training, such as the Meriden Family Programme (Falloon et al., 1985; Falloon et al., 2006) which three nominated CCO were undertaking at the time of the audit. This training is a significant move in line with Department of Health (2007) recommendations that CCO should be delivering low-level psychosocial interventions with supervision from a Clinical Psychologist which may help to improve FI referral rates from the present 0%. Crucially, this provides one solution to managing the potential increase in referrals that may occur as a result of training by ensuring staff members are adequately skilled and equipped to meet this demand. However, as emphasised by Jolley et al. (2013), ensuring training competence is not sufficient as protected time is also required. One way of achieving could be through the introduction of a set psychology consultation model for CCO to discuss cases with a Clinical Psychologist, which 23% reported they would find helpful. An alternative form of training could be on a more informal in-house basis, aided by the involvement of clients which has been shown to have positive impacts for both parties (Omeni et al., 2014) in terms of empowering people and challenging assumptions (Happell et al., 2003). Moreover, a co-produced leaflet containing features important to clients, such as those recommended below by the personal experience representative, would be a useful tool.

The other area highlighted for improvement was the referral route which currently necessitates CCO presenting a case at a multidisciplinary team meeting. This framework, while helpful in creating shared learning opportunities (Bryne, 2006), raised concerns for some CCO as they felt unsure about the level of information required and client suitability. To support CCO to feel better equipped, a checklist and framework could be introduced, firstly, in helping identify the psychological needs of their clients and, secondly, the information required for presenting the case in the meeting.

Recommendations

During consultation with a personal experience representative, they outlined three main areas for improving the provision of psychological support. Firstly, transparency about available options and having CCO advocate for these, secondly ensuring information materials provide real case examples of individuals and families accessing support and, lastly, ensuring everyone’s individuality and the uniqueness of distress is appreciated and recognised.

Drawing together the aforementioned, the below suggestions are made to help improve referral numbers for psychological interventions for psychosis:

- Psychological interventions to be offered routinely to all clients and for this to be documented on the electronic case note system
- Following psychological assessment, if intervention is deemed not suitable, a clear rationale must be documented
- Information on available interventions to be circulated to the staff team and co-produced leaflets to be available for clients and their families with real case anonymised examples included
- Staff to receive training on psychological interventions and their effectiveness with particular focus on suitability in terms of age and acute phase
- Review CCO caseloads to ensure it is appropriate for their relevant pathway which may benefit for being renamed from current terminology of psychotic and non-psychotic distinction
- Ensure accurate recording of CBTp, FI sessions on electronic recording system to allow for a case note audit to be completed
- Introduce a framework for referral information on the psychological needs of clients
- Provide protected time for CCO trained in psychological interventions to be able to carry out therapeutic work
- To monitor implementation of the above recommendations through regular auditing

Service Feedback

The audit findings and associated recommendations were subsequently disseminated to the service by the author via a PowerPoint presentation. Unfortunately, due to delays resulting from the COVID-19 pandemic, incorporating these recommendations remains in relative infancy. However, the service aims to begin undertaking a review of caseload allocation to ensure these are representative of the CCO pathway and to start designing a co-produced service leaflet. Moreover, it is hoped that the findings will help present a case for further investment in staff training going forward.

Limitations

The sampling method adopted in this service evaluation focused exclusively on CCO caseloads as of February 2020, thus excluding those clients who may have previously received psychological interventions but were subsequently closed to the service. It would be useful for future evaluations to explore this using an extended time frame to potentially reveal greater referral numbers. Moreover, while the use of CCO enquiry helped to overcome issues around the reliability of recording, it is possible their responses were not wholly accurate (RCP, 2018). In an attempt to mitigate this, and where possible inter-coding reliability checks were conducted. However, these were limited by documentation, and therefore, it would be useful to do a case note audit once a period has elapsed to allow for improved recording.

Conclusion

Overall, this audit has highlighted the services current level of need, provision and areas for improvement, which in line with existing research is alarmingly low (Ince et al., 2016). Thus, despite the presence of limitations, the findings and recommendations will ultimately be highly valuable in helping implement the psychological intervention for psychosis pathway.

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“That could have been me”: An Interpretative Phenomenological Analysis of Healthcare Professionals Experience of Managing the Professional and Personal Impact of Patient Death in Motor Neurone Disease

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Main Research Project
May 2022

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Word count (excluding tables and references)
7500

Target journal:
Journal of Death & Dying
(Word limit: 7500 - excluding tables, abstract and references)
Rationale: The journal has a good impact factor and welcomes qualitative papers about death and dying, and is used as a resource for health care professionals affected by such

Introduction

Motor Neurone Disease (MND) is an umbrella term given to a group of progressive and, as yet, incurable neurodegenerative diseases affecting 4.5 in 100,000 individuals globally (Logroscino et al., 2018). Characterised by rapid degeneration in the functioning of motor neurones controlling limb movement, swallowing and respiration until paralysis ensues (Oliver, 2019), MND has a life expectancy of between 2-5 years from symptom onset (Mehta et al., 2017; Whitehead et al., 2012). Moreover, for around 50%, the later stages of MND may also involve changes in personality, behaviour and cognition (Andersen, 2012; Kiernan et al., 2011). Consequently, healthcare professionals (HCP) working in MND will inevitably confront patient death, the salience of which is considered one of the most emotionally challenging aspects (Carter et al., 1998; Hunt et al., 2019). Despite this, the professional and personal impact of patient death for HCP working in MND remains under-researched and seldom discussed.

Caring for dying patients requires significant emotional investment (Meier & Beresford, 2006). As a result, HCP can experience considerable distress (Cevik & Kav, 2013), with frequent death exposure documented to generate feelings of anxiety, helplessness, grief, and ultimately heighten the risk of compassion fatigue and burnout (Peters et al., 2013; Rickerson et al., 2005). Currently, the impact of patient death for HCP has been explicitly examined across disciplines, including but not limited to oncology (Braun et al., 2010; Cochrane et al., 1990), general nursing (Deffner & Bell, 2005) and crisis care (Niemeyer et al., 2001). Yet, comparatively, neurology as a discipline, and specifically MND, have been largely overlooked.

This absence of research is of concern, given, firstly, the growing recognition for a palliative care approach in MND (Voltz et al., 2015), and secondly, the rapidity and diversity of MND symptoms, which, relative to other neurological conditions, HCP report as more practically and emotionally challenging (Carter et al., 1998; Oliver, 2019). A study by Hunt et al. (2019) elaborates on this, by highlighting how HCP face challenges surrounding MND necessitating consideration of death at diagnosis, compounded by increasing patient dependence and often poor acceptance of its terminal nature. Interestingly, despite emotionally negative effects on HCP, positive impacts were also documented, including promoting an appreciation for ‘living life to the full’. Similarly, in a recent study by Gamskjaer et al. (2021) exploring job satisfaction in MND, HCP reported their work had generated positive perspectives on living and led them to establish a more ‘relaxed’ relationship with death. However, as both studies were conducted at single sites, the findings may not wholly represent the wider profession. Moreover, their generalised approach to canvasing experiences of working in MND did not explicitly focus on managing patient death, and, hence, it is likely that other pertinent issues have yet to be explored, including consideration of the emotional challenge for HCP in terms of confronting their own vulnerability and mortality which requires further research.

Presently, research into death and dying in MND has focused mainly on patients and carers (McVeigh et al., 2019; Whitehead et al., 2012). Such findings have cited how individuals face fear and anxiety associated with death and, notably, experience a lack of HCP receptiveness to discuss such issues, leaving them feeling unprepared for death (Harris et al., 2018; McVeigh et al., 2019). This is concerning, as guidelines emphasise the importance of early and open discussions regarding the progressive and terminal nature of the condition to facilitate acceptance and decision making (MND Association, 2016). However, to date, whether HCP in MND echo such views and share similar anxieties has yet to be explored despite the possible impact on well-being and delivery of care (Clare et al., 2020; Peck, 2009, Black, 2007).

One potential reason for HCP reluctance to discuss such topics could be the presence of their own death anxiety (DA), whereby confrontation with the vulnerability of life serves as a reminder of one's mortality, thus triggering a sense of apprehension (Abdel-Khalek, 2005). DA is considered a multi-dimensional construct (Lehto & Stein, 2009), comprising two main facets; fear of death, such as being forgotten and fear of dying, including the pain associated with this (Mckenzie et al., 2017). In other conditions, high DA has been shown to increase negative attitudes toward dying patients, reduce willingness to broach death-related topics with patients and increase endorsement of life-prolonging treatments (Cochrane et al.,1990; Werner & Carmel, 2001). Moreover, if unaddressed, DA heightens the risk of staff burnout (Mallet et al., 1991) and the development of psychological difficulties (Iverach et al., 2014). Yet, to date, the possible impact of HCP DA has not been examined in the MND arena, despite its characterisation as a terminal condition most prevalent in the older population (Logroscino et al., 2018); which are two notable factors associated with higher DA (O'Connor & McFadden, 2012).

Terror Management Theory (TMT) (Pyszczynski et al., 2004) has been proposed to explain how individuals manage fears related to death, and a large body of empirical research exists supporting the theory (Juhl & Routledge, 2016; Lifshin et al., 2017). TMT posits that when death is salient, individuals participate in defences to reduce anxiety and promote self-esteem, categorised into proximal and distal (Greenberg et al., 2000). The former involves conscious level attempts to shift mortality thoughts from focal awareness, including through denial and thought suppression (Greenberg et al., 2000). While intended to be protective, the employment of such defences can negatively affect therapeutic relationships, leaving those with terminal conditions isolated with their concerns (Melo & Oliver, 2011). Furthermore, as death thoughts remain pervasive outside consciousness awareness, individuals employ distal defences that focus on symbolic immortality and worldviews that promote feelings of worth and purpose (Abeyta et al., 2014). Thus, gaining insight into how HCP in MND manage the personal impact of patient death and whether certain strategies are employed remains necessary. Crucially, it is hoped that doing so will shed light on possible intervention areas to support HCP in managing the personal and professional costs of frequent death exposure and related anxiety, which is necessary given mixed support for the utility of current provisions outside of MND (Mallet et al., 1991; Mcllwaine et al., 2007; Potash et al., 2014).

At present, nurses' and doctors' experiences are disproportionately represented in DA research, with limited multidisciplinary perspectives (Draper et al., 2019; Peters et al., 2013). However, as MND necessitates a team approach to meet the specialised needs of those affected, incorporating the views of other professionals is paramount (Lau et al., 2018). Moreover, studies have primarily utilised quantitative methods to explore the personal impact of death and related anxiety on care attitudes and provision (Draper et al., 2019; Peters et al., 2013). Although fundamental in aiding the development of theoretical understanding of concepts, there are shortcomings. For example, possible under-reporting due to participants' apprehension of acknowledging their fear or through the successful engagement of proximal defences, which standardised measures may not be sensitive to detecting (Abeyta et al., 2014; Neimeyer et al., 2004). Consequently, utilising alternative methods, such as qualitative enquiry, to investigate the topic sensitively is necessary (Neimeyer et al., 2004).

