"A period of limbo": The experience of being a male family member of a person in a prolonged disorder of consciousness (PDoC); an Interpretative Phenomenological Analysis

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Declaration and signature of candidate

I confirm that the thesis submitted is the outcome of work that I have undertaken during my programme of study, and except where explicitly stated, it is all my own work.

I confirm that the decision to submit this thesis is my own.

I confirm that except where explicitly stated, the work has not been submitted for another academic award.

I confirm that the work has been conducted ethically and that I have maintained the anonymity of research participants at all times within the thesis.

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Thesis Abstract

This thesis explores the multifaceted challenges faced by families dealing with acquired brain injury (ABI) and prolonged disorders of consciousness (PDoC) in the United Kingdom (UK). Comprising of three key papers, this investigation aims to contribute to a comprehensive understanding of the impact on families and the ways in which they made sense of and cope with this situation. The literature review and the empirical paper have been prepared for submission to the journal, Neuropsychological Rehabilitation. Author Guidelines are listed in Appendix B.1.

Paper one, a literature review, examines experiences of ambiguous loss in UK families affected by ABI, as despite the significant implications of ABI for individuals and their families, there is limited literature on this topic, and professionals may lack a nuanced understanding of these ABI-related challenges. Through a comprehensive review, twelve high and moderate quality studies were analysed, revealing two central themes: Characteristics of ambiguous loss and coping with ambiguous loss. Synthesising existing literature, theories, and guidance this paper offers valuable insights into the unique nature of ambiguous loss in the UK context, aiming to enhance understanding and support for affected families.

Paper two presents an empirical study on the experiences of male family members of loved ones with PDoC in the UK. Recognising the limited literature on this complex and challenging experience, semi-structured interviews were conducted with six adult male family members. Interpretative Phenomenological Analysis (IPA) revealed three key themes: 1) ‘Facing the Unknown: The Emotional Journey’; 2) ‘Finding Meaning and Navigating Forward’; and 3) ‘The Landscape of Care’. These findings highlight the emotional challenges faced by male family members and their efforts to find meaning and navigate care, underscoring the need for a family-oriented approach that offers understanding, compassion, holistic support, and collaboration in care.

Paper three is an executive summary that consolidates the background, rationale, method, key findings, and recommendations of the empirical study. This executive summary aimed to inform and benefit study participants, family members, and professionals working with PDoC, with external feedback on its content and design being considered to improve accessibility.

Paper 1: Literature Review

The experience of ambiguous loss in families of people with an acquired brain injury within the UK: A systematic literature review

This systematic literature review has broadly been prepared in accordance with the requirements of the journal *Neuropsychological Rehabilitation*. Author Guidelines are listed in Appendix B.1.

Word Count: 8000

Abstract

Background: Acquired brain injury (ABI) has significant implications for individuals and their families, yet there is limited literature on ambiguous loss in families affected by ABI in the United Kingdom (UK), with some suggesting professionals lack understanding of ABI (Norman et al., 2020; Kreutzer et al., 2016).

Objective: This review synthesised existing literature to explore the experience of ambiguous loss in UK families of individuals with ABI, assessing its consistency with existing literature, theory, and guidance.

Method: A comprehensive search identified studies on family experiences of ambiguous loss in ABI within the UK. Studies were critically appraised and thematically synthesised using the Thomas and Harden (2008) approach.

Results: Twelve high and moderate quality studies were included, revealing two themes: Characteristics of ambiguous loss and coping with ambiguous loss.

Conclusions: The findings highlight the common experience of ambiguous loss in UK families affected by ABI, offering valuable insights into the unique nature of this type of loss and ways of coping to enhance understanding and support.

Introduction

Acquired Brain Injury (ABI)

An acquired brain injury (ABI) refers to non-degenerative brain injuries caused by factors like head injuries, strokes, brain tumours, and other conditions since birth. In the UK, hospital admissions for ABI have increased by 12% since 2005-2006, with an admission occurring every 90 seconds in 2019-2020 (Headway, 2022). Estimates suggest that over 1.3 million people in the UK have ABI, with stroke and traumatic brain injury (TBI) being the most common causes (Barnes, Bennet, & Etherington, 2018). Male admissions for head injuries are 1.5 times higher than female admissions, which have risen 28% since 2005-2006 (Headway, 2022). People aged between 80-90 had the highest number of TBI cases across all severities, while severe TBI cases showed a smaller peak in the 20-30 age group. Younger patients were more often injured due to road traffic collisions and assaults, while older patients had a higher proportion of injuries from falls (Lawrence et al., 2016).

ABIs can have adverse effects on an individual's physical, communicative, cognitive, emotional and behavioural functioning, varying in severity and duration (Headway, 2019). The more severe the ABI, the more pronounced and complex the long-term effects can be. Even those who recover physically may experience persistent non-physical symptoms, impacting various cognitive functions (Dikmen et al., 2009; Schretlen & Shapiro, 2003; Lezak et al., 2012; Levin & Grossman, 1978; McAllister, 2013). Furthermore, psychological and behavioural effects may include depression, increased aggression, impulsivity and emotional instability (Arciniegas & Wortzel, 2014). These effects can hinder daily activities and the ability to live independently, including driving, work or education, social participation, fulfilling family roles and maintaining relationships (Baker et al., 2017).

Impact of ABI on the family

An ABI is a life-changing event that creates uncertain and challenging futures for individuals and their families, even with rehabilitation, support and community help (Masel & DeWitt, 2010; Ponsford & Schonberger, 2010). In the UK, after being discharged from an Acute Rehabilitation Unit, the majority of ABI patients return to live with their parents or partners who often take on caregiver roles themselves,

which can cause significant changes and stress for both the family unit and the individual members (Baker et al., 2017; Gagnon et al., 2016).

ABIs have a well-documented impact on families, including increased caregiver burden, marital and relational dysfunction, unmet family needs, change in family roles and responsibilities, psychological distress and social isolation (Blais & Boisvert, 2007; Doser & Norup, 2014; Ergh et al., 2003; Kelley et al., 2014; Marsh et al., 1998). Family members often experience higher distress levels than the individual with ABI and are at a higher risk of emotional and social difficulties (Brooks, 1991; Kreutzer et al., 2009; Mauss-Clum & Ryan, 1981).

The life-changing experience of ABI can involve a sense of grief for family members (Jeffreys, 2011). Traditionally, grief refers to the natural process of mourning a loss after a bereavement, and can include yearning, sadness, anger, guilt, regret, anxiety, loneliness, fatigue, shock, emotional numbness and physical symptoms. Grief is an individualised process that can change overtime, and often be intertwined with multiple losses (Saban & Hogan, 2012; Giovannetti et al., 2015; Townshend & Norman, 2018). It can also extend beyond the loss related to death, encompassing the loss of opportunities, dreams, health and identity (Abi-Hashem, 1999; Bowlby, 1998; Jeffreys, 2011). The grieving process allows individuals to come to terms with their loss and adapt to a new life after ABI (Cipolletta et al., 2014). However, the experience of loss for families of ABI is magnified, due to the often sudden and unexpected life-changing event and the uncertainty and lack of closure involved (Giovannetti et al., 2015).

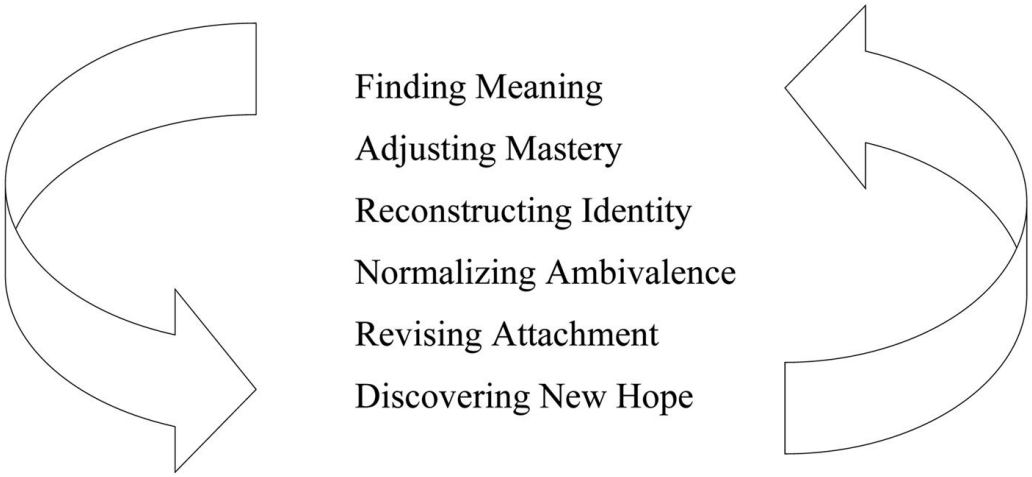
Ambiguous Loss

Ambiguous loss, coined by Boss (1999), refers to a type of loss that causes prolonged and complex grief due to an unclear or not recognised absence or change. This disrupts the meaning of loss, hindering resolution and closure, leaving family members in a state of frozen coping and grieving to construct their own truth about the absent person's status, living with the paradox of absence and presence. The ambiguity can distress families, as the need for finality remains unfulfilled, and the absence of grieving rituals further hampers support, causing relationships to dissipate (Boss, 2006).

Ambiguous loss can manifest either as the physical absence but psychological presence of a loved one (type 1), such as with a missing child, or the psychological absence but physical presence of a loved one (type 2), such as a parent with dementia. Ambiguous loss after an ABI is associated with type 2, referred to as a "Good-bye without leaving", where the survivor remains physically present, but is changed mentally (Boss & Yeats, 2014, p. 64). Boss (2006) defines identity as knowing oneself and one's role within the family. ABI causes identity confusion for both survivors and family members, as the lasting consequences of injury alter abilities and family roles. Boss and Yeats (2014) suggests that healing can occur by helping family members build resilience to live with ambiguous loss; to live well despite the 'not knowing'. Boss (2006) acknowledges the challenges of this for mastery dominated cultures and suggests six recursive, non-linear and flexible guidelines that can facilitate resilience building, as displayed in Figure 1 below.

Figure 1

Six Guidelines for Resilience with Ambiguous loss



Importance for Clinical Practice

Family members experiencing this kind of loss may experience increased loneliness, risk of depression and stress as they navigate ongoing ambiguity and adjust to a new reality while mourning the changes in their loved one (Braine, 2011; Townshend & Norman, 2018, Calvete & López de Arroyabe, 2012).

In a previous literature review by Kreutzer et al. (2016), they highlighted the relevance of ambiguous loss theory in understanding and helping families after brain injury, suggesting incorporating ambiguous loss theory into the evaluation and treatment of families by mental health professionals serving families after TBI. Kreutzer et al. (2016) describe an empirically supported brain injury family intervention with similar goals of building resilience to those outlined by Boss (2006). However, there is a lack of knowledge and understanding of ABI among health and social care professionals in the UK, resulting in limited funding for post-discharge services and a sense of abandonment and anxiety among families (Norman et al., 2020; Barnes et al., 2018; Kehoe et al., 2015).

While family involvement in the survivor's rehabilitation has been emphasised in earlier research, there is growing recognition of the specific needs of families affected by ABI. Kreutzer et al. (2016) concluded that while ambiguous loss is a common experience after ABI, the literature around ambiguous loss in families after ABI is limited compared to other populations.

The Current Study

The focus of this literature review is to provide a comprehensive overview of the experiences of ambiguous loss for UK families affected by ABI by critically appraising the quality and findings of existing qualitative research. The aim is to better understand lived experiences of this common yet under-researched area and improve services and support for families after ABI.

The research questions addressed in this review are:

- What is known from existing literature about the experience of ambiguous loss for UK families affected by ABI?
- Is there consistency in the existing literature regarding guidance on supporting individuals experiencing ambiguous loss in this context?

Method

This review adhered to Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) 2020 statement guidelines (Page et al., 2021).

Search Strategy

A comprehensive search strategy was devised to identify research on the experience of ambiguous loss for families of individuals with ABI in the UK. Online searches were conducted between 22/01/23 and 25/01/23 using the following databases: APA PsychINFO, APA PsychArticles, PubMed, Pub Med Central, MEDLINE, CINAHL Plus with Full Text and JSTOR. An initial literature search using Google Scholar was also performed to refine the search strategy and search terms and to identify relevant grey literature. Haddaway et al. (2015) concluded that performing searches on Google Scholar for grey literature yields more results and recommends focusing on the first 200 to 300 results. The initial search is summarised in Appendix A.1.

Table 1 displays the search terms and their variations based on existing literature which were used with Boolean operators to focus the search. No date range limiters were applied in order to broaden the scope of the search.

Table 1

Key search terms and variations

Key Search Term	Variations used
Experience	Qualitative, Interview
Ambiguous Loss	Boundary ambiguity, frozen grief, prolonged grief disorder
Famil*	Caregiver, relative, partner, sibling, child, parent, spouse, grandparent
Brain Injur*	Head injur*, head trauma, ABI, TBI

Eligibility Criteria

Inclusion and exclusion criteria (see Table 2) were used to select studies for this review. Only studies that met these criteria were included, while those that did not were excluded. To minimise publication bias, the search included both peer-reviewed articles and grey literature.

Table 2

Inclusion and exclusion criteria

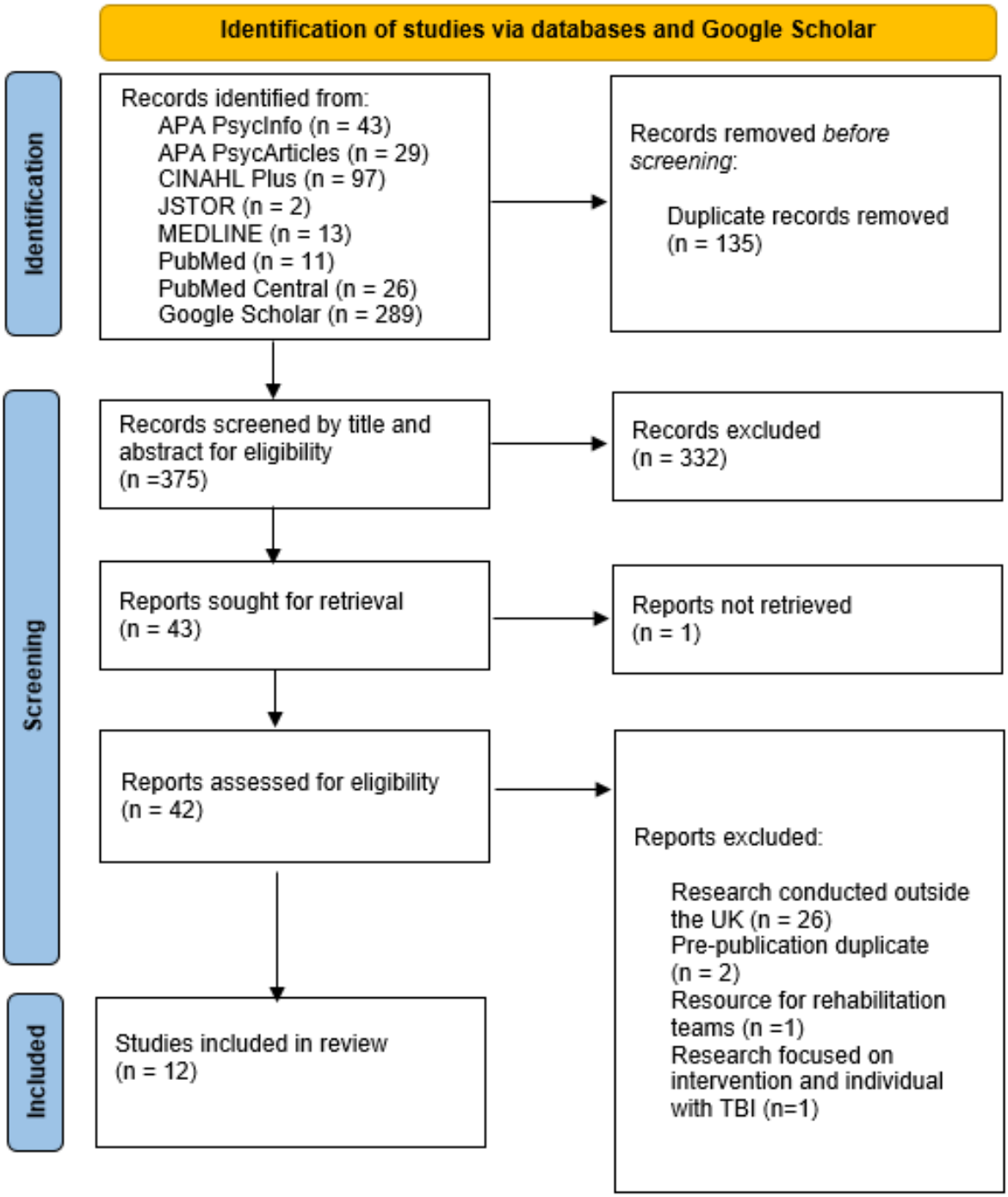
Inclusion Criteria	Exclusion Criteria
Must involve primary research.	Any literature pertaining to ambiguous loss that does not relate to an ABI e.g. physical loss such as with a missing person or degenerative brain conditions such as Alzheimer's or Parkinson's.
Must have a clear focus on the experience of family members of people with ABI within the UK.	Any literature that solely focuses on intervention or the individual with the ABI.
Must have some reference to the concept of type two ambiguous loss or any of its defining features.	Any literature not in English, due to the lack of resources available to translate any material.
	Any primarily quantitative research, as interested in perspectives on or experiences of ambiguous loss.

Study Selection

Following the PRISMA flow chart (Page et al., 2021), duplicates were removed, and titles and abstracts were screened using the eligibility criteria. Uncertain articles were retained for further screening (see Figure 2). The full versions of selected articles were obtained and screened using the eligibility criteria and quality assessment. Out of 510 articles initially identified, 12 met the criteria and were included in the final literature review.

Figure 2

PRISMA flow chart (Page et al., 2021)



Data Extraction

Data on the general characteristics of each study, including study design, focus, participants, and relevant findings related to the experience of ambiguous loss, were extracted and are presented in Table 3.

Quality Assessment

The methodological quality of each study was assessed by a single researcher using the Critical Appraisal Skills Programme (CASP, 2018) checklist for qualitative studies. The CASP was chosen as it is a widely used criteria-based tool for quality appraisal in health and social care-related qualitative evidence syntheses, recommended for novice qualitative researchers (Long et al, 2020).

Whilst the CASP was designed to be used as a pedagogic tool, it does recommend that classifying quality as high, moderate or low is acceptable. A scoring system used by Butler et al. (2016) was adopted, and as shown in Appendix A. 2, each article was assessed for quality in each of the 10 CASP domains, resulting in an overall study quality rating. This rating was considered when evaluating the weight of their individual contributions in the synthesis.