Accordingly, the current study uses a qualitative approach to explore the following research question; *What are HCP experiences of confronting and managing the professional and personal impact of patient death in MND?* By identifying themes related to this question, it is hoped that a better understanding of the challenges faced by HCP encountering patient death in MND can be gained with consideration of how this impacts their views of their mortality, and ultimately, providing valuable insight into areas for support.

Method

Design

This qualitative study adopted a semi-structured interview design using an interpretative phenomenological analysis (IPA) approach to explore the lived experiences of HCP managing patient death in MND. IPA is a qualitative and inductively driven method of inquiry drawing upon the tenets of phenomenology, hermeneutics, and idiography (Smith et al., 2009). It focuses upon the personal lived experience of a particular phenomenon (Smith et al., 2009) and is frequently used in health research (Dwyer et al., 2019; Smith, 2011). Adopting a constructivist epistemological framework (Moon & Blackman, 2014) researchers engage in a double hermeneutic by making sense of participants accounts who are, in turn, themselves engaging in a meaning-making process (Smith & Nizza, 2022). Thus, IPA researchers must acknowledge and reflect upon their own biases, positionality, and preconceptions throughout the analytic process.

Participants

Participants were recruited using purposive sampling based upon the characteristic of being HCP with specific experience of working with clients with MND. Eligible participants had to (1) have at least one year's experience to ensure they had witnessed the breadth and rapid nature of MND and (2) read and speak English sufficiently well to engage in the interview. Individuals who had not worked with clients with MND for more than two years were not eligible due to potential challenges in recalling experiences.

Participants were recruited through contacts in health care trusts and services, with project details and consent form sent via email (Appendix J). The details of this document were co-created in consultation with three HCP working in MND. Potential participants were invited to correspond with the researcher via email to express interest and informed consent was sought. Moreover, snowball sampling was adopted by asking participants to recommend other individuals in their network who met the research criteria, an approach frequently combined with purposive sampling (Parker et al., 2019). In total, ten participants were recruited, which is considered a suitable sample size for doctoral IPA research (Smith et al., 2009). The demographics and characteristics of these participants are listed in Table 1, enabling readers to consider theoretical transferability (Smith & Nizza, 2022).

Procedure

Ethical approval was obtained from the University of Bath ethics committee (Appendix K). Upon expressing interest in the study, eligible participants were invited to meet with the researcher to discuss the study. After consenting, participants were asked to complete a demographic questionnaire and arrange an online interview hosted via Microsoft Teams. The first author interviewed participants about the personal and professional impact of their experiences of patient death in MND.

The semi-structured interview schedule (Appendix L) was designed according to IPA best practice guidance (Smith et al., 2009) through literature consultation and discussion with authors and HCP representatives to allow flexible exploration of areas relevant to the research question. Interviews lasted an average of 64 minutes and were audio-recorded using a digital recorder and transcribed verbatim. After participating, a debrief form (Appendix M) with wellbeing signposting was sent, and participants were reminded of their right to withdraw their data within two weeks of the interview.

Table 1

Participant Demographics

Participant ID	Age Range	Gender	Ethnicity	Religion	Profession	Years in profession	Years working in MND	Work Setting	Training in talking about death	Training in managing death personally
P1	51-60	F	White British	-	Specialist Nurse	30+ years	11-20 years	MND specialist service	Yes	No
P2	51-60	F	White British	-	Nurse	30+ years	11-20 years	Long term health condition Service	No	No
P3	41-50	F	White British	Atheist	Palliative Medicine Consultant	11-20 years	11-20 years	Palliative care service	Yes	Yes
P4	41-50	M	White Welsh/ British	Christian	Palliative Medicine Consultant	20-30 years	11-20 years	MND specialist service, palliative care service	Yes	Yes

P5	21-30	F	White British	Christian	Specialist Occupational Therapist	6-10 years	6-10 years	Long term health condition service	No	No
P6	41-50	F	White British	-	Speech and Language Therapist	11-20 years	11-20 years	Community neurology service	Yes	No
P7	41-50	F	White British	Agnostic	Palliative Medicine Consultant	11-20 years	11-20 years	Palliative care service	Yes	Yes
P8	51-60	F	White British	-	Speech and Language Therapist	20-30 years	11-20 years	Community	No	Yes
P9	41-50	F	White British	Atheist	Consultant Neurologist	11-20 years	6-10 years	MND specialist service, neurology service	Yes	Yes
P10	60+	M	White British	Agnostic	Neurologist	30+ years	30+ years	Neurology service	No	No

Analysis

The analysis followed the procedure outlined by Smith and Nizza (2022), with each transcript initially analysed in isolation by the first author, an illustration of which is shown in Table 2. Firstly, interview recordings were listened to alongside the repeated re-reading of the transcript to ensure immersion within the data. Secondly, in-depth exploratory coding was conducted in the left side margin capturing descriptive, linguistic, and conceptual features (Smith et al., 2009). Next experiential statements which offer a concise higher level of abstraction were recorded in the right-side margin capturing the implied psychological dynamic noted though initial coding and interpretation. Finally, these experiential statements were clustered together into those of a similar theme or function within the transcript to create personal experiential themes that acknowledge the convergence in the underpinning experiential statements (see Appendix N for an illustrative example). Once completed for each transcript, a cross-case analysis was conducted to explore convergences and divergences between participants' accounts. This enabled the creation of group experiential themes, which in line with guidance, were considered evident if present in at least half of participant accounts (Smith et al., 2009).

Reflective Statement

Throughout, respective IPA guidelines were followed to enhance credibility and validity (Nizza & Smith, 2021; Smith, 2011) as such the first author kept a reflexive journal and attended a peer-led IPA supervision group. Moreover, coding and transcripts were discussed between authors with excerpts analysed by the second and third author while each reflecting upon their positions and assumptions. As such, the primary etic perspective (Pietkiewicz & Smith, 2012) offered is through the lens of the first author, a White British, Cis-woman, Trainee Clinical Psychologist, with placement experience in a neurology service and a special interest in grief and staff wellbeing in healthcare contexts.

Table 2

Illustrative Excerpt of Exploratory Notes and Experiential Statements

Exploratory Notes	Transcript	Experiential Statements
Differing views and outlooks on death Promoting life at all costs Death still a taboo among professional colleagues – the stance of the NHS- promote life at all costs Worse outcomes than dying. What are these? *Echoed twice is this to affirm the importance of this position.* *Even though comfortable talking about death still utterance of challenges use of 'you know' does that reflect difficulty naming it Or still linguistic/ taboo language within society over how to determine a 'good death'* *A fear of pain or loss of awareness is worse?* Worse fates than death Death is not to be feared at all costs. *Sudden change from first person (I) to third person* is this a distancing strategy as then groups experiences relative to whole human experiences?	I think sometimes that erm, well I know nurses and doctors often look at death in a completely different way and I think that, doctors tend to promote life at any cost and what I often say to people is that there are worse things than dying. There are worse things that can happen to you than a natural you know, a peaceful death it always a difficult one but, you know a natural death. There are worse things that can happen in life. I would hate to have a massive stroke and be incapacitated, I would rather die if that happened to me and in certain circumstances, I would prefer death over a lot of fates. But people tend to, that need to cling onto life at any costs. I think it's a very human need and it's really interesting that when you're talking to people and kind of, helping to manage their care I think a lot of that fear is, is letting go.	Differing perspectives among colleagues The taboo of death Promoting life at all costs Death is not the feared outcome A good death The payoff of choosing life at all costs A fear of letting go of life and what might be A human necessity

Note. Plain text = descriptive, *italic text=linguistic,* underlined text= conceptual

Results

Four group experiential themes were identified during the analysis process which were endorsed by at least half of the participants (Smith et al., 2011) as outlined in Table 3 and described in detail below with supporting quotes.

Table 3

Group Experiential Themes and Sub themes

Group Experiential Theme	**Sub Theme**	**Participants included in this theme**
Death is part of the job	A familiarity with death	10
	Unravelling the mystery	10
Nuanced challenges in MND	Death as a certain end, to an uncertain path	10
	Characteristics of the population	10
	Revises the paradigm of death	7 (P1, P2, P3, P5, P8, P9, P10)
Places death on your personal agenda	It could have been me	7 (P1, P2, P3, P5, P8, P9, P10)
	Reflecting on own relationship to death and dying	9 (P1, P2, P3, P4, P5, P6, P7, P8, P9, P10)
	Expressing end of life wishes	10
	Reframing perspectives on living	10
Caring for oneself to care for others	Keeping work and life scales balanced	10
	Having time for consolidation and reflection	10

Death is part of the job

The first group experiential theme illustrates participants' sense that confronting and discussing death represents an inherent part of their professional role and is signified in two subthemes.

A familiarity with death

All participants described how interactions with dying patients form an integral cornerstone of their work, as echoed by participant 5, who explained it as “the bread and butter of what I do”. Initially, many participants described death as in their “comfort zone” (P4), as expressed by participant 9; “I've got more comfortable looking after people with MND and people who are reaching the end of their lives, you have to have difficult conversations, so I have become much more comfortable with it”. However, there appeared to be a linguistic component to this, whereby participants instead of comfort were alluding to a sense of familiarity with death that gives them the ability to maintain a sense of assurance in their role, as participant 9 later distinguishes:

> I think it's working with people that do die, so you sort of see a bit more of it, so I guess I became a bit more comfortable with death - I don't know if that's the right way to put it. I'm not horrified of a dead body. (P9)

Consequently, while participants undoubtedly held familiarity with death in emphasising “death is a part of life” (P7), therapeutically, there were gains in keeping some element of discomfort. These included the ability to recognise their role “as a privilege” (P1) and maintain an awareness of the perspectives of those around them, as outlined by participant 4:

> I don't know about more comfortable and again, I don't think my comfort probably is my goal because there is a certain amount of tension a certain amount of discomfort to sustain… and whilst it’s much more difficult for the person dying than me, it should be hard, shouldn’t it, it isn’t easy. It is emotional, and it is difficult. (P4)

Unravelling the mystery

Because of their familiarity with death, participants, as outlined in the extract below, spoke of the need to remember their position of power and privilege surrounding death knowledge and the need to disseminate this:

> I think the thing is, as health professionals, you kind of forget that you have a very privileged view on what happens to people when they deteriorate, and other people don't know that, and you can't take it for granted, but you do have to be mindful that all of this is very new for everybody. (P2)

Participants recognised without doing so, death can remain “a bit of a mystery” (P2), particularly due to increased use of alternative terminology, which participants felt had dehumanised the death process, and perpetuated fear, as such participants recognised the need for if “talking about dying, you're talking about dying, you're not talking about passing” (P7). Moreover, participants acknowledged that for many patients “death is all too abstract” (P10), and this may be the first time translating this into concrete terms. Thus, participants alluded that such conversations are in many ways an art, balancing “how much they really want to know” (P1) with the recognition “that I haven't done my job properly if I don't mention it” (P9). Participants spoke of empowering it can be to “talk about things to help people who haven't been here before to see what might be coming around the corner” (P4) in supporting patients “face the element of the journey without fear” (P10) whom may otherwise be “frightened to broach the subject” (P2).