Table 3

Characteristics of included studies

Author & date	Design	Focus of the study	Participants	Findings relevant to the experience of ambiguous loss
Buckland et al. (2021)	Mixed qualitative design (Constructivist-interpretivist stance, semi-structured interviews, thematic analysis) with supporting quantitative scale (Brain Injury Grief Inventory (BIGI), demographic information, ANOVA).	Individual and family experiences of loss after acquired brain injury.	Registered Headway Cambridgeshire clients with an ABI of at least two years post-injury, along with family members involved both before and after the injury. Relatives included 14 spouses, 6 parents, 1 sibling and 1 son. 32% male, 68% female. Included 17 dyadic pairs, (53% spouses, 41% parent/child and 6% sibling relationships). 19 relatives participated in semi-structured interview, 22 relatives completed the BIGI.	• 7/16 relatives experienced ambiguous loss as the 'loss of person', grieving for the psychological aspect of the person in the physical body. • Ambiguous loss can persist as a profound focus of loss even years after injury. • Individuals with ABI and their relatives may have different experiences of loss, unrelated to functional losses. • Relatives experience personal loss alongside losses for their loved ones. • Despite the loss, individuals can find positives in accepting the new person and experiencing a coexistence of affection and sadness. • Relatives may struggle with a dominance of ambiguous loss, finding it challenging to witness changes in the person and respond positively without personal experience.
Coppock et al. (2018)	Constructivist stance, semi-structured interviews, thematic analysis.	The experiences of young people and their families following parental acquired brain injury.	3 families with a parent at least one year post-injury, experiencing moderate to severe functional impairment, with at least one child aged 8-16 were recruited from local Headway branches and an NHS ABI service in the South East of England.	• Limited knowledge about ABI among young people leading to health anxieties due to parents withholding information. • Role change and parentification occur as family members take on additional roles. • Negative impact of ABI on emotional well-being of young people. • Younger participants express loss related to their previous roles and activities with their parent. • Fear of further loss is present, with an overestimation of the likelihood of additional loss while recognising the fragility of life.

				• Loss is experienced within the context of pre-injury relationships, particularly in families with traditional gender roles. • Differences in experiences of loss may be influenced by ABI severity and the nature of the pre-injury relationship with the parent.
Ghosh-Cannell et al. (2022)	Semi-structured interviews, Interpretative Phenomenological Analysis (IPA).	The experiences of wives when noticing and making sense of changes following their husbands' ABI.	9 participants whose spouses had experienced ABI at least one year prior to recruitment, were recruited from local services supporting individuals and families (3 via support groups and 6 via service staff). All participants were female, white British and married. Aged between 50 and 73. The duration of spousal relationships ranged between 13 and 52 years.	• Not explicitly referring to ambiguous loss, but relevant features are highlighted: • Spouses experience emotional separation and question their beliefs around marriage, relationships, and identity. • Spouses feel trapped in the post-ABI lifestyle and struggle with its permanency while hoping for future improvements. • Accepting change requires bravery and involves acknowledging challenging emotions and loss of partnership over time. • Restoring a balanced family system after ABI is challenging and requires adaptation to a "new normal." • Long-term support is crucial for addressing identity changes after ABI. • Coping with ambiguous loss involves balancing knowledge of unwanted truths and tolerance of the unknown. • Previous research has focused on negatives, potentially hindering recognition of positive outcomes.
Glennon et al. (2022)	Critical realist approach, semi-structured interviews, grounded theory.	Explored the process of identity change following adolescent brain injury from the perspectives of adolescents and their mothers.	6 mothers of adolescents with ABI at least 6 months post-injury, recruited from a community based NHS paediatric specialist neuro-rehabilitation service.	• Not explicitly referring to ambiguous loss, but relevant features are highlighted: • Mothers express "hereness" and "gone-ness" experiences regarding their child. • Conflicting experiences emerge between grieving for the child and the remaining child. • Mothers experience tension in reconciling a disability identity with a non-disabled one for their child. • One mother sees no difference in her child, aligning with her role as a mother.

				• Interactions with the grieved-for child vary, for one mother, sometimes struggling to recognise him. • The duality of remaining and lost elements of the child presents a unique challenge to grieving. • Mothers strive to minimise identity discrepancies and distress for their child while meeting their needs, indirectly highlighting difference and change. • Mothers express a form of loss or grief about changed aspects of their child. • Shared experiences of identity adaptation and movement towards a tentative equilibrium as discrepancies are resolved or changes are accepted.
Hadden (2012)	Thesis, semi-structured interviews, IPA.	The experiences of loss in adolescents who have a parent with an acquired brain injury.	5 female adolescents, aged 14-18, with a parent with an ABI at least 6 months post-injury, recruited from Brain Injury Rehabilitation Trust units nationwide.	• Universal theme of loss experienced by each participant, including loss of child role, loss of parent, and loss of parent's role. • Participants' experiences support the theory of ambiguous loss, perceiving their parents differently despite physical resemblance, with the loss of who the parent used to be as the most distressing. • Four participants ruminated on their parent's past self, leading one participant to reduce visits due to distress. • Intense feelings of hopelessness initially, persisting over time due to constant reminders of changes. • Adolescents may become overly attached to the memory of their parent, idealising them and struggling to accept the finality of the situation. • Coping mechanism of expressing gratefulness, focusing on positive aspects of the injury. • However, feelings of gratefulness accompanied by a sense of duty, creating internal conflict as participants wanted to grieve but felt guilty for not being more grateful.
Holloway et al. (2019)	Semi-structured interviews,	Experiences of challenges and	16 family members of people with severe ABI, at least 2 years post-injury (15 female,	• Ambiguous grief experienced by family members, developing over time and maintaining involvement.

	inductive thematic analysis.	support among family members of people with acquired brain injury.	1 male, 7 partners, 7 mothers). Recruited from a cohort of respondents to a national online survey distributed amongst a variety of national brain injury organisations.	• Uncertain prognosis and functional outcomes hinder proactive planning, leading to day-to-day management. • Varying availability and quality of support exacerbate difficulties and isolate family members. • Families undergo complex grief similar to partial bereavement, lacking recognised closure ceremonies. • Ongoing adjustment due to the ambiguity of loss. • Nearly half of participants express ambivalence about the quality of life for the injured person. • Professionals often fail to recognise family dilemmas and difficulties. • Issues include lack of information, unsupportive attitudes, and limited access to suitable services. • Families lack clarity and support in navigating changed roles, relationships, and expectations. • Positive experiences with professionals involve specialist knowledge, supportive attitudes, inclusiveness, recognition, and understanding of the family's perspective.
Kean (2010)	Family group interviews, constructivist grounded theory.	The experience of ambiguous loss in families of brain injured ICU patients.	9 family interviews (12 adults and 12 children/younger people), in which the brain injured patient has been in ICU between 7 days to 3 weeks at time of interview. 6 families with husband/father critically ill and 3 families with the adult son or brother in ICU. Recruited by ICU nurses in a large teaching hospital.	• Ambiguous Loss identified in themes of clinical and functional uncertainty. • Family experiences reflect type 2 ambiguous loss, causing significant trauma. • Some family members refer to the affected family member in the past tense. • Ambiguity of loss leads to confusion and suffering. • Ambiguous loss lacks rituals for closure and moving on. • Ambiguous loss profoundly impacts family dynamics and roles. • "Mapping the future" theme explores the impact on everyday life and future prospects. • Future mapping influenced by family positions and hopes for recovery.

				• Gender, power dynamics, and socially constructed relationships affect the impact of ambiguous loss on families.
Lond & Williamson (2022)	Semi-structured interviews, IPA.	Analyses the accounts of people caring for a long-term partner with brain injury to identify coping mechanisms and support systems that enhanced well-being.	8 participants (6 women, 2 men), all white British members of heterosexual marriage dyads who lived together, with at least 2 years' experience supporting a spouse with ABI, recruited from Headway support groups.	• Half of the sample confronted and managed ambiguous loss, with two participants discussing it extensively. • Grieving the loss of the partner before brain injury was challenging due to the ambivalence of the loss when they are still physically present. • Two participants would have found it easier to grieve and move on if their partner had passed away. • Closure and understanding are crucial in the grieving process. • Difficulty in grieving the loss of the partner before brain injury due to ambivalence of the loss while they are still present. • Both participants redefined their partners as different people after ABI, accommodating the presence of their new brain-injured partner while mourning the loss of their pre-injury partner. • Identity reformation aids in managing ambiguous loss and unresolved grief, providing a means to discuss the partner's injury with others. • The splitting and reformulation of identity help individuals grieve amidst recurrent feelings of ambiguous loss.
Odumuyiwa (2017)	Undergraduate research project, semi-structured interviews, IPA.	The experiences that those with ABI and their family members have with outside services.	8 participants (4 family members, 2 individuals with ABI and 2 professionals working with people with ABI) recruited via an advertisement through Headway, Respite service and online survey.	• Not explicitly referring to ambiguous loss, but relevant features are highlighted: • Participants expressed frustration with stereotyping of their family members with ABI by professionals and the public. • Participants felt unprepared and confused about the implications of ABI. • Diagnosis of ABI led to family members transitioning to the role of caregivers due to the person's inability to live independently.

				• Caring for someone with ABI had a detrimental impact on participants' psychological well-being. • Some participants experienced a sense of loss and grief when reflecting on changes in the person's identity. • Participants and professionals acknowledged the common experience of grief and identity change in individuals with ABI and their families. • Parental grief following identity changes after ABI differed from normal bereavement stages. • The study validated psychological effects such as depression and suicidal thoughts experienced by caregivers. • Long-term support for caregivers is essential, with options tailored to individual needs.
Olafsen (2022)	Thesis, semi-structured group interviews, IPA.	Families' experiences of loss following ABI.	4 families (Relatives included 4 parents, 2 siblings and 1 spouse) recruited from Disabilities Trust, Headway, private neuropsychological rehabilitation services and mailing lists.	• Families experienced various losses related to brain injury: independence, control, and future plans. • Brain injury resembled a non-linear and ongoing grieving process. • Dismissal of the grieving process led to isolation and loneliness. • Staying present helped families cope with the uncertainty of ambiguous loss. • Grief experiences aligned with Boss and colleagues' concept of ambiguous loss. • Uncertainty about the survivor's prognosis deeply affected families emotionally. • Loss post-ABI was unique, as the survivor's essence remained but with personality changes. • Simultaneous presence and absence of the survivor contributed to ambiguity and lack of closure. • Recognising consistent aspects of the survivor and family system aided in managing loss. • Uncertainty about the survivor's prognosis was closely associated with ambiguous loss.

Villa (2013)	Thesis, semi-structured interviews, IPA.	Explores spouses' experiences of their relationship and caregiving following partners acquired brain injury.	5 spouses (4 female, 1 male) of people with ABI at least 9 months and no more than 10 years post-injury, recruited through NHS out-patient brain injury service and branches of Headway.	• Not explicitly referring to ambiguous loss, but relevant features are highlighted: • Participants felt a loss of the person their spouses were before the injury, perceiving them as different individuals. • Glimpses of the old person were disregarded or unable to be integrated due to perceived fundamental changes. • Some participants experienced a sense of loss for the person, rather than loss of the person. • The perception of the person's identity was influenced by experiences of continuity and discontinuity. • Discontinuity led to depersonalisation, loss, and grief for the person seen as "gone." • Changes in mutuality/reciprocity, togetherness, and feelings of continuity-discontinuity characterised post-injury relational experiences.
Whiffin et al. (2017)	Social constructivist stance, unstructured interviews, narrative analysis.	An exploration of family biographical narratives and identity change following traumatic brain injury.	9 family members from 3 families of a relative with TBI, admitted to neuro intensive care. Completed 3 interviews; 1, 3 and 12 months post injury.	• Families confronted uncertainty about their relative's survival and the potential loss of their pre-injury self. • Divergent realities within families may strain cohesion and create feelings of isolation. • The injured member's departure from the shared narrative during illness disrupts assumptions of a shared narrative order. Misalignment of past, present, and future contributes to intangible and ambiguous losses following TBI.

Results

Included Study Characteristics

This review encompassed studies involving over 100 family members of individuals with ABI in the UK, including spouses, parents, siblings, and children. Most participants were female (approximately 76%), and their ages ranged from 4 to 79 years, (Mean = 37 years). The onset and severity of ABI varied across the studies. The studies recruited participants from UK-based brain injury organisations such as Headway and NHS neuro-rehabilitation services.

Different qualitative methods were employed, such as interpretative phenomenological analysis (5 studies), thematic analysis (3 studies), grounded theory (2 studies), narrative analysis (1 study), and mixed qualitative design with a quantitative scale (1 study). Data was collected through semi-structured interviews (10 studies), unstructured interviews (1 study), and family group interviews (1 study).

Appraisal Overview

All studies met the initial screening criteria, demonstrating clear aims and appropriate qualitative methods. They also all appeared to use appropriate recruitment and data collection methods and provided clear findings which demonstrated local value (CASP, 2018).

The quality assessment indicated that the consideration of the researcher-participant relationship was the weakest domain across the studies, with some studies lacking critical examination of potential bias or influence (Kean, 2010; Odumuyiwa, 2017). Additionally, certain studies provided limited detail in domains such as design justification, ethical considerations, and data analysis rigor. Overall, all 12 studies were appraised as moderate-high quality and relevant for this review. Their contributions were evaluated across the 10 CASP domains (Appendix A. 2).

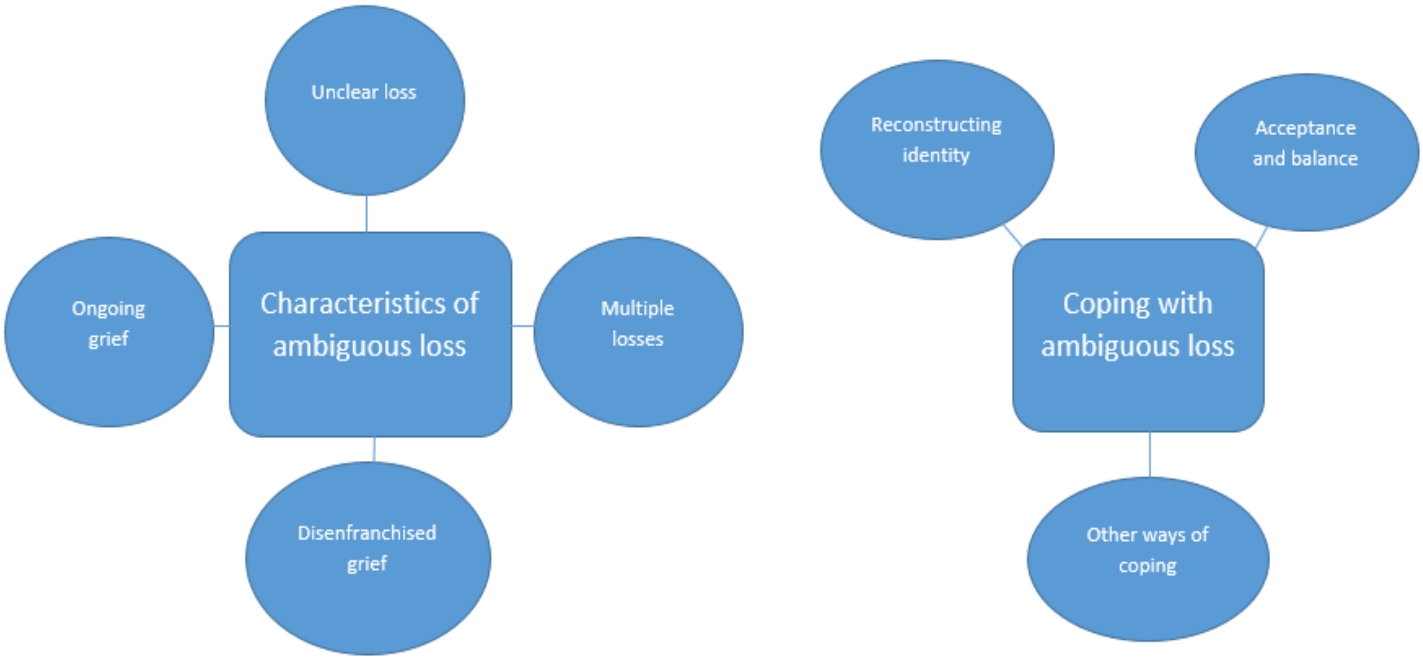
Thematic synthesis

Thematic synthesis, following Thomas and Harden's (2008) methodology, was used to analyse the data in this review. It facilitated systematic interpretation and traceability of conclusions to the original text. The process included open coding line-by-line to identify similarities and differences, forming descriptive themes. These

were then analysed in relation to the research question, leading to two main themes with seven sub-themes, as shown in Figure 3.

Figure 3

Summary of themes and sub-themes



Theme 1 – Characteristics of ambiguous loss

Characteristics of ambiguous loss is a main theme and includes features of how this is experienced by family members, which includes unclear loss, multiple losses, ongoing grief and disenfranchised grief.

Unclear loss

The studies all described family members experiencing an unclear loss when the person with ABI was physically alive but changed in an ambiguous way. “A shell that you’re used to but something on the inside was different” (Whiffin et al., 2017, p. 1264). “Even though we’ve got the same body, we’ve just got a different person that lives in it.” (Buckland et al., 2021, p. 15). Glennon et al. (2022) described this as a phenomenon of simultaneously incongruent experiences of the grieved for and the remaining person, as family members struggle with the duality of someone being

both here and gone, grieved for and remaining, “We’ve lost a daughter and gained another one” (Buckland et al, 2021, p. 15).

Perceptions of the severity of this loss varied among family members, with some viewing the person with ABI as a completely different individual, “a whole new person who has different memories and a different voice and a different sense of humour.” (Odiumuyiwa, 2017, p. 183). Villa (2013) noted depersonalising language such as “empty” or “gone” (p.81) was sometimes used to describe appraisal of partners with ABI.

Some family members expressed a sense of losing part of the person with ABI; “he still cares for me and all that, but most of him now, he’s like a friend now… It feels like you’ve lost something and it just feels like I’ve lost a bit of my dad.” (Coppock et al., 2018, p. 480). Villa (2013) found there were occasional “glimmers” (p.81) of the pre-injury person, but these were often discounted or not fully integrated due to the perceived fundamental change in the person. Certain studies found that these fleeting reappearances of the pre-injury person sustained grief by momentarily bridging the gap between the past and the present, contributing to the ambiguity and lack of closure surrounding the loss (Holloway et al., 2019; Olafsen, 2022).

Families expressed uncertainty regarding the prognosis of the ABI and how it would affect their future, which hinders the process of finding closure for their loss (Olafsen, 2022; Glennon et al., 2022; Holloway et al., 2019, Kean, 2010).

The studies collectively characterised the grief stemming from this unclear loss as unique, complicated, unresolvable and the most profound type of loss experienced (Lond & Willamson, 2022; Odiumuyiwa, 2017; Olasfen, 2022; Holloway et al., 2019; Buckland et al., 2019; Glennon et al., 2022).

Multiple losses

The studies highlighted the diverse impact of ambiguous loss on individuals and families, including personal sacrifices, lifestyle changes, loss of future prospects, and shifts in relationships and family roles.

The changes resulting from the family member’s ABI often led to a loss of independence, spontaneity and freedom; “We can’t just go out anywhere…the life we had is gone.” (Buckland et al, 2019., p. 21). Olafsen (2022) found that families

reported losses such as of finances, careers, friendships, and social connections. Younger children, as found by Coppock et al. (2018), emphasised the loss of shared activities.

Family members experienced a sense of loss for their own future, the future of the individual with ABI, and the family as a whole. They expressed a loss of unfulfilled potential and future aspirations (Glennon et al., 2022; Odiumuyiwa, 2017). “You think ‘what if? What if he hadn’t have had that? What would he be? What would he be like?’ He’s never going to fulfil what he could have been.” (Buckland et al, 2019, p. 23). Some family members appeared to use the past tense to signify this, “He had the world at his feet” (Kean 2010, p. 70). Family members also experienced the loss of future plans due to a change in achievable goals, for some leading to feelings of regret and a sense of denied possibilities (Buckland et al., 2019; Olasfen, 2022).

Spouses consistently reported a loss of intimacy, equal partnership, mutability, reciprocity and togetherness within their relationships (Buckland et al., 2019; Villa, 2013; Ghosh-Cannell et al., 2022). One spouse described feeling alone despite being married, “You’ve got all the disadvantages of living on your own, and you’ve got all the disadvantages of being married if you like, but none of the advantages either way it seems.” (Buckland et al., 2019, p. 19). Shared memories and habitual interactions, which helped maintain a connection as a couple, were also lost for some spouses (Olasfen, 2022; Ghosh-Cannell et al., 2022).

Relatives frequently mentioned a loss of valued identity or pre-injury family roles, affecting themselves and their loved ones (Buckland et al., 2021). Hadden (2012) spoke of the loss of the parent with ABIs parent role and the loss of the child’s role within the family. Ghost-Cannel et al. (2022) reported that the feeling of being settled within a married role was disrupted by the ABI and Coppock et al. described a loss related to traditional gender roles, “Dad had been the protector as it were.” (2018, p. 480). This loss necessitated a process of reconstructing identity and family roles, leading to a shift towards a more parental or caregiving role.

Ongoing grief

Relatives experience ongoing grief characterised by ambiguous loss following ABI. This grief can start in the acute stage of the injury and persist for years. It unfolds gradually through multiple experiences without a fixed end point, suggesting that

time alone may not diminish the feelings of ambiguous loss (Buckland et al., 2021; Holloway et al., 2019; Ghosh-Cannell et al., 2022; Glennon et al., 2022). The grieving process is non-linear and affects each individual in unique ways at different times, “I think for all of us it ((pause)) each of us it hits us at different times and in different ways because of different things.” (Olafsen, 2022, p. 70).

Families continuously grapple with ongoing loss, struggling to find meaning and face challenges in moving forward. The lack of resolution and closure intensify the ambiguity surrounding the loss, making it difficult to navigate (Kean, 2010; Olasfen, 2022; Lond & Willamson, 2022; Holloway et al., 2019).

Some family members feel hopelessness due to the perceived permanence and insolvability of the challenges they face (Hadden, 2012; Whiffin et al., 2017). Ghosh-Cannell et al. (2022) likened this to being trapped in an insolvable maze. According to Kean (2010), ambiguous loss leaves families suspended in time and space.

Disenfranchised grief

The majority of relatives in the studies experienced disenfranchised grief, finding traditional bereavements, such as attending a funeral, easier to navigate than the complex ambiguous loss in ABI (Buckland et al., 2021; Lond & Williamson, 2022).

Lack of knowledge about ABI and understanding from others contributed to feelings of loss, isolation, and frustration (Coppock et al., 2018; Holloway et al., 2019). Some relatives felt unsupported by professionals who communicated poorly, displayed excessive pessimism or optimism about ABI prognosis, undervalued family knowledge, or dismissed changes (Holloway et al., 2019; Odiumuyiwa, 2017). Odiumuyiwa (2017) highlighted the hidden disabilities of ABI, which society fails to acknowledge, suggesting preconceived notions about how ABI should manifest. Hadden (2012) noted that adolescents struggled with conflicting emotions of grieving and a sense of duty to remain positive and grateful that things were not worse.

Relatives reported there was a lack of grieving ceremonies or rituals to facilitate closure and moving on, leading to the confusing dilemma of wanting to grieve but feeling guilty due to the person still being alive (Lond & Williamson, 2022; Holloway et al., 2019; Kean, 2010). “In some ways it’s worse than a person being dead. If somebody dies you have a funeral and then you can get on with your life, perhaps

meet somebody new or whatever. But here you haven't got the funeral and moving on. You've got this grief going on indefinitely." (Lond & Williamson, 2022, p. 14). Buckland et al. (2021) emphasised the lack of suitable language to discuss ambiguous loss, as traditional terms might not capture the experience. Ghosh-Cannell et al. (2023) highlighted how metaphors might help relatives express their experiences more effectively, as seen in Villa (2013) when one spouse defined her pre-injury relationship as each being the others "rock" and post-injury as, "Well I'm a bloody boulder now" (p.88).

Theme 2 – Coping with ambiguous loss

The final main theme, coping with ambiguous loss includes key features of how individuals developed methods of coping, such as reconstructing identities in their relationships and seeking acceptance and balance in the changes as a result of ABI.

Reconstructing identity

Most relatives experienced role shifts and new social connections in relation to their family member with ABI. For example, some assumed a parental role within a marital relationship, while adolescents underwent parentification, taking on parental responsibilities (Olafsen, 2022; Coppock et al., 2018; Hadden, 2012). Others assumed a caregiver role with increased caregiving responsibilities, including providing personal care (Ghosh-Cannell et al., 2022; Coppock et al., 2018; Odiumuyiwa, 2017; Villa, 2013). "She's like the carer now for him, so like if he goes to shower she's always got to clean him, change him." (Coppock et al., 2018, p. 480).

Relatives underwent changes in self-identity, with varying experiences such as connecting with a drive to move forward or physical changes impacting post-injury life (Ghosh-Cannell et al., 2022; Whiffin et al., 2017). Whiffin et al. (2017) found narrative misalignment within families can lead to isolation and disconnection, and reconstructing a shared family narrative can foster closeness and unity.

Relatives often reconstructed the identity of the person with ABI to cope with ambiguous loss and navigate conversations about ABI (Lond & Williamson, 2022, Whiffin et al., 2017). Reframing loss in concrete terms allowed grieving while accommodating the continued presence of the post-injury person. The extent of this

reconstruction varied, with some finding it helpful to navigate conversations with others around the complexities of ABI, “We actually say ‘Old Adam’ and ‘New Adam’. Adam knows that and, in a way, it helps us cope.” (Lond & Williamson, 2022, p. 15). While others found it incongruent with their role, like a mother perceiving her child as a different person (Glennon et al., 2022).

Kean (2010) emphasised societal and gendered expectations on caregiving, noting that it is most often women in families who are expected to assume the role of caregiver. Holloway et al. (2019) described a sense of duty to provide care, driven by an uncertain reciprocity, “There are lots of times when I want to walk away, but I can’t, because I know he would do the same for me.” (p. 18).

Acceptance and balance

Relatives often coped with ambiguous loss by seeking acceptance and balance, the co-existence of acknowledging the new while mourning the losses (Buckland et al., 2021). Ghosh-Cannell et al. (2022) described this as establishing a ‘new normal’ (p.365), finding a tentative balance between continuity and change was emphasised, “it isn’t as much something that you get past, it’s more that you learn to live with it.” (Glennon et al., 2022, p. 1919).

Acceptance appeared to be a key factor in long-term adjustment for relatives dealing with ABI (Lond & Williamson, 2022). However, accepting the reality of ABI can be challenging and initially perceived as giving up or losing hope. Denial was used as a coping mechanism by some relatives to sustain hope of a full recovery and reject the permanence of ABI, however this undermined their ability to accept and adapt. Finding consistencies in identity and interpersonal moments were mentioned as helpful ways of working towards acceptance (Ghosh-Cannell et al., 2022; Coppock et al., 2018; Whiffin et al., 2017). Some family members mentioned practising staying in the present moment to aid in acceptance, such as through mindfulness, therapy or religious beliefs (Olasfen, 2022).

Other ways of coping

Relatives employed various coping strategies to navigate ambiguous loss, taking into account their pre-existing roles and context, of which the ones highlighted across the studies have been summarised in this theme.

Expressing gratitude, often that things could have been worse and focusing on the positives were common, offering relief and reducing feelings of loss (Hadden, 2012; Buckland et al., 2021). Appreciating the positives that have come from dealing with this loss, such as the time spent with their partner, a sense of maturity and pride from embracing new roles and appreciation for family support were mentioned as positive aspects of this experience. Recognising and demonstrating consistent characteristics such as determination, love, care and humour, also helped in the grieving process (Buckland et al., 2021; Coppock et al., 2018; Hadden, 2012; Olasfen, 2022). "Love the person when he had the stroke, to be there for them because love can cure people, can, can give hope." (Olasfen, 2022, p. 481).

Some parents used coping strategies like withholding knowledge about the ABI, planning ahead, and limiting exposure to challenges to protect their children (Coppock et al., 2018; Glennon et al., 2022). However, these strategies could inadvertently increase health worries in children or emphasise the differences the parents were trying to downplay. Similarly, some children hid their feelings of fear and anxiety about the ABI to appear strong for their family.

Relatives emphasised the importance of seeking support from professionals, family, and friends to cope with the challenges of ambiguous loss. Holloway et al. (2019) found that when others were understanding and supportive, this helped relatives cope with loneliness and maintain family unity. Olafsen (2022) highlighted the significance of a strong family unit that utilises shared and individual strengths to provide emotional and practical support. Peer support was valued for offering a validating space and facilitating knowledge exchange, "its sharing experiences and a way forward if you like. Pluses and minuses—dos and don'ts … trading knowledge, I think is the best thing." (Lond & Williamson, 2022, p. 17). Health and social care services, when available, were valued for their specialised knowledge, recognition of uncertainty, empathy, and flexibility (Holloway et al., 2019).

Discussion

This review addresses the lack of attention to ambiguous loss in ABI literature and aims to improve understanding and support for UK families affected by ABI. The findings are consistent with those of the broader ABI literature, indicating that ambiguous loss is a common and unique experience for family members of

individuals with ABI in the UK, characterised as being unclear, misunderstood and profoundly distressing, as the person with ABI is physically alive, but for the relative they are psychologically changed, seemingly within the context of their pre-injury identities, relationships and family roles (Kreutzer et al., 2016). The ambiguity surrounding this loss hampers the search for meaning and closure, resulting in existential, ongoing and non-linear grief for relatives.

Relatives experiencing ambiguous loss often lack support, knowledge, understanding, and recognition, resulting in feelings of guilt and exacerbating feelings of loss, isolation, and frustration. This loss impacts various aspects of their lives and for the family unit, including lifestyle, future plans, relationships, and family roles.

Relatives navigated ambiguous loss by reconstructing identities, shifting roles and adjusting to the realities of ABI. Coping strategies included expressing gratitude and seeking support. Most relatives strived for a balance between acknowledging the new and mourning what is lost, accepting the tension between continuity and change, presence and absence, and hope and fear.

These findings align with Boss's (1999) description of ambiguous loss and the experiences reported by families in the broader ABI literature (Kreutzer et al., 2016). Boss emphasised the goal of families facing ambiguous loss is to live well despite uncertainties, using dialectical thinking. This review's findings align with the six guidelines proposed by Boss (2006) and the features of Kreutzer et al. (2016) brain injury family intervention, focusing on building resilience in the context of ambiguous loss.

Relatives sought meaning in ambiguous loss through personal understanding, language, validation, connection, support, positive meanings and gratitude. This experience challenged relatives, as they had to embrace paradoxes and both-and thinking, such as acknowledging the anxiety of no closure while embracing the opportunity for personal growth. Boss (2006) suggests adjusting mastery, by increasing agency to live with ambiguity or decreasing the need for a solution, aligning with the theme of finding balance and acceptance reported by relatives.

The theme of reconstructing identity aligns with Boss’s (2006) guidance on redefining relationships after ambiguous loss. Relatives demonstrated flexibility in

family boundaries, roles and rules to address the impact of ABI, strengthening family connections and support. However, some family member's maladaptive coping appeared to hinder the process of resilience, by resisting change, isolating themselves and awaiting closure.

Conflicting feelings are common in ambiguous loss, and Boss (2006) advises discussing this experience can normalise ambivalence and foster resilience. Relatives emphasised the importance of sharing and seeking validation, exchanging information, and normalising the ambiguity and conflicting emotions. According to Boss (2006), denying these feelings hinders the process, as seen in this review as some relatives hid their emotions or denied themselves time to grieve out of guilt because the person is still alive.

Boss (2006) proposes embracing both-and thinking can help families build resilience, acknowledging the absence of closure while holding onto what was and seeking new relationships. The relatives in this review exemplified the loss and re-formation of close relationships through the reconstruction of family roles and social connections. They demonstrated simultaneously experiencing relational consistencies and changes using both-and thinking. Boss (2006) emphasises that acceptance and balance are needed to make sense of these dilemmas and revise attachments, aligning with the relatives' experiences in this review.

Boss (2006) states that as relatives embrace ambiguity, they can find new sources of hope such as redefining justice and envisioning a future. In this review, families initially felt hopeless due to unsolvable grief and uncertainty with ABI. However, through identity reconstruction, acceptance, balance, and exploring new meanings in the loss, families discovered new sources of hope, including sources such as looking ahead, accepting revised expectations, and providing support to one another and peers in similar situations.

This review also highlights the importance of language and critical thinking in forming narratives around this experience. Relatives lacked suitable language due to the distinct nature of this loss, often leading to metaphors and developing dialectical thinking skills. Further research can explore these aspects to enhance support and intervention.

Limitations

The identified studies varied in participant characteristics, limiting the transferability of these findings and their value. Additionally, as previously highlighted by Kreutzer et al., (2016), a limitation is the scarcity of ABI literature addressing ambiguous loss to draw from.

Cultural, ethnic, and faith-based differences were not extensively analysed in this review due to resource constraints and the focus on English-language papers. Therefore, this review may only provide a limited representation of minority voices and understanding of the broader socio-cultural impact. Rai et al., (2022) discuss the methodological whiteness found in health research, highlighting this inequity of ethnicity and race and the need for future research to take responsibility and more directly address the structural barriers that have excluded these individuals from the conversation so far in the UK. The review's reliance on a single researcher increases the potential for bias, and the use of diverse terminology in studies introduces another source of potential bias (Galdas, 2017).

Implications for research and practice

Future research should address the identified limitations by conducting high-quality studies that contribute to the literature on ambiguous loss in ABI, focusing on specific criteria and considering the social-cultural differences in the UK context. In order to mitigate bias, involving multiple researchers in the design, study selection, and synthesis process is recommended. Incorporating findings from quantitative studies would enhance understanding through statistical analysis and generalisable findings based on larger sample sizes.

The findings of this review have significant implications for professionals working with families affected by ABI. Ambiguous loss is a prevalent and complex experience in this population, extending beyond the injury itself. Therefore, understanding ambiguous loss can shed light on the distress experienced by this population, as already recognised in the ABI literature (Blais & Boisvert, 2007; Doser & Norup, 2014; Ergh et al., 2003; Kelley et al., 2014; Marsh et al., 1998). This review emphasises the importance of addressing the lack of knowledge and understanding of ABI among professionals in the UK, as it can contribute to the challenges faced by

families, leading to disenfranchised grief, uncertainty, isolation, and distress (Norman et al., 2020; Kreutzer et al., 2016).

Professionals and services should receive comprehensive training on ambiguous loss, emphasising long-term support. Interventions that acknowledge and validate the characteristics of ambiguous loss, while promoting acceptance and mindfulness-based approaches, can assist families in coping and reconstructing their lives (Boss, 2006; Kreutzer et al., 2016). Peer support groups can provide a validating space for sharing and discussing ambiguous loss (Kreutzer et al., 2016). Furthermore, education on ambiguous loss should be extended to the general public to promote understanding and the need for non-traditional grieving rituals specific to ambiguous loss, shifting focus towards family resilience and nurturing it further.

Conclusion

This review explored ambiguous loss among UK families affected by ABI. Findings revealed the commonality of this experience, highlighting unique aspects and common coping mechanisms. The results align with ambiguous loss theory and previous research, expanding the limited literature on ABI-related ambiguous loss. The findings offer valuable insights for professionals to better understand and support families in navigating the complexities of this type of loss.

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Appendices A: Literature Review Paper Appendices

Appendix A. 1: *Initial Search Summary*

Name of database/search engine	Date last accessed	Search pathway followed	Predefined keywords	No. of results	No. of results after duplicate removal
Google Scholar	22.1.23	Accessed Google Scholar and entered the predefined keywords. Expanders were used to include relevant articles of any type, published at any time and the results were sorted by relevance.	(Experience* OR Qualitative OR Interview) AND (“Ambiguous loss”) AND (Famil* OR caregiver* OR relative* OR partner* OR sibling* OR child* OR parent* OR spouse* OR grandparent*) AND (“brain injur*” OR “Head injur*” OR “Head trauma”)	289	269
APA PsychINFO	25.1.23	Accessed APA PsychINFO and entered the predefined keywords. Expanders were used to apply related words, equivalent subjects and also search within the full text of the articles. The Boolean/phrase search mode was used.	(Experience* OR Qualitative OR Interview) AND (“Ambiguous loss” OR "Boundary Ambiguity" OR "Frozen Grief" OR "Prolonged Grief disorder") AND (Famil* OR caregiver* OR relative* OR partner* OR sibling* OR child* OR parent* OR spouse* OR grandparent*) AND (“brain injur*” OR “Head injur*” OR “Head trauma” OR "ABI" or "TBI")	43	21
PubMed Central	25.1.23	Accessed the PubMed Central database and entered the predefined keywords.	(Experience* OR Qualitative OR Interview) AND (“Ambiguous loss” OR "Boundary Ambiguity" OR "Frozen Grief" OR "Prolonged Grief disorder") AND (Famil* OR caregiver* OR relative* OR partner* OR sibling* OR child* OR parent* OR spouse* OR grandparent*) AND (“brain injur*” OR “Head injur*” OR “Head trauma” OR "ABI" or "TBI")	26	24
PubMed	25.1.23	Accessed the PubMed database and entered the predefined keywords.	(Experience* OR Qualitative OR Interview) AND (“Ambiguous loss”) AND (Famil* OR caregiver* OR relative* OR partner* OR sibling* OR child* OR parent* OR spouse* OR grandparent*) AND (“brain injur*” OR “Head injur*” OR “Head trauma”)	11	6
MEDLINE	25.1.23	Accessed the MEDLINE database and entered the predefined keywords.	(Experience* OR Qualitative OR Interview) AND (“Ambiguous loss”) AND (Famil* OR caregiver* OR relative* OR partner* OR	13	0

		Expanders were used to apply related words and equivalent subjects. The Boolean/phrase search mode was used.	sibling* OR child* OR parent* OR spouse* OR grandparent*) AND (“brain injur*” OR “Head injur*” OR “Head trauma”)		
APA PsychArticles	25.1.23	Accessed the APA PsycArticles database and entered the predefined keywords. Expanders were used to apply related words, equivalent subjects and also search within the full text of the articles. The Boolean/phrase search mode was used.	(Experience* OR Qualitative OR Interview) AND (“Ambiguous loss”) AND (Famil* OR caregiver* OR relative* OR partner* OR sibling* OR child* OR parent* OR spouse* OR grandparent*) AND (“brain injur*” OR “Head injur*” OR “Head trauma”)	29	6
JSTOR	25.1.23	Accessed the JSTOR database and entered the predefined keywords. Expanders were used to search everything and a limiter was used to select journals only.	(Experience* OR Qualitative OR Interview) AND (“Ambiguous loss”) AND (Famil* OR caregiver* OR relative* OR partner* OR sibling* OR child* OR parent* OR spouse* OR grandparent*) AND (“brain injur*” OR “Head injur*” OR “Head trauma”)	2	2
CINAHL Plus with Full Text	25.1.23	Accessed the CINAHL Plus with Full Text database and entered the predefined keywords. Expanders were used to apply related words and equivalent subjects. The Boolean/phrase search mode was used.	(Experience* OR Qualitative OR Interview) AND (“Ambiguous loss” OR "Boundary Ambiguity" OR "Frozen Grief" OR "Prolonged Grief disorder") AND (Famil* OR caregiver* OR relative* OR partner* OR sibling* OR child* OR parent* OR spouse* OR grandparent*) AND (“brain injur*” OR “Head injur*” OR “Head trauma” OR "ABI" or "TBI")	97	48

Appendix A. 2: *Results from the CASP Quality Assessment*

Author/date	Clear aim	Appropriateness of qualitative method	Appropriateness of design	Appropriateness of recruitment	Appropriateness of data collection	Consideration of relationship between researcher and participants	Ethical issues	Rigour of data analysis	Clear findings	Local value	Overall quality rating
Buckland et al. (2021)	Yes	Yes	Yes	Yes	Yes	Unsure	Yes	Yes	Yes	Yes	**High**
Coppock et al. (2018)	Yes	Yes	Yes	Yes	Yes	Unsure	Yes	Yes	Yes	Yes	**High**
Ghosh-Cannell et al. (2022)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	**High**
Glennon et al. (2022)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	**High**
Hadden (2012)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	**High**
Holloway et al. (2019)	Yes	Yes	Unsure	Yes	Yes	Unsure	Yes	Yes	Yes	Yes	**High**
Kean (2010)	Yes	Yes	Yes	Yes	Yes	No	Yes	Unsure	Yes	Yes	**Moderate**
Lond & Williamson (2022)	Yes	Yes	Yes	Yes	Yes	Unsure	Yes	Yes	Yes	Yes	**High**
Odumuyiwa (2017)	Yes	Yes	Yes	Yes	Yes	No	Unsure	Yes	Yes	Yes	**Moderate**
Olafsen (2022)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	**High**
Villa (2013)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	**High**
Whiffin et al. (2017)	Yes	Yes	Yes	Yes	Yes	Unsure	Yes	Yes	Yes	Yes	**High**

Scoring system: Yes: 1 point, Unsure: 0.5 points, No: 0 points.