Nuanced challenges in MND

The second group experiential theme illustrates participants' characterisation of the challenges faced in MND as either unique relative to other conditions or displayed in a starker manner in MND, as represented by three sub-themes.

Death as a certain end to an uncertain path

All participants spoke of death as the only given in MND, as described by participant 10; “these patients will die, if they don't die you've got it wrong, and it is therefore set in a different dimension than when other patients of other type disease die”. This positioning generated for participants an ongoing sense of pressure “to stay ahead of the game, and maybe having to push people a little faster than they want to go” (P7). While on the one hand, participants spoke of how the decline in MND can happen “over time, little by little” (P6), as participant 4 explains, it can also be “very unpredictable and then on top of that you've got the propensity for the sudden deterioration and death”.

The participants shared the difficulties of such work within their perception of a curative culture of the NHS which they felt focuses on “treat at all costs” (P3), and a society that instils a sense of hope of recovery, which often means that patients come full of hope, and they have “to take the last little bit away” (P9) due to the lack of active treatments available in MND. Thus participants, hope for the patients was reframed and centred upon providing a 'good death', as described by participant 2, “helping a good death, is the most giving thing that you can do as a healthcare professional and it's important to get it right. And really get it right”.

Characteristics of the population

Beyond the certainty of death, participants spoke of the characteristics and nature of the work supporting patients with MND. For example, participants referenced the intimacy involved in their work and the opportunity to “really get to build a rapport as you’re with them through their whole journey” (P5). However, this heightened sense of intimacy could be challenging for participants, particularly due to a "relatively high proportion of young people on their caseload"(P4), as explained by participant 8:

> I have had really young people die, I think the youngest person that I’ve had die on my caseload was 29 and of course I couldn’t help but think, he had children and you do dwell on the shortness. (P8)

In addition to age, participants reported both being confronted by the "rapidity of decline you see in the population" (P1) and the breadth and intensity of the physical burden of the condition with patients often having "fears of dying from choking, drowning or breathlessness" (P3). Interestingly, despite such observations, there was an upsetting consensus that relative to other conditions, those with MND and their families receive much less support, which can be difficult to make sense of as participant 7 explained, "the nature of the support, it feels as though things are well established for cancers and it seems that things are more difficult for the non-cancer conditions, and I would include MND within that".

Revises the paradigm of death

For some participants, working in MND had emphasised the fallibility of seeking protection in previously employed 'death frameworks', such as viewing death as solely "a natural progression where organs wear out" (P2) or death as a hierarchical sequence of ageing, as described by participant 10; "going to weddings, and then it will be christenings, and then it's your children's weddings, then your friend's funerals and then your funerals, so you know that sequence of events". Instead, participants described revising their paradigm through their work to acknowledge that "ageing isn't really a thing because people can die at any age" (P5).

Places death on your personal agenda

The third group experiential theme captures the narratives surrounding how participants' experiences of working in MND fuelled an internal reflection upon their own mortality, as reflected in four subthemes.

It could have been me

Participants reflected how the characteristics of the population affected by MND and the subsequent confrontation of a revised paradigm of death exposed them to a sense of vulnerability regarding their own mortality, acknowledging, as expressed by participant 9; "it is easy to forget MND is actually quite rare, because it's not rare to me". For participants, work was most confronting when patients were “similar to your own life or whatever it might be” (P9), as participant 6 explains in the extract below:

> If they are a similar age, you think that could have been me. And I guess you've just got little things like, similar, well maybe not, but similar taste in music, similar life experiences. You may have similar professions, like if someone was in healthcare erm, so all of those things can just make it a little more close to you. (P6)

This narrative of similarity appeared to be core in driving such reflections, while at times, as explained by participant 6, this could be based on more superficial factors, most notably was the factor of age, as participant 7 explains, “you look at a date of birth and think oh that's quite close to my age”. This became increasingly difficult for participants when they were older than the patients they were supporting as participant 6 depicts “if they are at a similar age to you, or younger now that I'm getting older that can be difficult”

In addition, all participants reflected how, “when you work with people who have horrible things happen to them, you're also aware that horrible things could happen to you” (P9). For two participants (P9, P6), this awareness related explicitly to fears of potentially having MND themselves and spoke of how this can heighten the misinterpretation of everyday experiences, as participant 6 explains: “I have a little twitch in my eye because I'm tired or a twitch in my shoulder all of a sudden, oh my god I've got MND”.

Reflecting on own relationship with death and dying

Participants reflected on their own relationship with death and dying, acknowledging with consensus that this has increased with age, "you can't deny as you get older it's something that you think about" (P8). As echoed by participant 4, "If I had counted, I'll probably found that I think about it more now in my late 40s than I did at 20". At times, such reflections allowed participants to hold an appreciation for life's fragility and guide decision making. However, they acknowledged at times, it was paralysing and frightening as "it makes you fear how perilous it can be" (P8), as participant 2 remarked: “why would I want to put myself through the emotional trauma of dwelling on that I'm going to die, it's going to happen isn't it”. Thus, for participants, it was a careful balance of valuing opportunities for reflection and recognising "if that fear takes over it can become irrational" (P8).

Interestingly, all but participant 5 shared that they had reflected on their own death and dying to varying degrees. Intriguingly, participant 5 elaborated in the extract below, suggesting that other factors also affected the prevalence of reflections beyond age, such as having dependents.

> It really depends on where you are, if you have kids and family and things, people would definitely think about that. But at this point in my life, I don't have that, but if you were to ask me in a year or two's time, I'd probably have a really different answer. (P5)

The content of reflections on death and dying varied across participants. Most consistently, participants spoke of apprehension around dying, as participant 1 explains, “I think it is more about how you get there, because its sometimes not very pleasant and I don't want to be ill” and what this means for living. Elaborating on this, participants spoke of how working in MND exposes you to the vulnerability encountered when dying, as participant 7 explains “putting your life in the hands of other people when you're that vulnerable and I think MND is the most vulnerable death you can have if that makes sense”. Regarding thoughts on dying, participants spoke about being reassured by the presence of “someone I care about there” (P9), and ability to “be as comfortable as possible” (P3).

For a small proportion of participants (P2, P9) the feared outcomes centred upon death, and non-existence, particularly in people's lives they are survived by. Interestingly, in alluding to this effect, several participants employed metaphors rather than more explicit language, perhaps as a defence against a painful notion, as captured eloquently by participant 2:

> It's a bit like, you're watching a really good series on tv and then not being able to see the last one. It's like, you know, missing out on potentially what's going to happen to people, how they are going to be and that sort of thing. (P2)

Notably, for the other participants who did not speak of anxiety surrounding non-existence, a sense of legacy remained significant, with participants wanting to be remembered by both family but also for their professional accomplishments; as participant 9 explains, “I guess I'd want someone to acknowledge that I was a good doctor and that I did good in my professional life”.

Interestingly, some participants spoke of a guiding belief system that provided a framework and comfort for making sense of their relationship to death and dying. For some participants, this was expressed in a form of holding “faith in a sense of humanity” (P6). For participant 4 this was unique in that it was explicitly linked to his faith, as described below:

> I’ve got a fairly secure assured belief in what follows death. I'm a Christian, so I think what I confidently expect rather than a full on hope if that makes sense is that I go to heaven which feels like a good outcome. (P4)

Expressing end of life wishes

Driven by an awareness of life’s fragility and consideration of their relationship to death and dying, participants recognised the need to both consider and express their end of life wishes, as participant 7 explains, "it reinforces that element of advanced care planning, that element of being open with people about what your priorities are" which was echoed by participant 9:

> It’s definitely shaped my viewpoint for what I’d like for myself if I was in that situation, and I’ve definitely had a conversation with my husband that I’m sure other people haven’t about what I might find acceptable to me. (P9)

Some participants acknowledged that while they are able to facilitate such conversations, this can be more challenging for the recipients; as participant 6 explains, "I’m not scared to talk about subjects like death and dying, you know, which some of my friends find really weird". Interestingly, participant 10 posited one potential explanation below for this, which ties into the privileged position HCP hold of having a revised paradigm of death; “if I talk to medical people, nurses and the broader people with the services, they already have the framework and the notion that people in their lives die. Most people, fortunately, that doesn’t really happen.” (P10). Acknowledging, the potential apprehension that may occur for family members, some participants spoke of making their own end of life arrangements, as participant 2 explains below.

> people look at me as if to say, you’re in your 50’s why have you paid for your funeral and done all of this. And I guess it’s like life is very, very short and shit does happen, and you really don’t have any control over it. I guess it’s about saying, the little things I can do to maybe prepare, you know, just sort of lighten the burden. (P2)

For each of the participants, at the core of expressing their end-of-life wishes was an appreciation of the importance of quality of life, as participant 9 explains, “life at all costs isn’t necessarily what I would want for myself or for my relatives”. However, participants 7 and 10, acknowledged the limits of pre-emptive decision making, that “when you’re in that situation it's completely different from what you think it will be like, and it may be at this point that need for life does kick in” (P7).

Reframing perspectives on living

For all participants, their experiences had not only affected their outlook on their own mortality, but ultimately on living. Participants spoke of how their work, had fuelled an appreciation that “life is short and isn’t always fair” (P7) thus instilling in them a seize the moment mentality, as participant 1 shared; “it just makes me appreciate my life and think I've got to make most of it because you never know what's around the corner”. This led participants to reaffirm their priorities, such as “that relationships are the key thing in your life, money isn't, status isn't, it's the people that will be there and support” (P8). In addition, many participants reported increased use of comparative coping by contrasting aspects of their lives to their patients to generate a greater sense of appreciation, as participant 6 explained:

> Oh, this isn't so bad, just think about what my patients go through and that's actually quite a positive thing to be honest because you just think, well you can get through this don't be so anxious, far worse things can happen. (P6)

Caring for oneself to care for others

The fourth group experiential theme denotes participants' recognition of the need to care for themselves, as expressed through two subthemes.

Keeping work and life scales balanced

Participants spoke of recognising the “duty to care” (P4) for themselves by ensuring they have sufficient balance both within and across work and personal lives. In their professional roles, participants spoke of recognising the emotional strain they are under while also acknowledging “you get huge rewards from helping people at their most vulnerable” (P9). Thus, participants spoke of the need to know “the difference you have made” (P7) both in an intrinsic sense of accomplishment but also seeking this feedback from external parties as participant 4 stated that “it's about connecting the two because engagement can become quite toxic if it comes without the reward”. Importantly, participants noted how the rapid nature of MND can often consequently at times promote a harmful degree of engagement, as explained by participant 1:

> I think it's got to do with the rapid nature of the condition and things being quite time dependent like I don't like to think that people are left floundering without support… I do think well if I wasn't here nothing could be done, but I am here, and something can be done so why shouldn't I? (P1)

To balance this, participants spoke of valuable mechanisms for coping. Firstly, as echoed by all participants, was the importance of preserving emotional boundaries and distance, and how part “of being a professional is to be slightly out of the room but in the room” (P10). Secondly, participants shared ensuring they have appropriate outlets outside of work, such as spending time with family and friends, eating well, and pursuing interests. However, participants spoke of the impact of the COVID-19 pandemic on such pursuits, as described by participant 9, “I think some of the things that we do to help ourselves have been taken away now. You can't go and see your friends, you can't go to the pub”. Lastly, participant 8, spoke of the benefit of having a varied caseload, consisting of work with a rehabilitative focus, “I think that sometimes the rehab can give you that lift you don't get in condition management'.

Having time for consolidation & reflection

Due to the high levels of involvement with patients, an essential aspect of caring for oneself and maintaining an appropriate balance was having time for reflection and consolidation, as described by participant 5 below:

> It’s really important with MND, and we are still heavily involved in their life and ultimately at the worst time of their life that I feel like they need that period of closure and for us, we need that and it’s been hard for us too. (P5)

Some participants spoke of the need and value of more formal opportunities for reflection. In these settings there was recognition of the benefits of reflecting with colleagues "who really understand and are going through the same thing" (P8) within a space where it feels safe to disclose your honest experiences, as participant 9 explains:

> We have a really good psychology team that we work with, that are very aware that a lot of the patients that I work with day to day are emotive for all staff members, so we do debriefs you know. (P9)

The accessibility of this support was emphasised as important by participants, as they recognised the need for more space to reflect when “something is going on in your own life” (P9). Interestingly, participant 3 spoke of the importance of how such support is framed, as she shared a previous experience of being deterred from seeking support because of not “wanting to be seen in a certain light”.

All participants spoke of the value of “informal corridor conversations” (P4) with peers and the effective use of gallows humour. However, due to the increased physical proximity from colleagues and reliance on remote working because of the COVID-19 pandemic, some felt the organisation involved can "make it not feel as real, maybe, for some people" (P6). Thus, this highlighted the need for self-driven opportunities for reflection and consolidation, as described by participant 5; “it’s that consolidating period where you take your professional uniform on and off again and it’s that time to wind down and refocus and really reflective… to empower me to support them”.

Discussion

This IPA study explored HCP experiences of confronting and managing patient death personally and professionally in MND, with four group experiential themes identified. All 10 participants spoke of patient death as an integral aspect of their professional role and the specific nuances of MND. Notably, there was an interaction between patient death and participants' reflections on their relationship to death, dying and living. As such, participants recognised the importance of caring for themselves to continue to fulfil their roles.

Overall, participants spoke of accepting death as part of life and notably as a given in MND. In the literature, such an approach has been coined 'neutral acceptance', whereby individuals view death as a reality, neither overly welcoming nor fearing it (Wong et al., 1994), which is considered a positive attitude to dying with beneficial impacts upon delivery of care (Rooda et al., 1999; Zimmerman, 2012). For example, in the present study, one benefit was maintaining an awareness of their privileged position of power in facilitating conversations about dying. Interestingly, while participants spoke of initially accepting death as a reality of life, this was personified for many as part of a natural ageing process (Sáez Álvarez &

Medrano Abalos, 2020). A possible explanation for this relates to TMT (Greenberg et al., 1986) and individuals’ attempt to push death reminders outside of awareness by employing a distal defence through the construction of a 'death transcending reality' whereby it is viewed as only occurring at old age (Pyszczynski et al., 1999). However, participants spoke of how confronting the non-linearity of death and fragility of life in MND required a revision of such frameworks and, ultimately, adaptation to defences employed to maintain their protective cultural worldview (Greenberg et al., 1986).

While multifaceted, two commonly used defences in the current study were finding meaning and purpose and establishing a sense of symbolic immortality of what endures after death through the meaning of life (Greenberg et al., 1986). The former is consistent with previous research in MND, whereby HCP have shared the importance of gaining a sense of meaning and purpose from their work (Gamskjaer et al., 2022; Hunt et al., 2019), for example, by providing a good death as echoed by current participants. Thus, services need to consider how to help foster this sense of purpose (Horowitz et al., 2003), as a desire for work (Yaakobi, 2015) and professional achievements (Krakowski, 1971) are valuable buffers against DA, without which there is recognition of its negative impact (Pavelková & Bužgová, 2015). Moreover, consistent with existing literature, a sense of professional accomplishment was important for participants concerning their legacy and symbolic immortality (Krakowski, 1971). Interestingly, only one participant explicitly discussed their religiosity, which for them appeared to serve as an integral coping mechanism for death confrontation. However, presently the literature in this area remains mixed, with some scholars proposing that religiosity mediates the effect of DA (Fischer et al., 2006) while others have found no significant correlations (Bakan et al., 2019). Interestingly, a recent systematic review of 100 studies by Jong et al. (2018) highlighted an inverted-U relationship, whereby DA was lowest in those with high levels of affinity to non-religious beliefs or very religious beliefs. Unfortunately, while some other participants in the current study identified as atheists, the degree of belief was not captured, and thus, further research is needed to explore the nuance of the relationship between religion and managing death confrontation. Moreover, such research must consider the impact of culturally embedded views across different religions, as this remains an under researched area (Lester et al., 2007; Li et al., 2017; Peters et al., 2013).

In line with the dimensional construct of DA (Lehto & Stein, 2009) in the present study, participants distinguished between fear of death and dying; however, consistent with existing literature, dying was most frequently cited as the feared outcome (Carmel & Mutran, 1997; Werner & Carmel, 2001). Interestingly, reflections on both appeared to have increased with age, supporting Bodner et al. (2015), who found that fear of death correlated with participants' subjective nearness to death. Although evidence documenting the nature of the relationship between age and DA remains inconclusive (Fortner & Neimeyer, 2010), this offers a tentative explanation for why as the youngest in the sample, participant 5 was the only one not to have actively considered their relationship with death and dying. However, this may have also been influenced by factors cited to reduce DA, such as not having dependents (Ay & Öz, 2019).

Moreover, participants spoke of how similarities to patients, particularly regarding age, posed an existential threat to their mortality, likely due to activating their beliefs regarding subjective nearness to death (Bodner et al., 2015). This was arguably illustrated in participants' accounts of their caseload as young as perhaps such patients were most actively recalled because they triggered HCP mortality salience despite the mean age of onset in MND being between 58 and 63 years (Andersen et al., 2012). Consequently, it is fundamental that HCP are provided space to reflect upon their work and the interaction with their own attitudes toward mortality, facilitated by a skilled professional, such as a Clinical Psychologist (Cramond et al., 2020). This is important, because of the documented relationship between one's belief system and the delivery of care and treatment endorsements (Clare et al., 2020; Peck, 2009, Black, 2007; Werner & Carmel, 2001). Furthermore, as consistent with research in the palliative context, participants spoke of difficulties discussing death with their social networks outside of work due to differing death frameworks and understanding, thus valuing reflective opportunities with colleagues (Swetz et al., 2009; Gamskjaer et al., 2022). Notably, this could also offer space for HCP to consider the positive impact of their work in shaping their attitudes towards living, such as the value of the seizing the day, as reported by participants and echoed in previous research (Gamskjaer et al. (2021); Hunt et al., 2019). Yet, unfortunately, limited research has evaluated HCP experience of formal reflective practice related to patient death. Currently, most existing research has taken place with medical students, where reflective practice has supported students to consider the impact of patient death on academic, personal and emotional development (Chretien et al., 2008; Trivate et al., 2019) with positive feedback. Thus, while encouraging, especially considering research documenting the significance of positive early death encounters in lowering DA (Kent et al., 2012), further research is required with other professionals and those at different career stages.

Across the sample, only 60% had received formal training in talking about death with patients, and 50% on how to manage the personal impact of this, which given the length of service of participants, is low. Despite this, contrary to research with patients with MND who cite a lack of HCP willingness to discuss death (Harris, 2018), participants in this sample were willing to reflect upon both patient death and their own mortality. Consistent with previous research in MND and other palliative settings, participants spoke of communication about death as an art, requiring a balancing of hope, explicit language, and navigating patients' readiness for such discussions (Anestis et al., 2022; Bousquet et al., 2015). Positively, this aligns with the expectations of patients, who report valuing receiving information that, while truthful, contains some element of hope (Brown et al., 2011; Remm et al., 2019) which in the present study centred upon improving quality of life and providing a good death.

Irrespective of receiving training, participants spoke of developing self-care strategies aligned with previous findings, such as maintaining a healthy work-life balance, preserving emotional boundaries, utilising informal corridor conversation, holding a varied caseload and keeping outlets outside of work (Gamskjaer et al., 2022; Sapeta et al., 2022). Thus, services must consider how to integrate such elements, especially considering the changing landscape resulting from the COVID-19 pandemic with increased remote working and distance from colleagues (Musson et al., 2022). Interestingly those who had attended training did not explicitly discuss its benefits, despite albeit limited evidence highlighting the utility of education programmes on dying, reducing DA and improving confidence (Mcllwaine et al., 2007; Peters et al., 2013). Thus, it may be that the current provision of support offered is not meeting HCP needs, and as such, it is hoped the present findings may help inform the development of such training (Niemeyer, 2015).

Strengths & Limitations

By utilising a qualitative approach, this study explored a multidisciplinary perspective and demonstrated that participants' accounts were similar irrespective of professional background (Lau et al., 2018). Notably, participants were eloquently able to reflect upon patient death and own mortality. One explanation for this finding may be that the sample consists of HCP with low DA, perhaps due to high levels of clinical experience, as some scholars have documented those with more experience have lower levels of DA (Zyga et al., 2011; Lange et al., 2008). However, this finding is not universal (Chen et al., 2006). Alternatively, it may be adopting an interview approach, developed through consultation with HCP and hosted by a Trainee Clinical Psychologist with clinical skills, offered participants the opportunity to sensitively share their stories without engaging in defences (McGrath et al., 2019; Shamai, 2003).

However, this study is not without limitations, namely regarding the facets of diversity in the sample, which is entirely White British. This is concerning, as while DA in HCP is noted as a universal experience across cultures (Nia et al., 2016), research has cited variation in the severity. For example, Abdel-Khalek and Tomas-Sabado (2005) found higher levels of DA in Egyptian nursing students relative to those in Spain. Yet, there remains a limited understanding of the nuances of cross-cultural implications and why such differences exist. Therefore, further research is required, particularly in cultures where death is considered a less taboo topic, a valuable perspective not captured in the present study. Thus, current findings may not be fully transferable outside of this sample, and therefore, readers, in line with an IPA approach, are encouraged to employ theoretical transferability (Smith et al., 2008). Furthermore, this study was conducted within the context of the COVID-19 pandemic at a time of pervasive loss at many levels, and thus it is possible this impacted HCP experiences (Musson et al., 2022).