High-quality paper: Scores 9 -10 Moderate-quality paper: Scores 7.5-9 Low-quality paper: Less than 7.5 Exclude: Less than 6

Paper 2: Empirical Paper

"A period of limbo": The experience of being a male family member of a person in a prolonged disorder of consciousness (PDoC); an Interpretative Phenomenological Analysis

The empirical paper has broadly been prepared in accordance with the requirements of the journal; Neuropsychological Rehabilitation. Author Guidelines are listed in Appendix B. 1.

Word Count: 8000

Abstract

Prolonged Disorders of Consciousness (PDoC) are complex conditions characterised by sustained consciousness impairment lasting over four weeks following sudden-onset severe brain injuries, such as from a car accident. These conditions pose emotional and social challenges for family members. This study aims to enhance understanding of the lived experiences of male family members dealing with PDoC in the UK. Semi-structured interviews were conducted with six adult male family members, and Interpretative Phenomenological Analysis (IPA) revealed three Group Experiential Themes: 1) 'Facing the Unknown: The Emotional Journey'; 2) 'Finding Meaning and Navigating Forward'; and 3) 'The Landscape of Care'. The findings highlight the emotional challenges faced by male family members and their efforts to find meaning, resilience and navigate the care pathway. Insights for professionals include the need for a family-orientated approach that offers understanding, compassion, holistic support and collaboration in care.

Introduction

Disorders of Consciousness

Severe acquired brain injuries can lead to a Disorder of Consciousness (DoC), a condition encompassing three distinct states of consciousness impairment: coma, vegetative state, and minimally conscious state (Royal College of Physicians, 2020). Coma involves a complete lack of awareness and wakefulness, often acute and short-term, the vegetative state involves wakefulness without awareness, and the minimally conscious state involves limited interaction and awareness. Prolonged Disorders of Consciousness (PDoC) occur when unconsciousness persists for over four weeks following a sudden-onset severe brain injury, such as from a car accident.

Estimates for PDoC cases in the United Kingdom (UK) vary widely, with 4,000-16,000 patients in a vegetative state and potentially three times as many in a minimally conscious state (Bunn & Fritz, 2022). As PDoC is increasingly recognised as a spectrum of awareness and interaction, accurate diagnosis and prognosis is challenging (Andrews et al., 1996; Schnakers et al., 2009; Wade, 2018). Assessment tools have been developed to improve diagnostic accuracy (Seel et al., 2010), while technologies like functional magnetic resonance imaging (fMRI) and

electroencephalography (EEG) require further research before routine clinical use (Royal College of Physicians, 2020).

Advancements in brain injury treatment have increased PDoC cases, with many surviving for a decade or longer, showing potential for meaningful recovery early after injury (Giovannetti et al., 2013; Leonardi et al., 2012). However, emergence from a PDoC into consciousness and independence is rare; most individuals either remain in a PDoC or, after emerging, remain dependent due to lasting physical and cognitive impairments, often worsening with time in a PDoC (Katz et al., 2009; Laureys et al., 2010; McCrea et al., 2021; Royal College of Physicians, 2020).

Currently, no established treatments ensure effective PDoC outcomes, with interventions limited to specialist rehabilitation and care to prevent complications, like nutritional support, airway management and physiotherapy (Royal College of Physicians, 2020). Decisions on life-sustaining treatments and withholding or withdrawing treatment involves careful consideration of the patient's benefit and are made collaboratively with the family (Bunn & Fritz, 2022; Lewis, 2007).

UK clinical practice now prioritises quality of life over consciousness recovery, involving families in decision-making based on their best understanding of the individual's wishes (Royal College of Physicians, 2020). While traditional psychological interventions for individuals with brain injuries and their families focus on neurocognitive deficits and emotional distress, a shift towards strength-based approaches like Solution-Focused Therapy has emerged (Gan, 2020). However, despite recommendations for family support, tailored interventions for PDoC remain lacking (Soeterik, 2017).

Impact on Family

Families of individuals with a PDoC face complex emotional and social challenges. Leonardi et al. (2012) highlighted the substantial physical and mental health challenges encountered by relatives, revealing heightened emotional burden and decreased well-being compared to the general population. The uncertain clinical scenario, with a loved one lacking consciousness but still alive, contribute to a complex emotional journey for family members (Hamama-Raz et al., 2013).

Boss's ambiguous loss theory (1999) offers a useful framework for understanding this experience in a brain injury context, describing the psychological absence and physical presence of a loved one, leading to prolonged and complex grief due to an unclear absence or change (Boss, 2006). Boss and Yeats (2014) provide guidance that emphasises the importance of supporting families to build resilience despite this uncertainty.

Families play a pivotal role in assessment, decision-making, and caregiving (Raciti et al., 2021). Kitzinger and Kitzinger (2013) highlight the bioethical implications and legal contexts for families as they navigate decisions related to patients' wishes, the right to die, preventing unnecessary suffering, and maintaining or withdrawing life-sustaining treatment.

Although the Royal College of Physicians (2020) acknowledges these themes, literature exploring these experiences is scarce, possibly due to PDoC's low prevalence and lack of national data (Soeterik, 2017). Kitzinger and Kitzinger's (2014, 2015) interviews with 51 family members serve as a valuable resource that begins to address this gap, highlighting the array of psychological, social, and practical outcomes within this unique context, without pathologising family responses.

Comprehensive research on what families require when coping with PDoC is essential, as Chinner et al. (2021) highlight the unique challenges faced by families compared to general caregiving literature. Soeterik et al. (2017) review the psychological impact on caregivers, revealing experiences of grief, anxiety, depression, burden, and coping strategies. However, the review lacked qualitative UK-based studies, questioning transferability due to international differences in health and social care.

Soeterik et al. (2018) contribute to UK qualitative research, using interpretative phenomenological analysis to explore female caregiver experiences. They highlight complex losses and relationship transformations, recommending more systemic research to explore the whole family experience, including that of male family members.

Gender Differences in Informal Caregiving

Research consistently highlights women's predominant role as informal caregivers in the UK, particularly in long-term caregiving, although a later life shift towards male caregivers is emerging (Dahlberg et al., 2007; Lacey et al., 2019). While caregiving affects both genders, studies indicate that women often face greater health implications and bear higher burdens, particularly in intensive caregiving for complex needs (Amirkhanyan & Wolf, 2006; Arber & Ginn, 1995; Pinquart & Sörensen, 2006; Vitaliano et al., 2003; Yee & Schulz, 2000).

Lacey et al. (2019) found no psychological distress differences in men based on caregiving patterns, suggesting potential gender variations in caregiving responses. However, this variation is likely influenced by caregiving intensity and other factors such as time-demanding social roles like parenting, carer age, coping strategies, financial constraints, employment responsibilities, and access to social networks and leisure activities (Arber & Ginn, 2007; Carr et al., 2018; Dahlberg et al., 2007; Pearlin et al., 1990; Pinquart & Sörensen, 2006; Stansfeld et al., 2014).

Men and women may employ distinct coping strategies in response to caregiving stress (Brown & Chen, 2008; DeVries et al., 1997; McFarland & Sanders, 1999; Tamres et al., 2002). Spendelow et al. (2017) found that male informal caregivers of individuals with a chronic physical illness often used diverse coping methods, including deriving meaning, expanding roles beyond traditional masculinity, and retaining pre-illness identities.

The limited literature on gender differences in the psychological impact of PDoC on caregivers yields mixed findings (Chiambretto et al., 2001; Magnani et al., 2020; Pagani et al., 2014). Soeterik et al. (2017) noted that existing research mainly focuses on the primary caregiver, often women, leaving a gap in understanding the experience of male family members and the broader family network. This highlights the need for research into male family member experiences to comprehensively understand the needs of the whole family.

Research Aims

This research seeks to expand PDoC literature by exploring the experiences of male family members of a loved one in PDoC in the UK. The aim being to enhance

understanding of these experiences, ultimately informing clinicians providing support to these individuals.

Research Question

What are the experiences of male family members of a loved one in a prolonged disorder of consciousness (PDoC) within the UK, and what are the clinical implications?

Method

Participants

Six UK-based adult males, closely related to individuals with PDoC, were recruited between January 2023 and March 2024, using purposive sampling based on the inclusion criteria in Table 1.

Table 1

Participant Inclusion Criteria

Inclusion Criteria
• Identifies as male. • Over 18 years of age. • Lives within the UK. • Currently or previously had a family member with a diagnosed PDoC within the UK.

The criteria aligned the study population with the research aims, adopting the Royal College of Physicians (2020) definition of a family member as anyone with a sufficiently close relationship to the person in PDoC to be actively concerned with their management and wellbeing.

Participants were initially recruited via two NHS sites specialising in PDoC care. Informed clinical professionals approached eligible family members, providing study information through a Participant Information Sheet (see Appendix B. 2). Recruitment processes prioritised sensitivity due to the potentially distressing context, using careful clinical judgment to mitigate undue influence.

Due to low response rates, recruitment efforts were expanded online through the brain injury charity, Headway, and later to other third sector and private organisations. A recruitment advertisement (see Appendix B. 3) was repeatedly distributed across various online channels, including email, social media, and newsletters. Participant demographic data is presented in Table 2.

Table 2

Participant demographic details

Pseudonym	Age	Relation to individual with PDoC	Cause of PDoC	Years passed since initial injury	Time family member in a PDoC
Phil	68	Husband	Acquired Brain Injury	2	10 months (Deceased)
Ross	64	Father	Acquired Brain Injury	3	8 months (Deceased)
Matt	21	Son	Traumatic Brain Injury	3	4 months (Deceased)
Kevin	60	Brother	Acquired Brain Injury	4	4 years (Ongoing)
Andrew	57	Father	Traumatic Brain Injury	6	3 months (Emerged from PDoC)
Kyle	54	Brother	Traumatic Brain Injury	1	5 months (Emerged from PDoC)

Interview Design

Semi-structured interviews captured participant experiences, allowing flexible dynamic dialogue between the researcher and participant with adjustments to questions based on responses (Smith et al., 2021). An interview schedule (See Appendix B. 4) guided discussions to align with research aims. To improve clarity and relevance, the researcher completed an online training module in 'Communicating with Families' through the Coma and Disorders of Consciousness

Research Centre and incorporated feedback on the interview schedule from an online brain injury support forum in February 2023.

Procedure

Potential participants were offered an initial telephone call with the researcher to discuss study details and address any queries. Participants who wished to take part provided consent by signing a Participant Consent Form (see Appendix B. 5). Interviews were then arranged at a convenient time and location, lasting approximately 1 to 2 hours, conducted either in person at the participant's home or remotely via Microsoft Teams. The interviews were video recorded, and the audio was transcribed.

Ethics

This study received ethical approval from Staffordshire University Research Ethics Committee and NHS Trusts (see Appendix B.6). All participants provided informed consent and were informed about the interview's potential emotional impact, ensuring preparedness. The researcher maintained a compassionate approach throughout and offered time for reflection and signposting to relevant support services and information post-interview (see Appendix B.7). Participants reported finding the interview meaningful, helping them understand their experiences and contribute to improving family support.

No significant distress was observed during the interviews beyond what is expected when discussing emotive content. The researcher managed their own well-being in response to the emotive material through supervision, self-care, and self-reflection.

Methodology

Interpretative Phenomenological Analysis (IPA) was selected for data analysis, guided by Smith et al. (2021). IPA explores how individuals construct meaning from their personal and social worlds, identifying overarching patterns of meaning-making (Smith et al., 2021). This approach is particularly suited for exploring novel, emotionally charged, and complex experiences such as PDoC (Smith & Osborn, 2015). IPA's idiographic exploration and cross-case comparison align with the focus on male family members' individual experiences and existentialism (Eatough &

Smith, 2017; Shinebourne, 2011). Additionally, IPA has been widely used in research on psychological distress and carers' experiences (Smith, 2011).

IPA was chosen over other phenomenological approaches, such as Thematic Analysis (Braun & Clark, 2006), due to the under-researched nature of the topic and the focus on gaining a deeper understanding of family members' unique lived experiences and individual voices, rather than solely collective accounts and patterns.

Sample size in IPA emphasises quality over quantity. Typically, six to ten interviews suffice for a professional doctorate, although IPA studies have included fewer participants (Gamgee et al., 2023; Smith, 2004). Given the rarity of PDoC, low response rates, the topic's sensitivity, and the depth of the interviews, six participants was considered sufficient to provide valuable insights (Smith, 2004; Vasileiou et al., 2018).

Data Analysis

Guided by Smith et al. (2021), an iterative and idiosyncratic process of immersive reading and exploratory noting was conducted for each transcript. This involved capturing unique points of interest and exploration related to language, feelings, thoughts, and participant contexts, which were developed into experiential statements (See Appendix B. 8). These statements were laid out visually and organised randomly to facilitate a visual search for a more conceptual ordering. Through this process, connections between statements were clustered, and Personal Experiential Themes (PETs) were identified for each participant (See Appendix B. 9 and B. 10).

Connections, patterns, and divergent experiences were then explored across all transcripts to identify Group Experiential Themes (GETs) and sub-themes (See Appendix B. 11 and B. 12). A GET was included when present in at least half of the participants, capturing the specific experiences of male family members of individuals with PDoC. Appendix B. 13 offers an extract illustrating the overall analytic process.

To ensure credibility and a thorough exploration of meaning, descriptive data and emerging themes were discussed within IPA workshops and academic supervision (Brocki & Wearden, 2006).

Epistemology and Reflexivity

The researcher's ontological position was interpretivist, recognising the existence of multiple truths shaped by personal experiences and engagement with the world (Feast & Melles, 2010). As a result, a social constructivist epistemological position was adopted to guide the exploration of the participants' unique and interpreted realities of PDoC. This aligned with IPA's 'double hermeneutic', where the researcher actively interprets the unique meanings of participant experiences while being mindful of their own subjective biases, epistemological positioning, and other potential influences.

The researcher acknowledged that their own beliefs and background as a Trainee Clinical Psychologist and experience working within neurorehabilitation could influence data interpretation. For instance, their understanding of families facing unclear and distressing situations, along with a predominantly medical perspective on consciousness, balanced with an openness to spiritual interpretations. Contextual factors such as the impact of the COVID-19 pandemic on participants' experiences were also considered.

To manage these influences, the researcher maintained a reflection log, engaged in regular supervision, and participated in IPA workshops. Additionally, self-disclosure about the researcher's background helped establish rapport with participants and to acknowledge the collaborative construction of meaning. This facilitated participants in sharing their experiences openly and deeply, enriching the data collected.

Results

The analysis revealed three group experiential themes (See Table 3). Quotes were used to illustrate each theme and ground the analysis within the data. Key idiographic experiences have been detailed and discussed.

Table 3

Group Experiential Themes (GETs) and sub-themes

GETs and sub-themes	Participant Contributions
1) Facing the Unknown: The Emotional Journey	
"I didn't know what to expect" – Facing Uncertainty	All
"It sort of takes the person away completely" - Loss of Person	All
"Under that pressure for a long, long time" - Enduring Struggles	All
2) Finding Meaning and Navigating Forward	
"Collecting knowledge" – Seeking Clarity	Ross, Matt, Phil, Andrew, Kevin
"I couldn't allow myself to be broken" – Finding Purpose and Stability	All
"Not in your pocket, but they were there" – Embracing Support	Ross, Matt, Phil, Andrew, Kyle
3) The Landscape of Care	
"We got the personal touch" - Compassionate and Collaborative Care	All
"You were the guardian" - Being Their Voice	Phil, Matt, Kevin, Ross

1) Facing the Unknown: The Emotional Journey

This theme captures the emotional challenges participants faced, describing their experience of PDoC as "happening without warning" (Phil), being "traumatic" (Ross) and "horrendous" (Andrew), resulting in a "high mental and emotional load" (Matt).

"I didn't know what to expect" – Facing Uncertainty

Participants faced "a period of limbo" (Ross), a prolonged uncertainty regarding their loved one's state and prognosis, grappling with the unfamiliar and ambiguous nature of PDoC: "I didn't know [what] the difference between a minimally conscious state and a vegetative state was, and I still don't really know what that is now" (Matt). Phil

shared how this led to a lack of preparedness for the unknown ahead: “I was bracing myself, as I didn’t know what to expect”.

Initially, participants relied on their existing knowledge of coma, heavily influenced by media depictions: “What is really difficult with prolonged disorders of consciousness is that Hollywood films, books, movies have depicted [them] in such a particular way, that you sort of feel like you have an understanding of what a coma is.” (Matt). However, this often led to unrealistic assumptions about PDoC and its prognosis: “I’ve probably watched too many movies … you just assume he is just going to wake up, and we are going to be happy ever after, and you realise it just doesn’t work like that.” (Andrew).