Future Directions

Considering the present findings and remaining gaps within the literature, future research would benefit from exploring the experiences of other HCP whose voices are not captured, such as domiciliary carers and clinical psychologists, particularly those from other cultures. Moreover, it would be helpful to understand the nuanced role of hope in MND. Lastly, further research to explore more in-depth and evaluate the utility of recommended clinical implications listed in Table 3 would be valued.

Table 3

Clinical Implications of Findings

Implications
• HCP should be provided with reflective spaces hosted by suitably qualified clinicians to consider the personal impact of patient death, and possible reflections on own mortality. • There must be greater consistency across services in the delivery of training related to communicating about death and managing its personal and professional impact. There would be value in co-creating this with HCP in the field to ensure maximum benefit of content. • Services must consider how to cultivate a culture where HCP can engage in coping strategies they have developed, particularly considering service level changes resulting from the COVID-19 pandemic. • Services must consider how to support the facilitation of feedback from external parties on the delivery of care to help HCP to gain a sense of meaning and purpose, given their value as buffers against death anxiety.

Conclusion

In conclusion, the experiences of HCP caring for those with MND are consistent with existing palliative care literature. However, the certainty and rapidity of death heightens many of these experiences. There is recognition that caring for those dying increases one's own awareness of their mortality and an appreciation for the importance of caring for oneself, both through intrinsically driven means and those delivered at service levels. Clinical implications and areas for future research have been discussed in reference to the broader literature, and it is hoped that this research and future projects continue to support the valuable work of HCP in MND.

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Executive Summary

This portfolio contains three studies, although independent, share the overlapping theme of being conducted with under-represented groups. Therefore, it is hoped the respective study findings will help enhance the provision of support in psychosis (service-related project), prolonged disorders of consciousness (literature review), and motor neurone disease (main project). Notably, the latter two studies are also linked by their focus on caregiving and loss within the field of neurology.

Literature Review

People with disorders of consciousness necessitate a demanding schedule of care, which is often provided either solely or in part by family caregivers. Consequently, family members must navigate unexpected and sudden changes to their daily lives and relationships as they assume caregiving responsibilities while also making sense of their loss and maintaining hope about potential recovery. Therefore, it is unsurprising that quantitative research and reviews have documented significant distress in this population, which is corroborated by participants' accounts in qualitative research. However, aside from one scoping review, which focused exclusively on quality of life, no attempt has been made to synthesise the qualitative research in the field to further conceptual understanding and offer valuable insight into areas for support.

The present meta-ethnography using Noblit and Hare’s (1988) principles aimed to address this gap by exploring family caregivers' caregiving experiences in disorders of consciousness. A literature search of five electronic databases was conducted in July 2021, identifying 302 papers, of which 11 met the inclusion criteria. Included papers underwent quality appraisal and data extraction with the coding of first and second-order constructs. Similarities and differences in concepts were compared across studies, and a process of reciprocal translation was conducted to create third-order constructs providing a synthesis and holistic model of family caregivers' experiences. A total of eight third-order constructs were identified: around the clock caregiving; redefining the relationship; disrupted relationships; modifications to life; living with uncertainty; holding hope; navigating the middle path; wider system pressures. Thus, this meta-ethnography has highlighted the unique paradox family caregivers face in navigating a loss with an 'open system' of an ongoing physical presence, yet a forever changed relationship dynamic. While at the same time experiencing disruption to other significant connections and networks, which further heightens the burden they experience. As such, family caregivers draw upon a diverse range of coping strategies, some of which are only useful in the short term. Thus, health care services can use these findings to ensure services are adapting to meet the needs of this population and are responsive to the uncertain landscape they face.

Service-Related Project

Despite published National Institute for Health and Care Excellence (2014) guidelines advocating the provision of individual Cognitive Behavioural Therapy CBTp and Family Interventions (FI) for psychosis, a significant discrepancy remains in implementation rates at a service level. Consequently, this project aimed to conduct a service evaluation audit to investigate this in a Community Mental Health Team using a care coordinator enquiry approach with the hope of findings ultimately aiding the development of a psychological intervention for psychosis pathway. The audit captured the number of those with psychosis on respective caseloads, numbers referred and receiving psychological support, reasons for non-referral and strategies that may help improve referral rates. The findings revealed alarming low referral rates, with 0% referred for FI, and only 7.3% for CBTp, with further training identified as the most helpful means of improving referral numbers. The findings from this project were presented to the team alongside recommendations to help establish the psychological support for psychosis pathway.

Main Research Project

Given the terminal and rapid nature of motor neurone disease, health care professionals working in the field frequently confront patient death. Presently, in other terminal conditions, a body of research has documented the impact of such work, including heightened anxiety, compassion fatigue, and burnout (Peters et al., 2013; Rickerson et al., 2005). Moreover, consideration has been given to the role of death anxiety, whereby exposure to the vulnerability of life reminds individuals of their mortality, leading to a state of apprehension which has been cited to negatively impact healthcare professional's well-being and delivery of care (Cochrane et al.,1990; Werner & Carmel, 2001. At the same time, some studies have highlighted the positive impacts of working with dying patients, such as generating a greater appreciation for life (Hunt et al., 2019). Yet, despite necessitating consideration of death from diagnosis and patients citing a lack of receptiveness from health care professionals to discuss death (Harris et al., 2018), the experience of patient death for health care professionals in motor neurone disease has not been explicitly examined. This study looked to address this gap, using semi-structured interviews with 10 multi-disciplinary healthcare professionals to address the question; w*hat are their experiences of confronting and managing the professional and personal impact of patient death in motor neurone disease?* Interviews were transcribed verbatim and analysed using an interpretative phenomenological approach. Four group experiential themes were identified with 11 sub-themes; death is part of the job; nuanced challenges in MND; places death on your personal agenda; caring for oneself to care for others.

Consistent with literature in other terminal conditions, the findings revealed an interaction between confronting patient death and reflection on their own mortality, which had increased with age, and were most prevalent when there were assumed similarities with a patient. However, this did not impact participants' willingness to discuss death and dying topics; instead, recognising the power and privilege they hold in facilitating conversations. Participants acknowledged the importance of finding meaning and value in their work, preserving boundaries, maintaining a healthy work-life balance, and opportunities for reflection to help manage the emotional impact of patient death. Moreover, participants reported that their work and an appreciation for life's fragility also positively shaped their attitudes toward living. Thus, the findings provide recommendations on how services can better support health care professionals working in MND. Namely, by facilitating reflective spaces to consider the effects of patient death and possible reflections on own mortality and cultivating helpful coping strategies, such as support with achieving a healthy work-life balance.

Acknowledgements

First and foremost, I would like to thank all the clients, families, services, teams, and participants I have had the pleasure of working with during doctoral training. I am humbled and grateful that you have shared your experiences with me and enabled me to be part of your journey, as you are mine, and thank you for your influence in shaping the clinician I am today.

Secondly, I would like to extend my thanks to all my project supervisors, Dr Anna Strudwick, Dr Leon Dysch, Dr Pamela Jacobsen, Jonathan Paulett, Dr Jo Daniels and Dr Ben Frayne, for the continued support, kindness, and encouragement you have shown me during training. I am struck that, despite an unprecedented time, with each facing the challenge of navigating a global pandemic and new ways of working, you have continued to hold my research in mind and share with me your profound knowledge and passion.

Thirdly, I would like to thank the wider Bath DClinpsy course. Firstly, to the academic and admin team for the fantastic teaching opportunities and support offered, and secondly, to the whole 2019 cohort. My fellow trainees have been a valuable source of support, laughter, and friendship, and I can attest that it is true what they say; nobody quite understands the demands, tests, and delights of training, as your peers. I cannot wait to see you all flourish professionally and personally in the years to come.

Finally, an enormous thank you to all my family and friends for helping me to keep things in perspective across these past three years. Your unfailing support, patience, and companionship, each displayed in your unique ways, has allowed me to choose and develop a career pathway I am truly passionate about, and as a person, I hope you are all proud of. A special mention to my partner, Dominic, for your endless love and support. Knowing you have got my back, both metaphorically and physically, has allowed me to embrace the joys and challenges of life and training, for which I will be forever thankful.

Appendices

Appendix A
LR: Authors reflexive statements

N.S

I am a white, British, cis-woman in my mid-twenties. I am currently in my final year of clinical doctoral training. I have a clinical interest in topics related to grief and loss and have experience working with family caregivers in other physical and mental health conditions, including volunteering in a brain injury setting. During training, I completed a placement in a neurology service with both rehabilitative and progressive conditions. However, I do not have any direct clinical experience supporting people with disorders of consciousness or their families, nor do I have personal experience with disorders of consciousness.

A.S

I am a white, British 42 year old cis-woman who has worked as a clinical psychologist in the NHS for 13 years. I am heterosexual, married and would describe myself as middle class. My main area of clinical work has been with older people and their families experiencing a range of mental health problems, including dementia. I am currently training in systemic psychotherapy and have a strong interest in compassion focused therapy. I have previously worked as a lecturer at a British University and have some experience in qualitative research. I have never worked clinically with people with disorders of consciousness or their families and I have no personal experience of disorders of consciousness.

J. P

I am a white British, 47 year old married heterosexual cis-man. I am a neurological Occupational Therapist with 20 years of experience of working in this speciality. My current main area of clinical work is in community based condition management of neuro degenerative conditions and rehabilitation and management of other complex neurological presentations.

I have previously worked in a dedicated inpatient neurological rehabilitation facility, where I developed knowledge and skills in the assessment of prolonged disorders of consciousness (PDOC). I hold an Advanced Accreditation in the use of the Sensory Modality Assessment & Rehabilitation Technique (SMART).

I have worked as a Brain Injury Case Manager instructed by third party insurers, personal injury solicitors and Court Appointed Deputies to assess, plan, commission and monitor rehabilitation, medical and therapeutic interventions for survivors of catastrophic neurological injury and polytrauma, including PDOC. Both my inpatient and case management roles involved significant family liaison, education and general support.

I am a guest lecturer in a British University, I provide an overview of PDOC for clinical psychology doctorate trainees. I have no research experience.

Appendix B

LR: Search terms and number of results for respective databases (conducted 15/07/2021)

Database	Search terms	Number of results
PubMed	((("Disorders of consciousness" OR "Low Awareness State*" OR "Post coma unawareness" OR "Unawareness state" OR "aphallic" OR "Vegetative State*" OR "Minimally conscious state*") AND (Qualitative OR Experience OR Interview OR Grounded theory OR Phenomenology OR Narrative OR Thematic OR IPA)) AND (Caregiv* OR Coping OR Needs)) AND (Famil* OR Spouse* OR Relative OR Caregiver* OR Parent OR Informal Caregiver)	65
Web of Science	(((ALL=("Disorder* of consciousness" OR "Low Awareness State*" OR "Post coma unawareness" OR "Unawareness state" OR "aphallic" OR "Vegetative State*" OR "Minimally conscious state*")) AND ALL=(Qualitative OR Experience OR Interview OR Grounded theory OR Phenomenology OR Narrative OR Thematic OR IPA)) AND ALL=(Caregiv* OR Coping OR Needs)) AND ALL=(Famil* OR Spouse* OR Relative OR Caregiver* OR Parent OR "Informal Caregiver*")	97
MEDLINE	(((TS=("Disorder* of consciousness" OR "Low Awareness State*" OR "Post coma unawareness" OR "Unawareness state" OR "aphallia" OR "Vegetative State*" OR "Minimally conscious state*")) AND TS=(Qualitative OR Experience OR Interview OR Grounded theory OR Phenomenology OR Narrative OR Thematic OR IPA)) AND TS=(Caregiv* OR Coping OR Needs)) AND TS=(Famil* OR Spouse* OR Relative OR Caregiver* OR Parent OR "Informal Caregiver*")	88
Embase	'disorder* of consciousness' OR 'minimally conscious state'/exp OR 'minimally conscious state' OR 'unawareness state' OR 'aphallic' OR 'persistent vegetative state'/exp OR 'persistent	15

	vegetative state') AND (('qualitative'/exp OR qualitative OR 'grounded theory'/exp OR 'grounded theory' OR 'experience'/exp OR experience OR 'interview'/exp OR interview) AND ('phenomenology'/exp OR phenomenology) OR 'narrative'/exp OR narrative OR thematic OR ipa) AND (caregiv* OR 'coping'/exp OR coping OR 'needs'/exp OR needs) AND (famil* OR spouse* OR 'relative'/exp OR relative OR caregiver* OR 'parent'/exp OR parent OR 'informal caregiver'/exp OR 'informal caregiver')	
PsychINFO	Any Field: "Disorder* of consciousness" *OR* Any Field: "Low Awareness State*" *OR* Any Field: "Post coma unawareness" *OR* Any Field: "Unawareness state" *OR* Any Field: "Apallic" *OR* Any Field: "Vegetative State*" *OR* Any Field: "Minimally conscious state*" *AND* Any Field: Qualitative *OR* Any Field: Experience *OR* Any Field: Interview *OR* Any Field: Grounded theory *OR* Any Field: Phenomenology *OR* Any Field: Narrative *OR* Any Field: Thematic *OR* Any Field: IPA *AND* Any Field: Caregiv* *OR* Any Field: Coping *OR* Any Field: Needs *AND* Any Field: Famil* *OR* Any Field: Spouse* *OR* Any Field: Relative *OR* Any Field: Caregiver* *OR* Any Field: Parent *OR* Any Field: "Informal Caregiver*"	37

Appendix C

LR: CASP Scores

Table 1

CASP scores by for each study by item

	Study Number										
	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**
Item											
1.Clear statement of aims?	3	3	2	3	3	3	3	3	3	3	3
2.Is the qualitative method appropriate?	3	3	3	3	3	3	3	3	3	3	3
3.Research design appropriate for aims?	2	2	2	3	3	3	2	2	3	2	3
4.Appropriate recruitment strategy?	2	1	3	2	2	3	2	2	2	1	3
5.Data collected appropriately?	2	2	3	3	3	3	2	2	3	2	3
6. Relationship between researcher and participants considered?	2	1	1	1	1	1	2	1	1	1	1
7.Ethical issues considered?	2	2	3	1	2	2	2	3	2	2	3
8.Data analysis rigorous?	3	2	2	3	2	3	3	2	3	2	3
9.Clear statement of findings?	3	2	2	3	3	3	3	3	3	3	3
10.How valuable is the research?	3	3	3	3	3	3	3	3	3	3	3
11. Total	25	21	24	25	25	27	25	24	26	22	28

Appendix D

LR: Synthesis Examples

Table 2

Data extraction table format into translations table

Newly formed Conceptual labels (groups of similar concepts)	**First Order Construct**	**Second Order Construct**
Caregiving as a time-consuming role	• “I reckon if I actually added up my hours and, you know, charged out at 40 bucks an hour . . . well, actually, probably more. I reckon I’m probably doing a C$60,000 a year job.” (Gonzalez-Lara et al., 2021) • I’m taking care of him 24 hours a day, day and night’ S3 (Giovannetti, 2015) • 'Caring for such patients is very difficult, I have to look after them from morning to night and I even had no time to rest'	Caregiving as central role around which others revolve (Gonzalez-Lara et al., 2021) Difficulty in care (Goohski et al., 2019) Challenging care (Imani-Goghary & Ghaljeh, 2021) Erosive Care (Goudzari et al., 2018)

Appendix E

LR: Narrative Translation of Reciprocal Synthesis

Table 3

Narrative translation of conceptual label created into third order construct of caregiving as a full-time job

Synthesis- Caregiving as a full-time job
In paper 1 (Gonzalez-Lara et al., 2021), FC identified strongly with the role of caregiver, which was multi-faceted, encapsulating the provision of physical/ practical care, advocacy and decision making. Often this role would be assumed by a primary-care giver. For some, this was a personal decision; for others, this was decided out of a sense of obligation/duty, with some believing others in the wider family/support network would not provide such support. This caregiving role was often an all-consuming 24/7 job with a high emotional burden, making it hard for FG to maintain other aspects of daily life. In paper 2 (Imani- Goghary & Ghaljeh, 2021), FG acknowledged the around-the-clock and pervasive nature of caregiving responsibilities to a totally dependent family member while balancing other commitments, often with limited support from wider networks. Moreover, acknowledgement was given to the idea that even if not providing direct care, FG's must be constantly vigilant of their loved one's condition, and thus caregiving could easily become all-consuming. In paper 3 (Gooshki et al., 2019), FG acknowledged the full-time nature of FM's care and the unique needs of those in a VS as demanding and isolating. In paper 4 (Goudzari et al., 2018) FG reported an obligation to provide care, again further reiterating the dependent nature of their family member in the VS requiring a spectrum of caring responsibilities, including some specialised care such as feeding through a tube for which they often had to seek additional education. As in paper 1, there would often be one primary identified care provider supported by the wider network, and the emotional demands and sacrifices were noted. In paper 5 (Lovstad et al., 2018), FG acknowledged an aspect of their caregiving role, involves helping their loved one maintain a sense of social connectedness, whether by facilitating a space for friends to visit or bringing the individual home for celebrations. In paper 6 (Soeterik et al., 2018) FG acknowledged that the role of caregiver went far beyond practical aspects, acknowledging symbolic relating and a strong sense that they had to become the person's voice an advocate for them, which was echoed in paper 1. In paper 7 (Giovenetti et al., 2015) many FG identified strongly with the role of caregiver, accompanied by the belief they were best placed to do so. FG reported a feeling of being trapped by the caregiving role, acknowledging that even if not providing physical care, they are consumed by thoughts about their relative 24 hours a day and as a result, don't have an opportunity for themselves. In paper 8 (Goudzari et al., 2015) FG likened caregiving of their loved ones to that of a newborn child or plant due to the dependent, all-consuming nature involving high levels of need. Consequently, this prevented FG from attending to their needs and thus feel at a standstill in other aspects of their lives, trapped by domestic imprisonment. In paper 9 (Cipolletta et al., 2014), FG talked of wanting to supervise the work of medical staff, feeling as though they were abandoning family members when care was provided outside of the family, and therefore if not

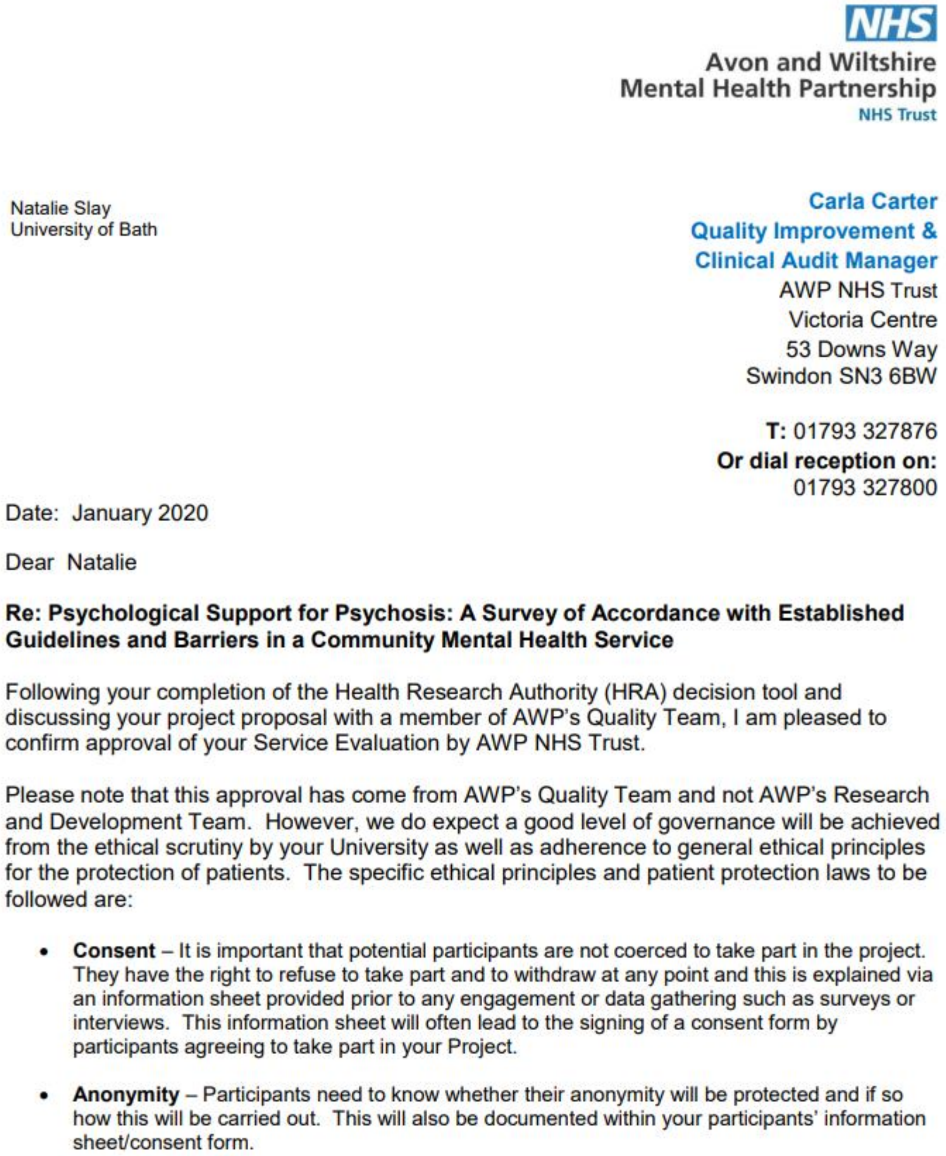
providing care themselves, the need for constant vigilance remained. In paper 10 (Covelli et al., 2014) participants spoke of identifying with the role of a caregiver and how this had become a dominant role yet were often struck by the strength they had discovered to fulfil this. In paper 11 (Hamama-Raz, 2013), FG reported a sense of taking responsibility for the care of their loved one, which was often viewed as a double-edged sword; on the one hand, it provided a meaningful experience which provided them with a sense of strength, but on the other hand a sense of burden.