Some participants reflected on the limitations of more commonly known language when trying to understand PDoC. Matt highlighted comas lack of specificity due to the “huge nuance” between PDoC states: “Coma is not a typically used word, it’s more like disorders of consciousness or minimally conscious states … it feels less specific.” Kevin criticised terms like “vegetative state” as “Victorian”, reflecting on their dehumanising and outdated connotations.

All participants shared the immense difficulty in assessing their loved ones' awareness. Andrew compared it to fishing, emphasising the ambiguity of the situation and the patience and persistence required: “It’s a bit like fishing you are just sitting there, waiting for the fish to bite … desperately waiting for something to move.” Initially participants often interpreted movements as signs of awareness and interaction, creating a sense of hope and connection: “We would hold his hand and he did appear to be holding our hand if that makes sense.” (Ross). However, this was often overshadowed by the realisation of the complexity surrounding PDoC, leading to “loads of unknown” (Kyle) and a "massive amount of misunderstanding" (Ross). This ongoing uncertainty compounded their distress: "that is the horrible thing that played on my mind, like how aware is he?" (Matt).

“It sort of takes the person away completely” - Loss of Person

Participants experienced a profound loss extending beyond physical changes to core psychological aspects and relational dynamics. They expressed varying extents of loss for their loved ones, ranging from a feeling of the person being "trapped in their body" (Kevin), to fleeting moments of potential awareness, " we thought he was

back, but brief ... glimpses, and then he was gone again" (Kyle) to a complete loss of person: “It sort of takes that person away completely.” (Phil).

Witnessing physical changes in their loved ones was described as “scary” (Andrew) and “distressing” (Matt), including injuries, altered appearances such as grooming and clothing, medical devices, body movements, and facial expressions. Phil recalled the initial shock of seeing the reality of PDoC: “she was worse than I expected to see… it ripped my heart out.”

For some participants, this loss extended to meaningful connections integral to their relationships. Matt expressed this as “you have lost the person in all the ways you want” highlighting the struggle with ambiguity because: “physically they still exist, but they’re not around the house, you can’t speak to them.” Some participants spoke of losing shared activities that defined their relationships. Ross expressed the loss of activities that contributed to his “paternal bond”: “We used to do a lot of things together, so it broke me.” Phil described the absence of familiar physical connections from his daily life pre-injury: “You are missing the pair of cold feet and the warm body that has been a constant by your side for so many years.”

Some participants expressed grief, with Matt stating, “You are grieving from minute one”. However, due to the ambiguity of the situation, some experienced disenfranchised grief, not readily acknowledged or understood by others. This led to a sense of isolation due to a lack of social validation and support, as “people didn’t know what to say to us” (Ross). Phil noted discomfort in others being “wary” and unsure how to express their sympathy. Ross highlighted the absence of social norms for grieving during PDoC, noting that unlike typical bereavement, there were no clear societal guidelines to navigate and express their grief: “Had he [son] just died, it’s a finite situation. People know what to do in those situations.”

“Under that pressure for a long, long time” - Enduring Struggles

The enduring nature of PDoC was described by Ross as “a horrible experience” compounded by living “under that pressure, for a long, long time.” Kevin's ongoing four-year experience of his brother in PDoC highlights the extended duration families can face.

Matt reflected on the transition from the initial post-injury period to PDoC, as a shift from dynamic uncertainty to mundanity, symbolising a loss of hope and vibrancy: “When it was all up in the air, it felt more dynamic and colourful … there was a vibrancy to what was going on and it then got to sort of grey monotony.”

Matt illustrates the change from a dynamic state of uncertainty where “it felt about life” to a prolonged, emotionally draining monotony, in which “it started to feel more about lifelessness”. This change symbolises some participants’ journey from initial hope for recovery to a realisation of the prolonged and indefinite nature of PDoC: “What you don’t realise is how long it is going to be, at all … at the start you are kind of going is he going to survive?” (Kyle).

Even with signs of improvement, Andrew emphasised the unsettling nature of PDoC over time, from witnessing his son move through varying states of awareness and interaction, akin to “watching a dead person come back to life”, evoking distressing imagery “like you see in horror movies”.

Most participants expressed the cumulative personal costs and fatigue of living with the emotional impact of PDoC over time, characterised for many by a lack of change and loss of hope. Matt described reaching a point of exhaustion, “it got to a point where we were so tired” while Phil referred to “care fatigue”. Kyle expressed cycling through “every emotion”, ranging from “anger”, to “upset” and “feeling really down”. Andrew expressed how this cumulative emotional toll eventually “caught up” with him, resulting in a sense of burnout impacting his wellbeing and ability to cope.

2) Finding Meaning and Navigating Forward

This theme illustrates how participants sought to understand PDoC to inform their hope for improvement and how they coped with the challenges they faced.

“Collecting knowledge” – Seeking Clarity

Amidst uncertainty, participants sought clarity about consciousness and their loved one's state from various perspectives. Andrew described initial desperation, “we were on our knees”, emphasising their vulnerability as they “latched on” to any information from the care team.

The medical perspective helped some in making consciousness more “quantifiable”, by reframing it through the concept of responsiveness: “The big word that came up, was obviously consciousness, but also responsiveness, and I think that is really helpful.” (Matt). Ross shared how this differentiation helped to discern physical movements from signs of consciousness: “He wasn’t doing it to response… I think that was the difference.” (Ross).

This led some participants to characterise PDoC as a state where the body remained alive, but mental awareness had diminished. Phil likened it to: “a state of the living dead. Mentally she was dead … but the body was there”. As time passed with no significant change, hope for recovery waned, prompting acceptance that their loved ones were no longer the same individuals: “While he was alive, he wasn’t Richard … it took us a long time to come to terms with that.” (Ross). Expectations adjusted towards no further improvement, with Phil acknowledging, “there was only going to be one end game." (Phil).

Whilst participants respected the medical perspective, some felt it dismissed viewpoints outside standard clinical practice, including emerging research and rarer recovery cases. Matt acknowledged the complexities of understanding consciousness as an “absolute medical and philosophical phenomenon”, whereas Kevin expressed actively rejecting the prognosis, seeking out alternative perspectives to cultivate a more holistic understanding aligned with his beliefs and fostering hope: “I am collecting knowledge on it all, the diagnosis is prolonged disorder of consciousness yes, but why does it have to stop there? So that’s that and this is the person there?... No!”

Kevin expressed how spiritual beliefs formed an integral part of his understanding, which he sought to incorporate alongside the medical perspective: “We all have a soul, and we believe in the spiritual realm, and a life after death situation”. For Kevin, this meant viewing the body as a “vessel” for his brother’s soul and consciousness, which had become trapped “inside of there”.

“I couldn’t allow myself to be broken” – Finding Purpose and Stability

Participants derived purpose and stability from their familial and personal values, fostering resilience, acceptance, hope and a commitment to honouring their loved one in a PDoC.

Phil, despite experiencing “grief, anxiety, and anger”, focused on valued action, guided by the belief that “She would have gone mad, if I’d just sat here.” He chose to maintain stability through familiar routines to "pull things together”, emphasising life's fragility and prompting a renewed appreciation for each day: “What happened to her really focused my mind … make the most of every day, as it can just as quickly happen to you.”

Similarly, Matt reflected on his youth and the need to adapt and move forward despite adversity: “I can’t let this define me … I’ve got a whole life to live … just sort of like, cracking on.”

Ross, Andrew, and Kyle demonstrated resilience by prioritising their family roles and values to provide strength and support. Ross expressed his determination not to “allow myself to be broken”, while Andrew described entering “survival mode”, driven by “adrenaline” to support others over attending to his own needs. Kyle, while acknowledging the emotional toll, emphasised his “comforting role” towards his brother’s wife, recognising the importance of staying strong for her to maintain some stability: “You are not having the same reaction to it, because obviously you are trying to stay strong for his wife”.

Kevin found meaning and stability in drawing on family values of spirituality and positivity: “Only 10% or whatever come through this to which I said even it was only 1%, he would be that 1% person, because we live on positivity, and the glass is always half full rather than half empty”. This mindset strengthened his resilience: “where there is life, there is hope”, motivating him to “not give up”.

Participants also recognised the need to balance family responsibilities with preserving personal identities and routines. Participants highlighted the unintentional neglect of individual needs, as they were “desperate” (Andrew) and “just surviving, finding a routine that would work... without an awareness of our needs" (Matt).

Matt felt the pressure of becoming the sole man in the core family and questioned his readiness to assume new family responsibilities in this “man of the house” role, without family discussion: “My dad did everything around the house … something you have to be responsible for … sometimes I found that difficult”.

Ross acknowledged the importance of individual coping mechanisms between him and his wife, such as immersing himself in work, whilst maintaining unity in spousal and parental roles: “We are almost ships that pass in the night, but we're very much together... we have to cope in different ways." However, the emotional toll of PDoC also brought about changes, with Ross expressing diminished tolerance for responsibility and problem solving at work: "I don't want responsibility... that’s what it left me with … I find it very difficult to tackle problems."

“Not in your pocket, but they were there” – Embracing Support

Participants expressed the importance of social support in navigating their experience of PDoC, highlighting the supportive qualities received from a “very strong circle” (Ross) of friends, family, neighbours, and colleagues.

Matt and Phil highlighted the importance of others initiating social connections and the significance of having “people where their sole focus was me, not us as a family” (Matt), providing a compassionate space of individual-focused support. Phil valued friends treating him as an individual, fostering genuine connections: "You just wanted people to come talk to you, ring you up and have a chat."

Practical support, such as cooking meals, played a pivotal role in demonstrating care and presence: "They would bring you a cake, take you out for a meal, just to make sure that you knew they were there" (Phil).

Connecting with other families facing similar experiences was noted by Ross and Andrew as a powerful source of support and validation while navigating PDoC: “I think its… very powerful when you listen to another person who has lived that experience.” (Andrew).

Effective social support was characterised by flexibility, understanding and clear communication. Participants valued people who were available without being overbearing: "Not in your pocket, but they were there, and they would talk to you" (Phil). Matt, Andrew and Kyle all advocated for an ‘administrator’ within their support networks to disseminate information amongst family and friends, with Kyle taking on this responsibility himself, alleviating burden for core family members: “Give a really clear mandate and license to the people in your life on how they can help." (Matt).

Matt suggested concrete offers of assistance were more helpful than vague statements of support: "When people say, 'I'm here for anything,' that is a nothing phrase... 'I'm already at the shops, do you need me to pick anything up?' is much more helpful." Ross emphasised how this can reduce the burden felt by family members: "You don't need more decisions in your life".

3) The Landscape of Care

This theme captures the participants encounters with care teams, focusing on care towards themselves and their loved ones, working in partnership with the care team, and their role as advocates for their loved ones, making critical decisions regarding treatment and quality of life.

"We got the personal touch" – Compassionate and Collaborative Care

Participants emphasised the importance of compassionate care and effective partnerships with care teams. Ross highlighted the necessity of this, given the prolonged nature of PDoC: "this was going to be a long-term issue… we should have been treated differently … with more respect."

Challenges to compassionate care arose in impersonal and crowded hospital environments, where personal moments clashed with the clinical setting: "It is so impersonable … but at the same time, you are having the most difficult moments of your life" (Matt).

Participants desired a more personalised approach, including peaceful and private spaces, appropriate grooming, personal clothing, and displaying familiar items to maintain their loved one's sense of identity:

> He had not been groomed, he had not been washed, one of the things that was very important … we said, could we bring in clothes for him, it's part of, trying to put him in his own pyjamas, his own clothes, can we have some stuff for his room and that sort of thing (Ross).

The absence of these qualities left participants feeling their family members were dehumanised. Ross compared his son's treatment to being treated like "a piece of meat", fostering feelings of exclusion and dismissal as a "nuisance".

Some participants noted limitations in the medical perspective on PDoC, feeling it restricted diverse beliefs and hopes for improvement. Kevin's frustration exemplifies this when medical professionals stated his brother had little possibility of improvement, dismissing alternative views and denying the exploration of alternative treatments, leaving him feeling disregarded and sidelined, as he felt "[Put] in the corner, like the Victorian days". This highlights the importance of a collaborative, family-oriented approach, offering empathy, validation, and respect for diverse perspectives.

Positive care experiences occurred when the care team took the time to understand both the patient and the family, integrating meaningful actions to respect their identity and values: "They had got to know Jane and they had got to know me…the fact that we got the personal touch between them, and me, was great" (Phil). Participants emphasised that effective partnerships with the care team were essential for navigating PDoC and alleviating distress, highlighting the importance of "getting to know how their family dynamics work" (Kyle), which, as Ross noted, "eases the situation".

Participants also highlighted the need for proactive and compassionate psychological support for families. Andrew expressed dissatisfaction with the lack of discussion around psychological trauma and delayed inquiry into their well-being: "It probably took, 8 months before anyone asked me, how are you? How are you coping? … I was falling apart at that point".

Some participants felt power imbalances with medical professionals, struggling with new roles and complex decisions amidst sometimes differing viewpoints: "I did feel like I was fighting a constant battle, every time, all the time, and permanently." (Ross). In response, some participants adopted a proactive stance, asserting their needs and seeking clarity through pertinent questioning: "You knew what you were going in for, you knew what had got to be done and you wanted the answers to come with. So, you ask the questions, you weren't afraid to find them intimidating." (Phil).

Clear and honest communication was deemed "essential" by all, aiding comprehension and facilitating communication with wider support networks, even when conveying potentially distressing information: "If you have something to say to me, good, bad, you tell me straight from the hip." (Phil).

However, Andrew cautioned against care teams extinguishing hope, while acknowledging uncertainty: “Don’t kill the hope... But don’t tell us it is all lovely”. Kevin similarly appreciated balanced communication that continues to strive for improvement despite likely medical outcomes: “It’s not like we are right you are wrong, let’s just have a bit more positivity”.

Andrew suggested practical solutions like appointing a “family liaison officer” and providing resources focusing on lived family experiences of PDoC to bridge the gap between clinical knowledge and family needs.

“You were the guardian” - Being Their Voice

This sub-theme explores participants' roles as advocates, interpreting their loved ones' wishes and navigating complex treatment decisions. Phil exemplifies this role, portraying himself as a committed "guardian" to his loved one's care regardless of their state: "whether she was breathing and living, or in that state, I still had to look after her."

Reflecting on pre-injury qualities and values became crucial in quality-of-life discussions. Matt recalled conversations around his father’s views: “What was your dad like before? and what would be a good quality of life for him." Participants sought to ground themselves in their best understanding of their loved one's perspective, often requiring constant self-reflection, ensuring actions aligned with their best interests: "You also are always checking, are we putting ourselves first here?" (Matt).

Memories and shared experiences played a crucial role in informing decisions. Matt shared a poignant memory regarding his father's views on ending suffering, acknowledging the “stark” difference between “a deer on the side of the road and a person who is your dad in hospital”, while still drawing wisdom to voice his father’s views. Phil recounted his partner’s straightforward expression about quality of life and ending suffering, which Phil held as clear “instruction”: “She turned round to me and said if ever I get like that, shoot me… as far as I was concerned, I had got my instruction”.

Differing viewpoints within families and with the care team often led to tensions. Matt reflected on the difficulty of aligning family perceptions due to everyone’s personal

interpretations: "That was difficult because we were all shouting for dad and his corner, we just had different perceptions." Kevin expressed frustration at the differing viewpoints between families and the care team, regarding what constituted the best interests of their loved one: “doctors and things, you don’t own him, he is a part of us, and that’s where the frustration lies” (Kevin).

Participants recognised decision-making was influenced by various voices beyond the family. Matt emphasised the multifaceted nature of this process and the challenges associated with agency, recounting a distressing situation where the family's decision to withdraw treatment was overturned: "legally, medically you can’t just turn off the machines.”

Family dynamics played a crucial role in navigating treatment decisions. Matt described intimate family discussions as being like a "sofa cabinet," pivotal for decision-making: “It is where all the decisions were made, the hardest conversations would happen … those were the moments when we had to sort of bring it all together” (Matt).

Participants grappled with profound decisions often involving a lack of clinical information, life or death implications, low odds of success, uncertainty about their loved ones' views, and a fear of abandoning them: "It feels too tenuous to make a life and death decision." (Matt).

As hope for improvement diminished, some participants faced choices about maintaining or withdrawing life sustaining treatment. Discussing these options remained challenging, due to uncertainties, moral dilemmas, and cultural "taboos" around assisted dying. Ross felt discomfort as the care team "never explained what his options are," wanting to discuss withdrawing treatment but feeling he “didn’t have the right to ask”.

Some participants reflected on euthanasia and the ethical implications of ending life, revealing the need for open conversation: "when there is no future, then you should be able to sort of, have euthanasia" (Phil). Matt highlights the emotional weight of these choices, balancing medical reasoning with personal moral beliefs, revealing its nuanced and complex nature: "I knew it was right... I just didn’t feel right."

Discussion

This study explored how six male family members of individuals in a PDoC in the UK made sense of their experiences. The analysis was summarised into three GETs:

1) Facing the Unknown: The Emotional Journey
2) Finding Meaning and Navigating Forward
3) The Landscape of Care

These findings are discussed alongside relevant literature, clinical implications, research strengths and limitations, and future research directions.

Facing the Unknown: The Emotional Journey

These findings capture the profound emotional challenges faced by family members dealing with PDoC. These challenges are often sudden, traumatic, and marked by uncertainty about their loved ones' state and prognosis. Participants were unprepared for the ambiguous nature of PDoC, leading to unrealistic assumptions based on limited coma knowledge, highlighting widespread misunderstanding. Participants experienced profound loss, affecting psychological and relational dynamics. Grief was common but often disenfranchised due to PDoC's ambiguity. The enduring nature of PDoC was emotionally draining, with hopes for improvement often shifting to the harsh realisation of a prolonged and indefinite condition, leading to care fatigue and burnout.

Challenges for male family members align with existing literature focused on female family members (Soeterik et al., 2017, 2018). This emphasises the difficulties with prognosis, treatment, and emotional distress that distinguish PDoC from general caregiving (Bunn & Fritz, 2022; Chinner et al., 2021; Raciti et al., 2021). The profound psychological impact encompasses initial trauma, distress from witnessing physical changes, disrupted relationships and roles, complex loss, disenfranchised grief, and ongoing uncertainty about loved ones' state and future (Leonardi et al., 2012; Soeterik et al., 2017). Echoing Hamama-Raz et al. (2013), male family members navigated an ambiguous clinical situation marked by a lack of consciousness while the person remains alive, resonating with Boss's (1999) theory of ambiguous loss. PDoC introduces an unclear and unrecognised absence of

change in loved ones, disrupting conventional notions of loss and often leading to prolonged and complex traumatic reactions and grief experiences.

Finding Meaning and Navigating Forward

Male family members navigating PDoC undergo a dynamic process of understanding and adjustment, shaping their fluctuating hope for improvement or acceptance of their loved ones' condition. Relying primarily on the medical perspective, they viewed PDoC as a state where the body remains alive while mental awareness diminishes, leading many to revise their expectations for improvement over time. Some participants also integrated rare recovery cases and spiritual beliefs alongside clinical knowledge, aiming for a holistic view that acknowledges the complexities of consciousness and provides hope amidst uncertainty.

Participants demonstrate resilience by drawing strength from personal and familial values, maintaining roles and identities, and engaging with supportive social networks. This echoes other findings on the coping and adjustment strategies of male caregivers (Spendelow et al., 2017), emphasising the reinforcement of family roles and the pursuit of personal meaning. Boss and Yeats' (2014) guidance for resilience with ambiguous loss aligns with these strategies, highlighting the importance of finding balance, acceptance, and reconstructing family dynamics and social connections in the context of PDoC and its challenges.

The Landscape of Care

The participants interactions with care teams highlight the need for compassionate and personalised approaches that acknowledge both patient and family needs. This involves recognising and respecting diverse values, beliefs, identities, and hopes for improvement beyond conventional medical perspectives.

Active involvement in assessment, decision-making, and caregiving underscores the vital role of families within the care team (Raciti et al.,2021). This study illuminates the complex responsibilities and decisions families face, emphasising their significant contribution to care and desire for inclusion within the care team. Understanding family dynamics and establishing effective communication channels are crucial to this involvement.

Central to this is the role of family members as advocates, championing patients' prior wishes, evaluating quality of life, and making crucial decisions about treatment continuation or withdrawal. This aligns with the Royal College of Physicians' (2020) emphasis on family consultations, highlighting the valuable insights they bring to decision-making processes.

Additionally, this study explores bioethical implications, revealing male family members' struggles with ethical dilemmas such as patients' wishes, alleviating suffering, understanding consciousness, euthanasia, and life-sustaining treatment decisions (Kitzinger & Kitzinger, 2014). This deepens our understanding of the complex ethical landscape families navigate and the challenges encountered when collaborating with the care team.

Clinical Implications

This study highlights the essential role of clinical psychology in supporting families of individuals with PDoC, by providing direct care where this provision is available or by guiding other professionals, services and policymakers. The clinical implications outlined below demonstrate how psychological professionals can assist in improving support across the PDoC care pathway, including acute care, neurorehabilitation, long-term management, and end-of-life care.

Professionals need to understand the unique challenges facing families, beyond medical perspectives. Specialised training could ensure professionals are equipped with the knowledge to provide compassionate and responsive care which meets the unique needs of families at all stages of the care pathway. This could include workshops educating staff on families' experiences of being thrust into uncertain clinical situations with evolving emotional distress, and unique concepts such as ambiguous loss and disenfranchised grief. Additionally, it could consider families' efforts to make sense of and cope with these experiences and identify qualities that enhance their care experiences.

Family members experiencing PDoC should be offered specialised information on PDoC, including clear clinical information to understand this nuanced area of healthcare at each stage of the pathway and insights from the lived experiences of other families dealing with PDoC, to help validate their experiences and provide a framework for understanding and managing expectations.

Individuals and families need access to a range of psychological support options across the pathway, for a more personalised approach which can help address the emotional challenges they may face. This could include psychological interventions focused on resilience in the face of ambiguity. Boss and Yeats (2014) guidance for resilience with ambiguous loss could inform this, recognising the utility of finding meaning, adjusting mastery, reconstructing identities, normalising ambivalence, revising attachments, and discovering hope. Counselling services, such as bereavement counselling, could help address both ambiguous losses experienced throughout the pathway and traditional losses, such as in end-of-life care. Additionally, building a peer support network, such as PDoC support groups or access to resources on family experiences, may provide an alternative source of psychological support to traditional therapeutic interventions.

These findings highlight the importance of adopting a family-oriented care approach, beyond the traditional patient-focused care model. Care teams need to understand the family context, through awareness of individual and family values, beliefs, roles, and identities, to effectively support and work alongside them. For example, encouraging an approach where we work with families to help them understand the clinical perspective in a helpful way for them, without the need for them to necessarily agree or conform to the clinical perspective. This will allow clinical teams to tailor information and support to family experiences and context and where they are currently at in their understanding, potentially reducing the tension families experience from differing views and perspectives.

As recommended by Olding et al. (2016), a family-oriented approach can also involve integrating family members into research, policy, and practice as partners in care, ensuring they understand their rights to be involved and have a voice in their loved one's care and decision-making processes. This collaborative approach fosters trust and understanding, ensuring their views are heard and empowering families to regain some sense of agency and contribute meaningfully to the decision-making process, while promoting psychological safety by fostering open dialogue where family members can express concerns and collaborate (Grailey et al., 2021).

Furthermore, this approach enables professionals to guide families through the complex ethical and legal decisions associated with PDoC. Bullock (2011) highlights

discomfort and avoidance in discussing death and dying due to factors such as fear, cultural norms, and lack of communication experience in end-of-life discussions. Proactively offering clear information and consultation to families on these ethical issues, can create a safe space for families to voice concerns, contributing to ethically sound decision-making, which maintains respect for family values, alleviates taboos around discussing death, and improves readiness for end-of-life outcomes (Virdun et al., 2017).

Strengths and Limitations

This research provides original, rich and clinically relevant insights into the experiences of male family members of individuals in a PDoC in the UK, obtained through a rigorous approach, broadening our understanding of family experiences. However, several limitations should be considered, suggesting directions for future research.

The small sample size may limit the transferability of findings and is reflective of the recruitment challenges experienced despite extensive recruitment efforts over a year. This highlights the need for a national PDoC database, a network of professional contacts within the field, and support groups to increase public awareness and broader engagement with research across diverse PDoC presentations and settings.

Additionally, the exclusive focus on NHS care experiences in the UK may limit the applicability of findings to other contexts. All participants' experiences occurred during the COVID-19 pandemic (March 2020 to December 2021), adding complexity to the transferability of their care experiences.

While the study captures individual experiences and patterns, it does not specifically explore the varying family roles among male family members, post-injury durations, causes, outcomes, and specific states of consciousness impairment. These factors underscore the population's complexity and the need for further investigation.

While ethnicity data was not formally collected, the predominance of white British participants highlights broader issues of diversity in health research (Rai et al., 2022). Addressing this gap is crucial to ensure inclusivity and explore how diverse

cultural perspectives, for example those on consciousness, spirituality, and community support influence experiences of PDoC.

Conclusion

This research highlights the complex experiences of male family members of loved ones in PDoC in the UK, marked by profound emotional challenges, including uncertainty, ambiguous loss, enduring emotional distress and fatigue. Participants navigated these challenges by finding meaning and resilience while playing a key role within the PDoC care pathway. These findings expand the existing PDoC literature, adding the male family member perspective to a body of work that has predominantly focused on female caregivers, thus providing a more holistic understanding of the family experience. The study emphasises the need for family-oriented, compassionate care that prioritises understanding, communication, collaboration, and support, beyond the patient-focused medical perspective.

While offering valuable insights for both families and clinical professionals, the research highlights the challenges in researching this population, and the need for further exploration of PDoC's nuanced aspects, diverse family and cultural contexts, and larger, varied samples to enhance the transferability of findings and to ensure support strategies are inclusive and responsive to each family's unique needs.

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Appendices B: Empirical Paper Appendices

Appendix B. 1: Author Guidelines

Author Guidelines – Neuropsychological Rehabilitation

(https://www.tandfonline.com/action/authorSubmission?journalCode=pnrh20&page=instructions#ffs)

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

This title utilises format-free submission. Authors may submit their paper in any scholarly format or layout. References can be in any style or format, so long as a consistent scholarly citation format is applied. For more detail see the format-free submission section below.

Format-Free Submission

Authors may submit their paper in any scholarly format or layout. Manuscripts may be supplied as single or multiple files. These can be Word, rich text format (rtf), open document format (odt), or PDF files. Figures and tables can be placed within the text or submitted as separate documents. Figures should be of sufficient resolution to enable refereeing.

- There are no strict formatting requirements, but all manuscripts must contain the essential elements needed to evaluate a manuscript: abstract, author affiliation, figures, tables, funder information, and references. Further details may be requested upon acceptance.
- References can be in any style or format, so long as a consistent scholarly citation format is applied. Author name(s), journal or book title, article or chapter title, year of publication, volume and issue (where appropriate) and page numbers are essential. All bibliographic entries must contain a corresponding in-text citation. The addition of DOI (Digital Object Identifier) numbers is recommended but not essential.
- The journal reference style will be applied to the paper post-acceptance by Taylor & Francis.
- Spelling can be US or UK English so long as usage is consistent.

Note that, regardless of the file format of the original submission, an editable version of the article must be supplied at the revision stage.

Appendix B. 2: Participant Information Sheet

IRAS project ID: 321566 REC reference: 22/YH/0276

Version 1.2 (28/12/22)

Participant Information Sheet

Title of study

Male experiences as a family member of a person in a prolonged disorder of consciousness: A qualitative study.

I would like to invite you to participate in this research project which forms part of my professional doctorate research. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please get in touch if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

People who have a family member with a disorder of consciousness after a brain injury can face many challenges. For example, having to suddenly learn a lot about the injury and medical teams, cope with the uncertainty of the diagnosis and future, juggle the changes to home life and cope with the impact of the injury on their own lives.

We recognise that these challenges are often shared by the whole family, and therefore want to explore what this experience is like for male family members, as there is limited research on this.

The aim of this study is to investigate the experiences of male family members of people who have a disorder of consciousness within the UK, to better understand this experience, which may help us consider what support may most help families in this situation.

Why have I been invited to take part?

You have been invited because you meet the criteria outlined below:

- You identify as male.
- You are over 18 years of age.
- You live within the UK.
- You have a family member with a diagnosed prolonged disorder of consciousness within the UK.

It is important to note that in line with the Royal College of Physicians (2020) prolonged disorders of consciousness guidelines, we define a family member as anyone who has a sufficiently close relationship with the person, to be actively concerned with their management and wellbeing. Therefore you do not need to be a family member by legal ties or blood relations.

What will happen if I take part?

If you would like to find out more, your contact details will be given to the researcher for this study, Connor Watkins. You can also make contact yourself using the contact details at the end of this information sheet. You will then be contacted by him to discuss the research and answer any questions. If you wish to continue, you will be asked to read and sign a consent form and then he will arrange a time with you to conduct an interview.

The interview will involve answering questions and discussing your experience of what it is like having someone close to you with a prolonged disorder of consciousness. The interview will either take place face to face in a quiet room or be conducted online in a private space. We will aim to conduct the interview at a time and place that is most convenient to you. If face to face, this could be conducted in a private place such as a room at Staffordshire University, a NHS site, a private healthcare site or your home. If conducted online, this would be done by online video call via Microsoft Teams and it will need both the researcher and participant to be in a quiet uninterrupted environment such as in the comfort of your own home. You would also need to have access to a device that allows you to do online video calls. The interview should last between one to one and a half hours, depending on how much you have to say.

All interviews will be video recorded and some notes may be taken during the course of the interview. This will only be done with your consent and the researcher will indicate the start and end of the recording. Once the interview is over and it has been recorded, the audio will then be transcribed by the researcher Connor Watkins and analysed in an attempt to make sense of your personal lived experience.

Do I have to take part?

No. Participation is completely voluntary. You should only take part if you want to and choosing not to take part will not disadvantage you in anyway or affect your family members care. Once you have read the information sheet, please contact us if you have any questions that will help you make a decision about taking part. If you decide to take part we will ask you to sign a consent form and you will be given a copy of this consent form to keep.

What are the possible risks of taking part?

Whilst you may find that discussing issues of concern is helpful, it is possible that some people might find it distressing to talk about their experience. We would like to reassure you that you will be very much in control of the information you choose to share with us and you can refuse to answer any questions you would prefer to avoid, take a break or decide not to continue with the interview without having to justify why.

At the end of your participation we will have some time to talk about how you have found the interview and we can suggest to you some sources of further support and information if this is required.

What are the possible benefits of taking part?

A potential benefit of the research is that you have the chance to feedback on your experiences, which some people can find helpful.

In the longer-term, the findings of this study has the potential to add to our understanding of what it is like to have a family member with a prolonged disorder of consciousness within the UK, with the hope that this may then help inform what support services offer to families.

Data handling and confidentiality

Your data will be processed in accordance with the data protection law and will comply with the General Data Protection Regulation 2016 (GDPR).

All information about your participation in the study will be kept confidential. Any information about you or family members will be either removed or changed so that you or they cannot be recognised. The recording of the interview will be erased once it has been transcribed. All data will be stored securely in a password protected folder and will only be shared with the research team, if they wish to check that the study is being carried out correctly. The data will only be used for the purposes of the current study. All data stored within the university system will be kept for ten years and then destroyed.

Your name will be changed and replaced with a pseudonym (Such as on the saved file of the recording of the interview and the interview transcript).When the study is written up we will use some quotes from the interviews as examples of what people have said. If we use any extracts from your interview they will not contain your name or anything that identifies you as an individual and it will be completely depersonalised and anonymous.

If during the course of the interview I become aware of any risk of harm to yourself or others or criminal activity, I will be obliged to report this to the relevant authorities.

Data Protection Statement

The data controller for this project will be Staffordshire University. The University will process your personal data for the purpose of the research outlined above. The legal basis for processing your personal data for research purposes under the data protection law is a 'task in the public interest'. You can provide your consent for the use of your personal data in this study by completing the consent form that will be provided to you.

What if I change my mind about taking part?

You are free to withdraw your data from the study without having to give a reason **within one calendar month** of the date of your interview, after which withdrawal of your data will no longer be possible, due to the data having been already processed and anonymised by this time. Withdrawing from the study will not affect you in any way.

If you change your mind about taking part you will need to contact the researcher Connor Watkins within this time and he will then be able to delete your data.

If you choose to withdraw from the study, we will not retain any information that you have provided us as a part of this study.

How is the project being funded?

This project is being funded by Staffordshire University.

What will happen to the results of the study?

The results will be used to help the researcher understand the unique experiences of families of people with a prolonged disorder of consciousness and what support may be most useful for families. The study may also be written up for publication in scientific journals

and may be presented at scientific conferences. Any quotes that are being used in reports or in presentations will be completely depersonalised and anonymous. If you would like to know the results you can be provided with a summary sheet.

Who should I contact for further information?

If you would like to participate in this study, or if you have any further questions about this study, please read and sign the attached Permission to Contact Form and return this to the clinical professional who gave you this information. The researcher, Connor Watkins will then contact you to discuss your participation further.

Or you can contact the researcher yourself using the following contact details:

Mr Connor Watkins, Trainee Clinical Psychologist.

Telephone: 07971793024 Email: w026427l@student.staffs.ac.uk

Staffordshire University, College Road, University Quarter, Stoke-on-Trent, Staffordshire, ST4 2DE

If within **one calendar month** we do not hear from you or you do not respond after we receive the Permission to Contact Form we will assume you do not wish to participate and destroy any contact information we have received.

What if I have further questions, or if something goes wrong?

If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study, you can contact the study supervisor or the Chair of the Staffordshire University Ethics Committee for further advice and information:

Dr Kim Gordon, Research Supervisor

Tel: 01782 294830 Email: Kim.Gordon@staffs.ac.uk

Dr Tim Horne, Chair of the Staffordshire University Ethic Committee

Email: ethics@staffs.ac.uk

Thank you for reading this information sheet and for considering taking part in this research.

Appendix B. 3: Participant recruitment poster

Appendix B. 4: Interview Schedule

Interview Schedule

Version 1.1 (28/09/22)

- Thank person for agreeing to participate.
- Brief on how long interview will take.
- Remind them of their right to withdraw and confidentiality.
- Remind them they do not have to answer any questions they do not want too, can ask to take a short break and can stop at any time.
- Remind of the purpose of the interview – That this is about them and their experience, there are no right or wrong answers.
- Ask if there are any questions before we begin.
- Start recording and double check this is working.

1) **I wanted to start by doing a family tree with you. This gives me an idea of the important people in your life and also makes sure I know who you are talking about during the interview.**

2) **What do you understand about X 's condition (diagnosis, treatment, prognosis) at the moment?**

Example prompts: What can they do? What can't they do? What do you believe they can understand now? What do you believe the reasons are for their non-responding?
Probe: How have you found out information (Internet, other families, Headway, ward staff).

3) **What does their condition mean for you?**

Example prompts: Can you give me any examples of things in your life you've had to change since their injury? How did that feel? What bothers you most about the situation you've found yourself in?
Ask about thoughts and feelings (mood, work, finances, childcare, role changes).

4) **What is visiting them like for you?**

Example prompts: What do you do when you are visiting? What do you think about? How do you feel when you visit? How often do you visit? Do you do anything to make it easier to come?

5) **How do you see things will be in the future?**

Example prompts: What, if any, certainty about the future is there? How do you see their longer term outcomes impacting on your life and future? What type of relationship do you see with them going forward?

6) **What have you done to cope with this situation?**

Example prompts: What help have you had that has made a real difference for you? What do you think would have been or would be helpful for you now? Thoughts, feelings and Uncertainty?

7) **What do you think might be important for other people in your position to know and do, to help them cope?**

8) **Is there anything we haven't talked about that you think is important?**

- Thank them for participating.
- Discuss what will happen to the results and the study.
- Remind them of confidentiality and in order to keep the information confidential I will use a pseudonym so no one knows who you are.
- Remind them of my contact details.
- Ask if they want to receive details of the study when it is finished and how to contact them for them.
- Switch off recording and check.

Appendix B. 5: Participant Consent Form

IRAS project ID: 321566 REC reference: 22/YH/0276

Version 1.2 (28/12/22)

Participant Consent Form

Title of study

Male experiences as a family member of a person in a prolonged disorder of consciousness: A qualitative study.

Name of Researcher: Connor Watkins Please Initial

1) I confirm that I have read and understand the Participant Information Sheet Version 1.2 (28/12/22) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	
1) I have had enough time to consider whether or not I want to be involved with this study. I understand that my participation is voluntary and that I am free to withdraw at any time within **1 calendar month** from the date of my interview without giving any reason.	
2) I understand how my data will be handled and stored.	
3) I give consent for regulatory authorities to access my data for audit purposes.	
4) I understand that anonymised quotations maybe used in the research reports.	
5) I agree to take part in the above study.	

Your Name (Participant):	Date:	Signature:

Name of Researcher taking consent:	Date:	Signature:

Would you like to receive a summary of the study once it is completed?

Please Circle: Yes / No

Appendix B. 6: IPR approval and HRA/NCRW REC approval

IRAS project ID: 321566 REC reference: 22/YH/0276

INDEPENDENT PEER REVIEW APPROVAL FEEDBACK

Researcher Name	Connor Watkins
Title of Study	Male experiences as a family member of a person in a prolonged disorder of consciousness: A qualitative study
Status of approval:	**Approved**

Thank you for your submission to the Independent Peer Review (IPR) Panel. Your application is now approved

Action now required:
You must now apply to the Integrated Research Applications System (IRAS) for approval to conduct your study. You must not commence the study without Health Research Authority (HRA) approval, and relevant site-specific approvals. Please note that the University Sponsor contact to be named on the form is Prof Nachi Chockalingam.

Please forward a copy of the letter you receive from the IRAS process to ethics@staffs.ac.uk as soon as possible after you have received approval.

Once you have received HRA approval, and participating Trusts/organisations have confirmed their capacity and capability to support your study, you can commence your research.

You should note that any divergence from the approved procedures and research method will invalidate any insurance and liability cover from the University. You should, therefore, notify the Panel of any significant divergence from this approved proposal.

When your study is complete, please send an end of study report to Edward Tolhurst: e.tolhurst@staffs.ac.uk. A template can be found on the ethics Blackboard site.