Appendix F

LR: Author Guidelines

- QHR accepts qualitative methods and qualitatively-driven mixed-methods, qualitative meta- analyses, and articles addressing all qualitative methods.
- Abstracts should be 250 words or less, and Original Research Articles should be 6,000 words or less excluding the abstract and references
- Abstract: Maximum of 250 words. This should be the first page of the main manuscript, and it should be on its own page.
- Length: Original Research Articles should be 6,000 words or less excluding the abstract and references.
- Methods: QHR readership is sophisticated; excessive details not required.
- Ethics: Include a statement of IRB approval and participant consent. Present demographics as a group, not listed as individuals. Do not link quotations to particular individuals unless essential (as in case studies) as this threatens anonymity.
- Results: Rich and descriptive; theoretical; linked to practice if possible.
- Discussion: Link your findings with research and theory in literature, including other geographical areas and quantitative research.
- References: APA format. Use pertinent references only. References should be on a separate page.

Appendix G
SRP: Trust Approval



NHS
Avon and Wiltshire
Mental Health Partnership
NHS Trust

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Quality Improvement &
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Victoria Centre
53 Downs Way
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T: 01793 327876
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01793 327800

Date: January 2020

Dear Natalie

Re: Psychological Support for Psychosis: A Survey of Accordance with Established Guidelines and Barriers in a Community Mental Health Service

Following your completion of the Health Research Authority (HRA) decision tool and discussing your project proposal with a member of AWP's Quality Team, I am pleased to confirm approval of your Service Evaluation by AWP NHS Trust.

Please note that this approval has come from AWP's Quality Team and not AWP's Research and Development Team. However, we do expect a good level of governance will be achieved from the ethical scrutiny by your University as well as adherence to general ethical principles for the protection of patients. The specific ethical principles and patient protection laws to be followed are:

- **Consent** – It is important that potential participants are not coerced to take part in the project. They have the right to refuse to take part and to withdraw at any point and this is explained via an information sheet provided prior to any engagement or data gathering such as surveys or interviews. This information sheet will often lead to the signing of a consent form by participants agreeing to take part in your Project.

- **Anonymity** – Participants need to know whether their anonymity will be protected and if so how this will be carried out. This will also be documented within your participants' information sheet/consent form.

Appendix H

SRP: Audit Tool Items

1. What is your profession
2. Number of clients on caseload
3. Number of clients with psychosis or schizophrenia on care coordinators caseload per ICD-10 codes F20-F209
4. Since care coordinating, number of clients referred to recommended NICE guidelines psychological interventions: a) CBT-p b) Family therapy c) Other psychological intervention)
5. Number of clients who have received the respective therapy within CMHT based on minimum of 2 session attendance rate
6. Number of clients undertaking CBTp who dropped out of treatment
7. If the psychology intervention has not been carried out, please list reasons for this [restricted options given, with option of other]
8. What would help you feel more confident in referring clients with psychosis for psychological support?

Appendix I

SRP: Author Guidelines

Article Types
Original Articles; Research and Evaluation Articles

- Should be written with the following elements in the following order: Title page (to be uploaded separately and must not appear on the Main Document); Abstract (Background, Aims, Methods, Results, Conclusions); Keywords; Main text introduction; Materials and methods; Results; Discussion; Acknowledgments; Declaration of interest statement; References (in the correct format); Appendices (where appropriate - to be uploaded separately); Table(s) and caption(s) (on individual pages) - to be uploaded separately; Figures and figure captions (as a list) - to be uploaded separately.

- Should be no more than 4000 (excluding abstracts, tables and references) words

- Should contain an unstructured abstract of 200 words.

- Should contain between 3 and 7 **keywords**. Read making your article more discoverable, including information on choosing a title and search engine optimization.

- When submitting an Original Article or a Research and Evaluation Article, please include a sentence in the Methods Section to confirm that ethical approval has been granted (you must provide the name of the committee and the reference number). If ethical approval has not been necessary, please say why.

- Please include a sentence to confirm that participants have given consent for their data to be used in the research. If consent has not been necessary, please say why.

- Manuscripts are limited to a maximum of 4 tables and 2 figures to be uploaded separately – please advise where in your manuscript these are to be located.

- Please ensure that author details are not on the Main Document.

- Please ensure that author details are not included in the file name.

- Participants: language must be in the style of the APA. Our policy therefore is to refer to study participants as opposed to patients or subjects.

- Please note we do not accept pdf’s. Please save your documents in the .doc format.

Appendix J

MRP: Participant Information, Consent & Demographic sheet

Participant Information Sheet for Individual Interviews

Study Title

Health Care Professionals' Experiences of Managing the Professional and Personal Impact of Patient Death in Motor Neurone Disease (MND).

Who am I?

My name is Natalie Slay, and I am a Trainee Clinical Psychologist, based at the University of Bath.

What is this study about?

I am conducting this study as my main doctoral research project, to help better understand how different health care professionals manage both the personal and professional impact of patient death, specifically within MND. I am interested in understanding the effects of encountering patient death, how healthcare professionals communicate about this, and potential impact on your outlook and views of mortality.

Who can be a participant?

Any health care professional either actively working with patients with MND or has done so within the last two years. If you have not actively worked with patients with MND for more than two years, you will not be eligible due to potential challenges in recalling information and experiences.

What will I be asked to do?

I am looking for individuals to take part in face-to-face, online Microsoft Teams, or telephone interviews. If you consent, to taking part in the interview, we would talk about the above topics. There are no right or wrong answers – I want to hear your own personal and unique ideas, thoughts, and experiences. The interview will last about 45-60 minutes and will take place at a time that best suits you. The interview will be audio-recorded, and then transcribed, removing as much identifiable information as possible, and the audio-file then deleted to protect your anonymity. Before the interview, you will also be asked to complete a death anxiety measure and demographic form to capture information such as years experience in MND and whether you have received specific training on managing patient death. This demographic information will be reported in the write up of the findings.

Do I have to take part?

Taking part in this research is entirely voluntary **(you are under no obligation to participate)**, and you are free to make your own choice about whether you want to participate. If you agree to take part, you can choose not to answer any questions, and **you are free to withdraw from the interview at any time**. You do not need to provide a reason to be able to withdraw. You can withdraw your data from the study up to TWO WEEKS from your interview date. Again, you do not need to provide a reason for your withdrawal. After two weeks have passed since your interview date, it will NOT be possible to withdraw your data.

What are the possible benefits of taking part?
There are no direct benefits of taking part in the project. However, the information that you and other participants provide will help us better to understand the impact of patient death on health care professionals working in MND and to consider areas for future staff support.

What are the possible disadvantages of taking part?
While there are no disadvantages to you taking part in the project, as the project is talking about patient death and the personal impact of this, this may be an emotive topic for you. If you are asked a question that you do not want to answer for any reason, you can choose not to answer. Opportunities for breaks will be scheduled in to the interview, however you can request to take additional breaks at any point. I also encourage you to familiarise yourself with your employers wellbeing service ahead of the interview in case you felt this support was necessary. Alternatively, contact details of my Supervisor (Dr Anna Strudwick- Clinical Psychologist) and other services are provided if you feel additional support is required.

What will happen to the information I provide?
Should you decide to take part, the interview will be recorded. These recordings will then be typed up and the files stored on a private computer drive that myself, my internal supervisor Dr Anna Strudwick will be able to access. Any potentially identifying details, including your name, will be removed. At this point, you will be assigned a participant ID which corresponds with information completed on the demographic questionnaire. The interview and demographic information will not be linked to any contact, or personally identifiable details that you provide. The information you provide will be analysed to inform my dissertation project. However, if you decide you want your data withdrawn from this analysis, **you can do so up to TWO WEEKS after your interview date.** After these two weeks, it will not be possible to remove your data from analysis. Once this project is completed, other researchers at the University of Bath may conduct related research projects which would benefit from the use of the data that you have provided. Further use of your data will only occur with your consent and the University of Bath’s approval, where data will continue to be stored in accordance with GDPR. So again, your name or other identifying information will not be disclosed in any presentation or publication of the research.

What will happen to the results of this research?
The answers to your questions will form the results and discussion of my doctoral main research project. As a requirement for doctoral training, these will be submitted

to the University of Bath for review. The findings of the research may also be published in research journals or used in presentations. If you would like to be sent a summary of the findings, please let me know, and we can arrange for this.

University of Bath privacy notice
The University of Bath privacy notice can be found here:
https://www.bath.ac.uk/corporate-information/university-of-bath-privacy-notice-for-research-participants/

Who has reviewed this study?
This study has been reviewed by BSW Research Hub on behalf of Virgin Care BaNES (REF: 2020_011) and the University of Bath Psychology Ethics Committee (REF:20-212).

What do I do if I would like to take part or have any more questions?
You can contact me, Natalie Slay (Email: ns2082@bath.ac.uk), to arrange a suitable time or to discuss any questions you might have.

Who do I speak to if I have any concerns about the study?
In the first instance please talk to the researcher (Natalie Slay- n2082@bath.ac.uk), if you still have concerns you can contact the supervisors (Dr Anna Strudwick- a.strudwick@bath.ac.uk) or (Dr Leon Dysch- Leon.Dysch@virgincare.co.uk) or the University ethics committee (psychology-ethics@bath.ac.uk/ Department of Psychology, University of Bath, Claverton Down, Bath, BA2 7AY)

Many thanks for taking the time to read this. I would be delighted if you would be willing to take part.

UNIVERSITY OF BATH

Consent Form

Health Care Professionals' Experiences of Managing the Professional and Personal Impact of Patient Death in Motor Neurone Disease

Name of Researcher: Natalie Slay
Contact details of Researcher: ns2082@bath.ac.uk
Name of Supervisors: Dr Anna Strudwick & Dr Leon Dysch
Contact details of Supervisor: a.strudwick@bath.ac.uk

Please initial the box if you agree with the statement

1. I confirm that I have read the information sheet dated 16/07/2020 (version 1) for the above study. I have been provided with information explaining what participation in this project involves. ☐
2. I have had an opportunity to ask questions and discuss this project. ☐
3. I have received satisfactory answers to all questions I have asked. ☐
4. I have received enough information about the project to make a decision about my participation. ☐
5. I understand that I am free to withdraw at any time from the conducted interview without having to give a reason for withdrawing. ☐
6. I understand that I am free to withdraw my data within two weeks of my participation. ☐
7. I understand the nature and purpose of the procedures involved in this project. These have been communicated to me on the information sheet accompanying this form. ☐
8. I understand the interview will be audio-recorded for purpose of transcription. ☐
9. I understand the data I provide will be treated as confidential, and that on completion of the project my name will not be disclosed in any presentation or publication of the research.
10. I understand and acknowledge that the investigation is designed to promote scientific knowledge and that the University of Bath will use the data I provide for no purpose other than research.