Comments for your consideration: None

Signed: Dr Edward Tolhurst
University IPR coordinator

Date: 28th September 2022

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Mr Connor Watkins
639 Burnage Lane
Manchester
M19 1TF

Email: approvals@hra.nhs.uk

10 January 2023

Dear Mr Watkins

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Male experiences as a family member of a person in a prolonged disorder of consciousness: A qualitative study.**
IRAS project ID:	**321566**
REC reference:	**22/YH/0276**
Sponsor	**Staffordshire University**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **321566**. Please quote this on all correspondence.

Yours sincerely,
Alex Thorpe

Approvals Manager

Email: approvals@hra.nhs.uk

Copy to: *Dr Tim Horne, Sponsor's Representative*

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Copies of materials calling attention of potential participants to the research [Headway Research Advertisement Information]	Version 1.0	13 October 2022
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Staffordshire EL PL]	Version 1	28 September 2022
Interview schedules or topic guides for participants [Interview Schedule]	Version 1.1	28 September 2022
IRAS Application Form [IRAS_Form_09112022]		09 November 2022
IRAS Application Form XML file [IRAS_Form_09112022]		09 November 2022
IRAS Checklist XML [Checklist_30122022]		30 December 2022
Organisation Information Document [Organisation Information Document]	Version 1.0	02 November 2022
Other [Permission to Contact Form]	1.0	28 December 2022
Other [IRAS project ID 321566 (Favourable Opinion with Additional Conditions) Revisions]	1.1	30 December 2022
Other [IRAS Research Summary]	1.1	28 December 2022
Other [Risk Assessment]	Version 1.1	28 September 2022
Other [Staffordshire Uni Professional Indemnity]	Version 1	28 September 2022
Other [UHNM Peer Review by R&D and Lead Clinician]	Version 1.0	01 November 2022
Participant consent form [Consent Form]	1.2	28 December 2022
Participant information sheet (PIS) [Participant Information Sheet]	1.2	28 December 2022
Research protocol or project proposal [University Research Project Proposal]	1.1	19 October 2022
Schedule of Events or SoECAT [Schedule of Events]	Version 1.0	02 November 2022
Summary CV for Chief Investigator (CI) [Summary CV for CI/Student]	1	19 October 2022
Summary CV for Chief Investigator (CI) [Summary CV for CI/Student]	1.1	28 December 2022
Summary CV for supervisor (student research) [Academic Supervisor CV]		08 October 2022

IRAS project ID	321566

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
There is only one site type. Research activities and procedures as per the protocol and other study documents will take place at participating NHS organisations.	NHS Organisations will not be required to formally confirm capacity and capability, and research procedures may begin 35 days after provision of the local information pack, provided the following conditions are met. - HRA and HCRW Approval has been issued - The NHS organisation has not provided a reason as to why they cannot participate - The sponsor may start the research prior to the above deadline if the participating NHS organisation positively confirms that the research may proceed. The sponsor should now provide the local information pack to participating NHS organisations in England and/or Wales. A current list of R&D contacts is accessible at the NHS RD Forum website and these contacts MUST be used for this purpose.	An Organisation Information Document has been submitted and the sponsor is not requesting and does not expect any other agreement to be used with participating NHS organisations of this type.	No funding will be provided to sites, as detailed in the Organisation Information Document.	A Local Collaborator should be appointed at participating NHS organisations.	Where an external individual who does not already hold an NHS employment contract will be conducting any of the research activities that will be undertaken at this site type then they would be expected to hold an Honorary Research Contract. These should confirm Occupational Health Clearance and standard DBS checks and appropriate barred list checks.

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.
The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix B. 7: Participant Signposting Information

NHS
Northern Care Alliance
NHS Foundation Trust

Collated and developed by Kerry Watts (Senior Assistant Psychologist) and Dr Alistair Teager (Consultant Clinical Neuropsychologist)

Name	Services	Referrals	Website	Contact Details	QR Code
Day One Trauma	Practical and emotional support, alongside NHS clinical care, for patients and their loved ones. From day one and for as long as people need them	Online form	https://www.dayonetrauma.org/	Telephone: 0300 303 5648 Email: dayone@dayonetrauma.org	
Same You	Digital resources, shared experiences, UK neuro recovery directory (signposting)	Not Applicable	https://www.sameyou.org/	Not applicable	
Brain injury is big	Telephone support, online forum, support clinics, social events, financial support	Application form online	https://www.braininjuryisbig.org.uk/	Telephone: 01483 770999 (between 9am and 9pm) Email: info@braininjuryisbig.org.uk	

	(grant system)			Contact form online	
After Trauma	Recovery App, chatroom for trauma survivors, psychoeducation	Not Applicable	https://www.aftertrauma.org/	Online form	
Headway	Telephone support, financial support, psychoeducation, digital resources, approved care services, legal support directory, groups, online communities	Not Applicable	https://www.headway.org.uk/	Free, confidential helpline: 0808 800 2244 helpline@headway.org.uk General enquiries: 0115 924 0800 | Email: enquiries@headway.org.uk Online contact form	
Brain and Spine Foundation	Telephone support, psychoeducation, online support group	Not Applicable	https://www.brainandspine.org.uk/	Helpline: Tel: 0808 808 1000 Email: helpline@brainandspine.org.uk General: Tel: 020 3096 7880 Email: info@brainandspine.org.uk	

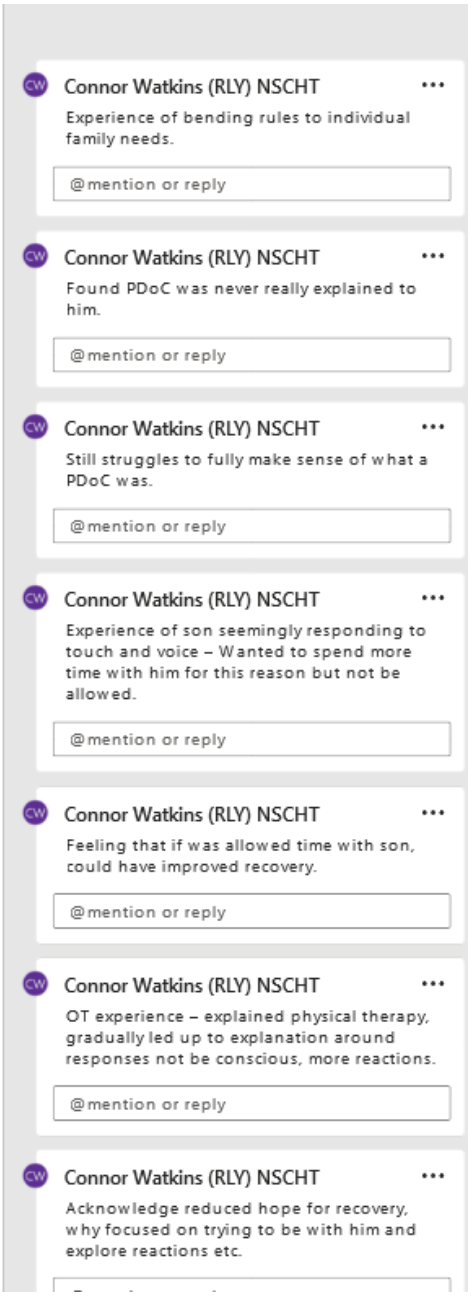
The Brain Charity	Helpline, online resources, family and carer support, groups		https://www.thebraincharity.org.uk/	Helpline Telephone: 0800 008 6417 Email: info@thebraincharity.org.uk	
Locked in trust	Information, advice, support with purchasing equipment	Not Applicable	http://www.lockedintrust.co.uk/	Online form	
Stroke Association	Information, advice, support groups, telephone support	Not Applicable	https://www.stroke.org.uk	Stroke helpline: 0303 3033 100 Supporter Care: 0300 3300 740 Email: helpline@stroke.org.uk	
Back up trust (Spinal Cord Injury)	Information and guidance, activity courses, family support (relative days, mentoring, forums, courses)	Not Applicable	https://www.backuptrust.org.uk/	Contact number: 020 8875 1805 Email: admin@backuptrust.org.uk Online contact form	
Spinal Injuries Association	Support sessions, information and guidance, family counselling	Not Applicable	https://www.spinal.co.uk/	Contact number: 0800 980 0501 *Support session web link (book on):* https://www.spinal.co.uk/find-	

				support-now/	
The Disabilities Trust	Assessments, rehabilitation centres, information and support	Contact: 0330 0581 881 Email: dt.referrals@nhs.net	https://www.thedtgroup.org	Contact form online	
Aspire (Supporting people with spinal injury)	Advice, home assistive technology	Not applicable	https://www.aspire.org.uk/	For information about services for people with Spinal Cord Injury: Accessible Housing Tel: 020 8420 6720 Email: housing@aspire.org.uk Housing Advice Tel: 020 8420 6709 Email: HousingAdvice@aspire.org.uk Assistive Technology Tel: 020 8420 6732 Email: technology@aspire.org.uk Independent Living Tel:	

				020 8420 6735 Email: advice@aspire.org.uk Welfare Benefits Advice Tel: 020 8420 6711 Email: welfarebenefits@aspire.org.uk	
BASIC (Brain and Spinal Injury Centre)	Complementary therapies, Exercise and well-being, Physical rehabilitation, Cognitive rehabilitation, Psychological support, Vocational support (for TBI/ABI, spinal cord injuries) – Private rehabilitation	Self-referral and professionals form online	https://www.basicharity.org.uk/	Phone: 0161 707 6441 Email: enquiries@basiccharity.org.uk Opening Hours: 10:00AM – 17:00PM (Monday – Thursday)	
Spinal Track	Free track days/rally experiences to disabled drivers (car enthusiasts)	Booking form online	https://spinaltrack.org/	Not applicable	

Appendix B. 8: Example transcripts showing exploratory noting and experiential statements (example from Phil and Ross)

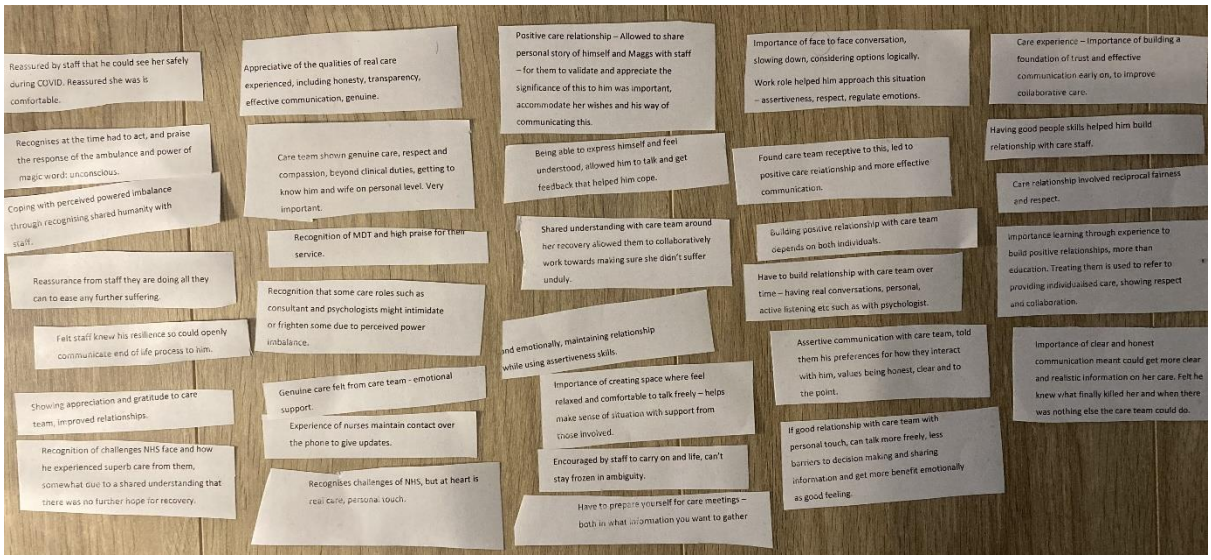
Experiential Statements	
(Capture lived experience, reflect description of their lived experience and how I have interpreted this/understood this, use of there language if possible).	
Lack of explanation of PDoC, still struggles to fully make sense of this.	*P: Yeah and they said, we have to have It on zoom. And I said that's ridiculous, I'm not having it on zoom, and she said actually, so she asked around, and said are comfortable sitting in a room with him? Yes, hospital management said no, so it's (laugh), these sort of things happen. So in terms of, getting on to what you are interested in, it was never really explained to me, and I consider myself reasonably intelligent, I never got my head around what exactly the prolonged disorder of consciousness was. Because to my mind, he was turning to our voice, he was clutching our hand and I wanted to spend more time with him and I wasn't allowed, and underlying all of that, there was that feeling that had I been able to spend more time with him, possibly, there may have been a reaction, you know we may have seen some improvement. And Jenny, and her co therapist explained to me what they were doing, physically therapy, and gradually leading up to explain to me the difference at that point as I understood it was that yes he would clutch our hands, but we told him to clutch our hands and he did it, that would be a different thing, he wasn't doing it to response, was the way I understood it, he did turn to the sound of our voice, but then he would turn away again, it wasn't specific to command, I think that was the difference. And at that point obviously we knew then how long he had been without oxygen, erm... But they were working with him. He was then moved, we felt we were making progress, he was still nit he side room, being looked after at that point virtually 24/7, I'm not convinced that was the case, but it was supposed to, it was what was told to me.*
Due to confusion over responses being signs of conscious awareness, meant more distress when not able to visit as often as would like.	
Wonders whether if was allowed more time with son, could he have had better chance at recovery.	*I: Sure.*
OT's in care team gradually began to explain the cause of reactions not being conscious actions. Also time without oxygen = realisation that low chance of recovery.	*P: and then without, telling us, they then moved him off the side room, at this point I was visiting just on a Saturday, without telling us they then moved him onto the general ward, still on H2, but with other people and what have you, and then they told us that they would have to stop visiting, because there was COVID on the ward they had moved him too (Laughs). So bare in mind, he still had a tracheotomy, was still very fragile, and there was no visiting, so they had moved him from a private room to a ward that had COVID on.*
Some mistrust in care team providing level of care they agreed upon, due to not being as involved in decision making and actions as wanted.	*I: Yeah, so essentially moved him to a more vulnerable space, one that limited the things you*
Feelings of anger towards hospital for lack of inclusion of them in sans care.	*P: Yeah, and we got very angry. So we then came to a separate agreement about visiting, after about 3 weeks, we would book a time to visit him which was all agreed, with covid tests, not a problem at all. They would push him out of the room, into what was like a break room almost.*
Not treating son as a person – By pushing him out, leaving him there, not grooming properly.	*I: Sure.*
	P: And leave him, and then they would let us in and (laughs). This was a covid restriction or interpretation of it, but it made it very difficult for us to understand, and we saw yet again that he had not been groomed properly, and we were told, that was part and parcel of what was making him more comfortable, and making him be more himself, that he would be groomed, he would be in his own clothes, people would be with him.



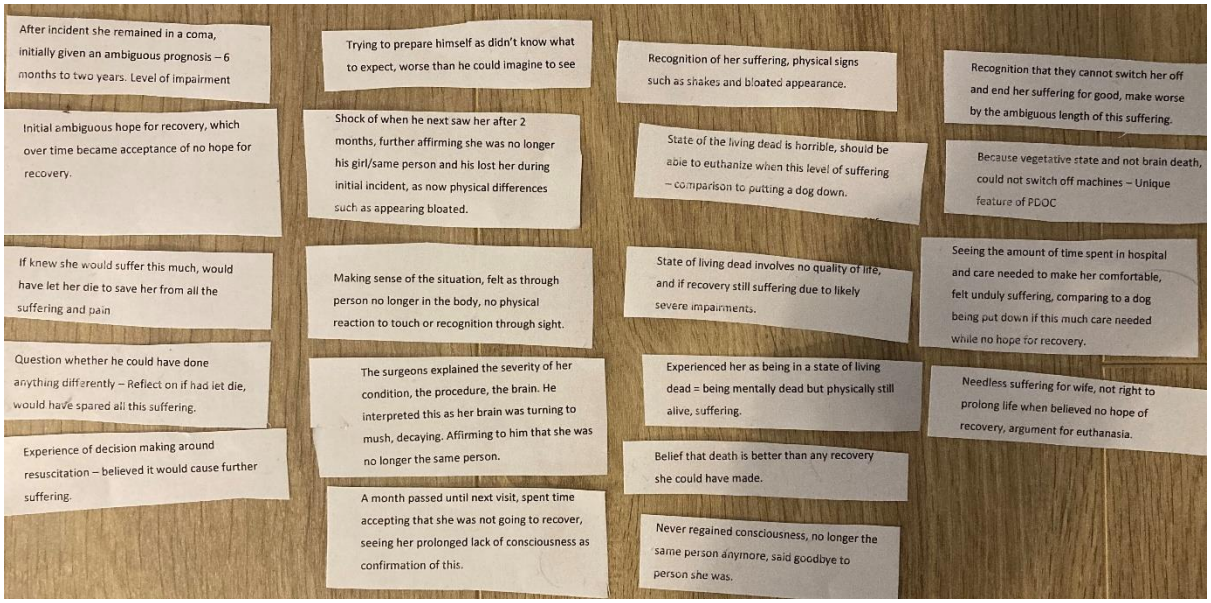
Importance of funeral not being traditionally black and macabre – Colour expression of celebration of her life. Respecting her wishes, being her voice again.	*P: And there was no black at the funeral, and 31 MGs behind her hearse.*	Connor Watkins (RLY) NSCHT No black, more of a celebration of life? Lots of friends? @mention or reply
	I: Yeah. Wow. Did it, I guess having that knowledge of those wishes and things, did it help in any way. I guess, knowing what she wanted, did that help put that across, you know you had some knowledge directly from her to share…	
Reminiscing on being present with each other, the conversations had, drawing from them motivation and directions of how to move forward.	*P: That's right. Yeah. I mean, it was strange, you could go out and have coffee at a garden centre, it was our time so to speak, nothing to distract you around you, and you would just talk about the strangest of things, but it's just bits that stick in your mind. You know, always looked after her, because it was like I said, she was under 5 foot, and she was basically my darling, so you always looked after her, she had her own ways and own things but you were there. You were the guardian. Whether she was breathing and living, or in that state, I still had to look after her.*	Connor Watkins (RLY) NSCHT Remembering all the random discussions, stick in your mind. @mention or reply
	I: That role remained constant?	
Role of guardian/duty to look after her, continues after life, to PDOC, to death. During PDOC experience this included preparation for meetings and information gathering.	*P: Yeah, and all the times we had the meetings at the hospital, it was always my concern. I always had my lists of questions, you know what it's like when you are talking to somebody and you, you forget stuff, and they would say something that throws you off track. Every time I went to a meeting, they knew I had a list of questions, so they knew I was prepared for that meeting and what I wanted to know.*	Connor Watkins (RLY) NSCHT Always looked after her – both living, inbetween, and in death? @mention or reply
	I: Would that be something you would spend time within the lead up to the meeting?	Connor Watkins (RLY) NSCHT Role of guardian – whatever state she was in, she still own person, but duty to be there. @mention or reply
Information gathering, sense making, decision making – All with care team. As way to cope and continue to be her voice.	*P: Yeah, as you went through stuff from the end of the previous meeting. The stuff would be going through your head, so you would write it down, and that would lead to something else. So you would always have that list, silly questions and other things you needed to know for your peace of mind. You know, what is the prognosis going to be? How long has she got? How long is this going to go on for? What are you going to do with her?*	Connor Watkins (RLY) NSCHT During MDT around care – always guardian role in mind. Took seriously with notes/questions etc. preparation. @mention or reply
	I: Did you feel with that, well I guess the very nature of that type of injury is that it can be quite ambiguous in terms of prognosis, length of time, you know even, if there are signs of regaining consciousness, the level of impairment, and it sounds like as you said, wanted to give straight questions and get straight answers for peace of mind, did you feel.. How was it, because I imagine they couldn't give straight answers to some but they could be as straight as they can?	Connor Watkins (RLY) NSCHT Decision making – writing down – silly questions, clinical, things for peace of mind. @mention or reply
Importance of clear and honest communication meant could get more clear and realistic information on her care. Felt he knew what finally killed her and when there was nothing else the care team could do.	*P: Well that was it, when you would ask the prognosis question they would sort of, because they could talk straight to me, they could say we are doing this, she is getting these infections, we are fighting them, because they have got to maintain life until such time as she regains… Because it was an infection in the end that finished her off, because she had a tracheotomy in, and they were basically, they were bug traps weren't they. And she got a chest infection, at which point they said they have got nothing that can actually beat this infection.*	Connor Watkins (RLY) NSCHT Information gathering - What will you do to her? How long for etc? @mention or reply