11. I understand that the information collected about me will be used to support other research in the future and may be shared anonymously with other researchers. ☐

12. I agree to the University of Bath keeping and processing the data that I provide during the course of this study and my consent is conditional upon the University complying with its duties and obligations under the Data Protection Act. ☐

13. I hereby fully and freely consent to my participation in this project. ☐

☐

☐

____________________	____________________	____________________
Name of Participant	Date	Signature
____________________	____________________	____________________
Name of Person taking consent	Date	Signature

Demographic Form

Thank you very much for agreeing to participate in this research. Please answer the following questions, by either circling the relevant answer or filling in the gaps where applicable.

1) What is your age?

a) < 20
b) 21-30
c) 31-40
d) 41-50
e) 51-60
f) 60+

2) What is your gender?

a) Female
b) Male
c) Other (please specify)

3) What is your ethnic group?

4) What is your religion/spiritual belief?

5) What is your profession?

6) How long have you worked in this profession?

a) < 1 year
b) 1-5 years
c) 6-10 years
d) 11- 20 years
e) 20-30 years
f) 30+ years

7) How long have you been working with patients with MND?

a) < 1 year
b) 1-5 years
c) 6-10 years
d) 11- 20 years
e) 20-30 years
f) 30+ years

8) What kind of service do you work in presently, or when you worked with patients with MND? (If you wish to provide further detail on the type of service, please feel free to do so)

a) MND Specialist Service
b) Community Neurological Service
c) Inpatient Neurological Service
d) Palliative Care Service
e) Other (please specify)

10) Where in the care pathway do you typically see people with MND?

a) Before diagnosis
b) Shortly after diagnosis
c) End of life stages/ palliative care
d) All of the above
e) Other (please specify)

11) How much of your typical working week, is spent working with patients with MND or their families/ carers?

a) Half a day
b) A day
c) Two days
d) Three days
e) Four days
f) Full time

12) Have you received any training on how to facilitate discussions on death and dying in MND with clients?

a) Yes
b) No

13) Have you received any training on how to personally manage patient death?

a) Yes
b) No

14) If you have answered yes to question 12 or 13, please can you provide a brief outline of what this covered (Examples may include how to communicate about patient death, or how to manage the personal impact of this.)

Appendix K

MRP: Ethical Approval Confirmation

Dear Natalie

Full title of study: Health Care Professionals' Experiences of Managing the Professional and Personal Impact of Patient Death in Motor Neurone Disease
PREC reference number: 20-212

On behalf of the Committee, I am pleased to confirm that you have received a favourable ethical opinion for the above proposal from the Psychology Research Ethics Committee.

Your application has received a favourable ethical opinion. However please be aware that a researcher (or supervisor in the case of UG or Masters students) is responsible for ensuring full GDPR compliance. Please seek further advice from dataprotection-queries@lists.bath.ac.uk if you have any concerns.
If you intend to display recruitment posters/materials, please ensure you obtain the appropriate permission to do so from those who manage the location(s) you choose.

Please inform PREC about any substantial amendments made to the study if they have ethical implications.

Please make sure you quote your unique PREC code, 20-212, in any future correspondence.

Rebecca Wise
On behalf of Psychology Research Ethics Committee

Appendix L

MRP: Interview schedule

Experience in MND

- How long have you been working in MND?
- How did you get into working in MND?
  - -experience prior this
- What sort of service do you work in?
  - - community/ palliative/ inpatient etc

- where in the care pathway do you typically see people with MND
  - -level of involvement
  - -length of time may see person for
- From your experience, what do you consider some of the more challenging aspects of working with people with MND?
  - -rapid decline/ breaking bad news/ supporting loved ones
- How do you manage these?
  - -support from team/ balance/ talking about it/ practical coping
- What parts of the work do you most enjoy?
- In your experience, do you feel differently about working with people with MND compared to people with other conditions?
  - -Neurodegenerative and other conditions
  - -Why?

Working with death & bereavement

- In your work, do you, and if so, how do you broach the topic of mortality and the terminal nature of the condition when working with people with MND and their families?
  - Proactive vs responsive
  - What experiences do you draw upon?
  - Barriers?
- How comfortable do you feel discussing the topic of mortality with individuals and their families?
  - Are there are situations, and specific things that make it harder or easier
  - Reaction of the patient
  - Practical vs emotional topics
  - Support system
- Do you find the experience of talking about mortality and death changes over time when working with clients, and their families?
  - -Diagnoses vs EoL care vs after bereavement
  - - Building up the therapeutic relationship
  - - Experience

- How have you found the experience of your team in discussing the topic of death?
  - -Impact of this
  - -Support

- In what ways does the terminal nature of MND affect the approach you take in your work?
  - Need to consider diagnoses from the outset
  - Impact on the relationship
  - Hope

- In what ways has working with MND affected the approach you take in your personal life?
  - -Positive and negative
  - -Appreciation
  - -Fragility

Personal impact of the loss

- Are there particular people you have worked with, that have impacted on you? Why do you think these people have? And in what ways have they changed the way you work and live?
  - -Sub types of MND
- What emotions do you experience who you hear that someone with MND has died?
  - -What factors influence this e.g. age, persons wishes
  - -Coping with these emotions
- How do you think experiencing the death of patients has impacted you?

-positive and negative
  - -views of death
- How do you cope after the death of a patient?

-can you describe any specific things you do?
both practically and emotionally?
-Support from a team

- Has how you manage and cope with the death of a patient changed over time working with patients with MND?

Views on own mortality

- When encountering patient death does this impact on your thinking about your ageing or mortality?

-Positively/negatively
-How have you noticed this?
-Particular cases
-What thoughts do you have?
-How do you manage these thoughts?

- Has the impact of this changed over time?
- Have you ever found your own personal experiences and views about death and dying to affect your work?
  - -E.g. a relative loss due to a terminal condition

- Do you feel supported to consider the impact of patient death personally at work?

-What things do you find helpful/ unhelpful?

-Are there other things you would find helpful?

We have now reached the end of my questions, is there anything you would like to add?

Appendix M

MRP: Debrief Form

Debriefing Information

Thank you for taking part in this research which has been investigating health care professionals' experiences of managing the professional and personal impact of patient death in Motor Neurone Disease. It is hoped, that your contribution combined with other participant responses will add to a body of literature considering how to better support staff working in this field. We hope that you have found it interesting, and your contribution is very much appreciated.

If you have found any parts of this experience to be distressing, and you wish to speak about this, we encourage you to contact a member of the research team on;

Natalie Slay (Researcher/ Trainee Clinical Psychologist): ns2082@bath.ac.uk
Dr Anna Strudwick (Supervisor/ Clinical Psychologist): a.strudwick@bath.ac.uk

Alternatively, please make contact with the relevant wellbeing service within your trust, or if you require 24-hour support, one of the organisations listed below:

- Samaritans
  A free 24- hour helpline offering emotional support - Tel: 116123

- NHS Wellbeing Support
  A free wellbeing support helpline, available from 7am-11pm seven days a week – Tel: 0300 131 7000

Thank you again for participating. If you would like to speak to us about the project, or to receive a summary of the findings please get in touch.

Natalie Slay; Email – ns2082@bath.ac.uk

You can also speak to the supervisor of the project, Dr Anna Strudwick; Email – a.strudwick@bath.ac.uk

Our address is: Department of Psychology, University of Bath, Claverton Down

Bath, BA2 7AY

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………………………

If you have any concerns related to your participation in this study please direct them to the Chair of the Department of Psychology Research Ethics Committee, email: psychology-ethics@bath.a.uk.

Appendix N

MRP: Personal experiential table

Table 3

Example of personal experiential theme table for Participant 1

Personal experiential theme and subthemes	Quote
Theme 1. Death as a topic for conversation	
Positioned as a death expert	"In NHS services, the message is "we've got to make you better, got to make you better". It is very medicalised, and recovery focused…so there's a great willingness of professionals to pass the buck to me to have conversations about death"
Tailoring communication	"I often ask them how much they really want to know? because patients and families ask the question but do, they really want to know"
Living within a death-avoiding system	"I will say to my daughters when its my funeral, I want X, Y, Z. Then they will be like, yes Mum we know what you want like they just don't want to engage in it at all"
Theme 2. The challenges of MND	
The clock is always ticking	"it's got to do with the rapid nature of the condition and things being quite time dependent"
Heightened sense of personal responsibility	"I don't like to think that people are left floundering without support… but then I do think well if I wasn't here nothing could be done, but I am here, and something can be done so why shouldn't I?"
Theme 3. Reflecting on own death	
The journey of dying	"For me, I think it is more about how you get there, because its sometimes not very pleasant and I don't want to be ill"
Seeing yourself in patients	"Well obviously people my own age, like they stick with me….I would say yeah particularly over my 11 years there have been two people, who have really

	stood out both my sort of age and had young children”
Evolving relationship with death	“I think it my perspective has changed in this role, as I’ve got older, and my nan died a few years ago who I was very close to and I think that had a huge impact on my perspective on life and grief”
Theme 4. Protective mechanisms for managing loss	
A guiding belief system	“Every now and again I think god I can’t believe there is nothing after death, and I have had this belief that there must be something after death which I think has helped me cope and manage my thought processes”
Compartmentalising work	“I've probably just learned to keep that emotional distance subconsciously to do that over the years and not that I don't feel what they're experiencing”
Finding purpose and value in work	“Knowing you are helping throughout such difficult times, and they appreciate it that means a lot”
Theme 5. Lessons on living	
Appreciating life’s fragility	“It just makes me appreciate my life and think I’ve got to make most of it because you never know what's around the corner”
Giving life perspective	“And I think like if something breaks, or it gets broken then I’m like well it doesn’t really matter. In the grand scheme of things, it’s not important”

Appendix O

MRP: Journal Submission Guidelines

Manuscript Submission Guidelines:

Manuscript must be word processed using Word or Open Office Writer, double-spaced, with wide margins. Paginate consecutively, starting with the title page.

Title Pages should be uploaded as a separate file and include the follow as is applicable:

- Full article title
- Acknowledgements/credits
- Each author's complete name and institutional affiliation(s)
- Grant numbers and/or funding information
- Corresponding author (name, address, phone/fax, e-mail)
- Up to five keywords as it should appear if it were to be published.

Abstracts of 100 to 150 words are required to introduce each article.

Most articles are between 5000-7500 words and while we accept long pieces that mandates additional evaluation because of space limitations.

Manuscripts should be saved in a Word .doc or .docx file type. The organization of the paper should be indicated by appropriate headings and subheadings.