Appendix B. 9: Generating Personal Experiential Themes (PETs) from Experiential Statements using visual search and clustering (example from Phil)

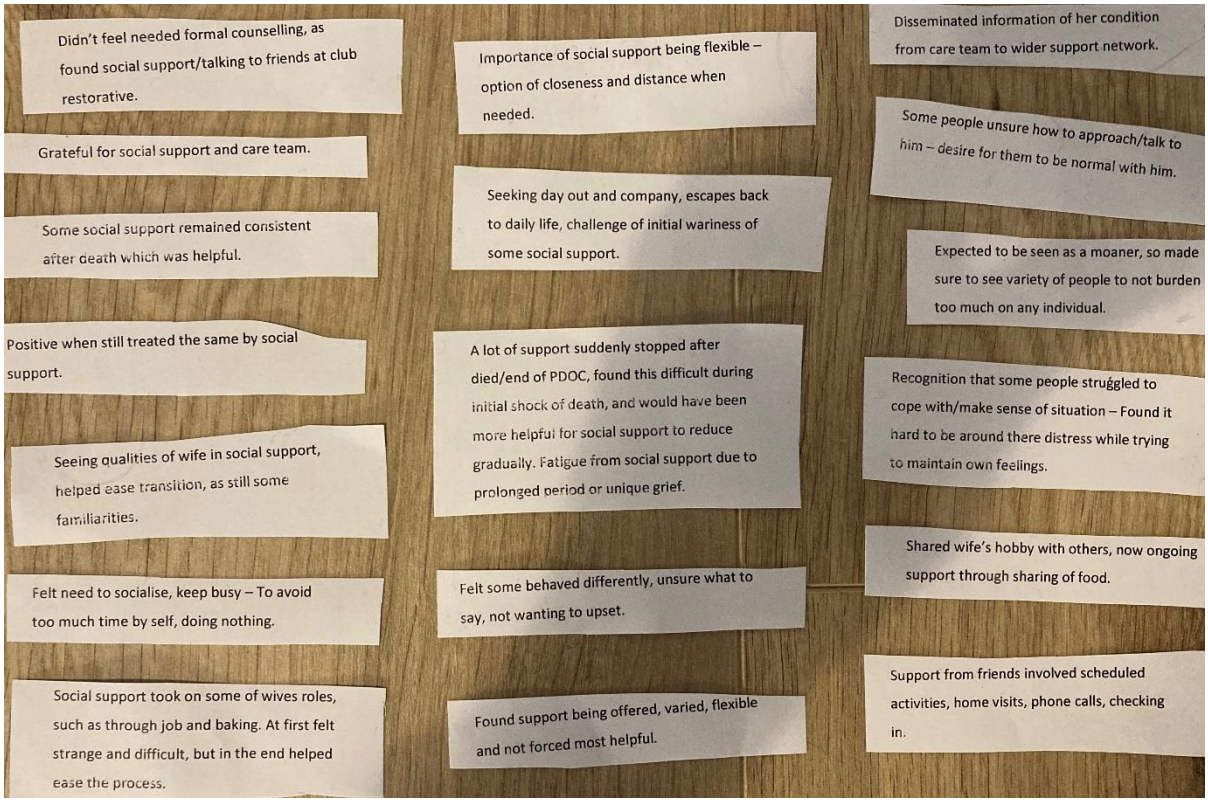
PET 1 – Collaborating with and receiving care team support



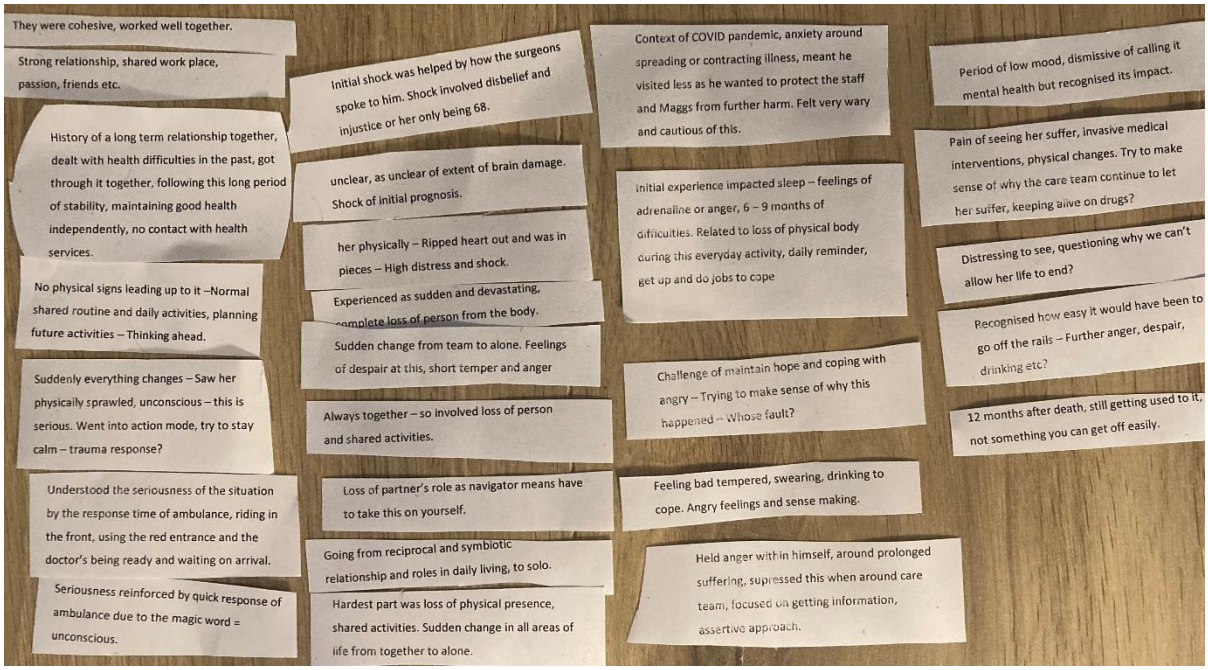
PET 2 – Witnessing PDoC in a loved one



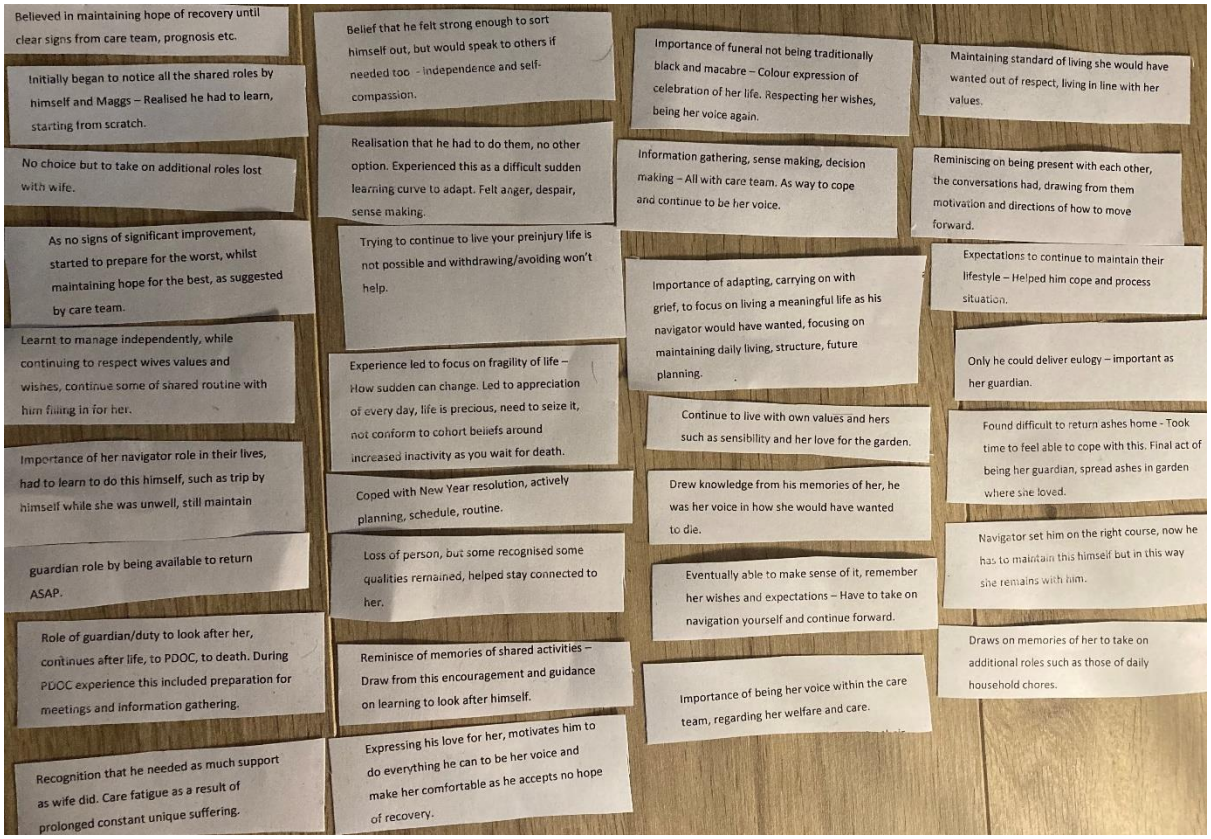
PET 3 – Engaging with community support during PDoC



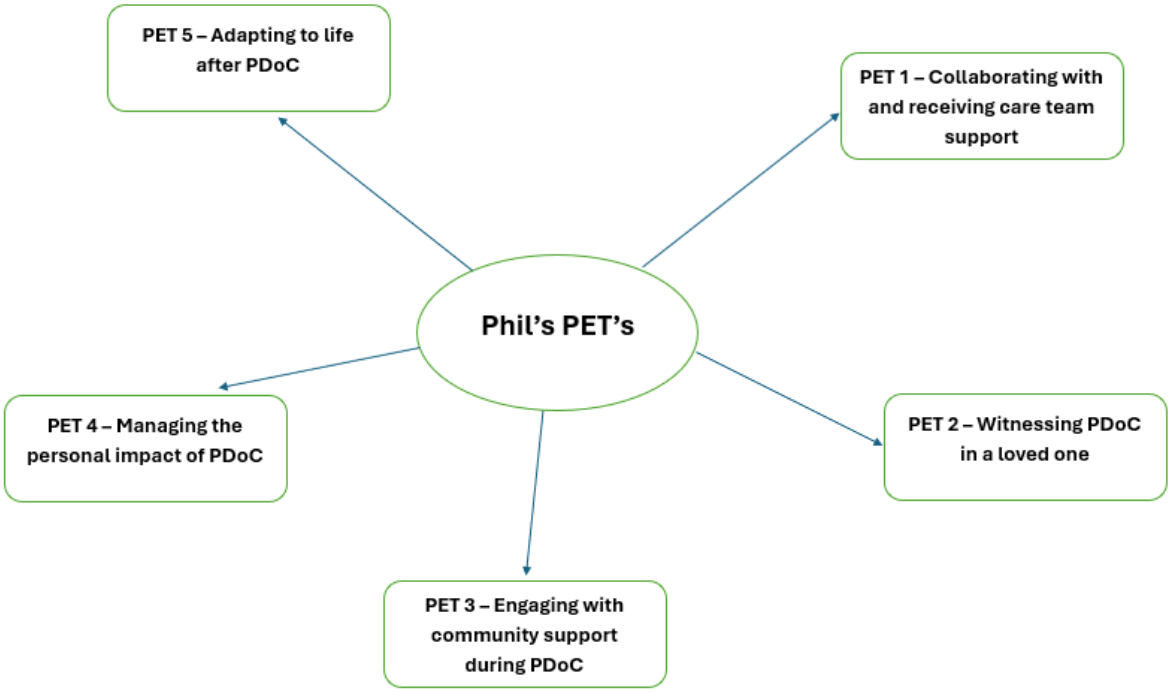
PET 4 – Managing the personal impact of PDoC



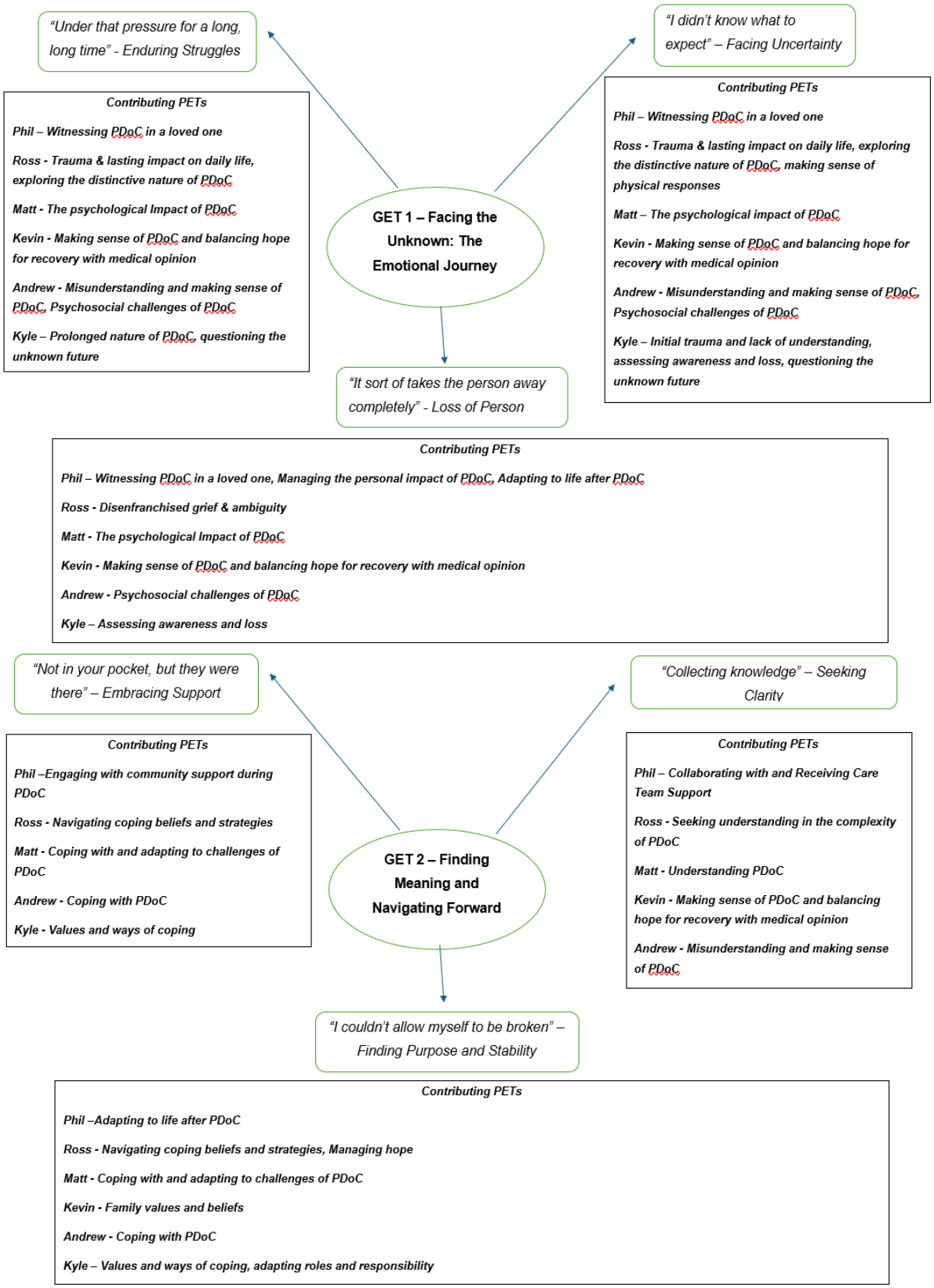
PET 5 – Adapting to life after PDoC

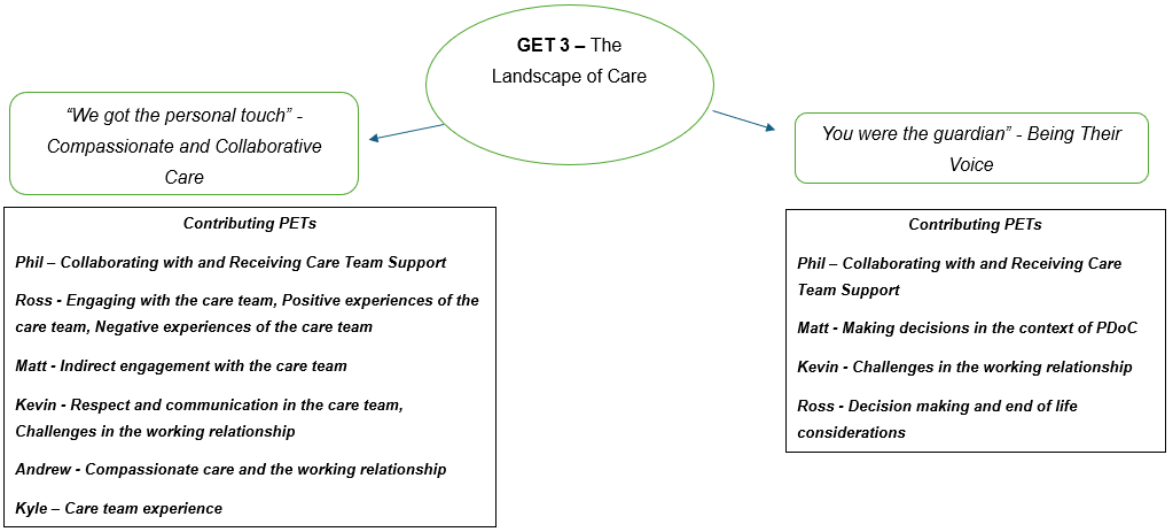


Appendix B. 10: Developing Personal Experiential Themes (PETs) (Example from Phil)



Appendix B. 11: Process of developing Group Experiential Themes (GETs) from Personal Experiential Themes (PETs)

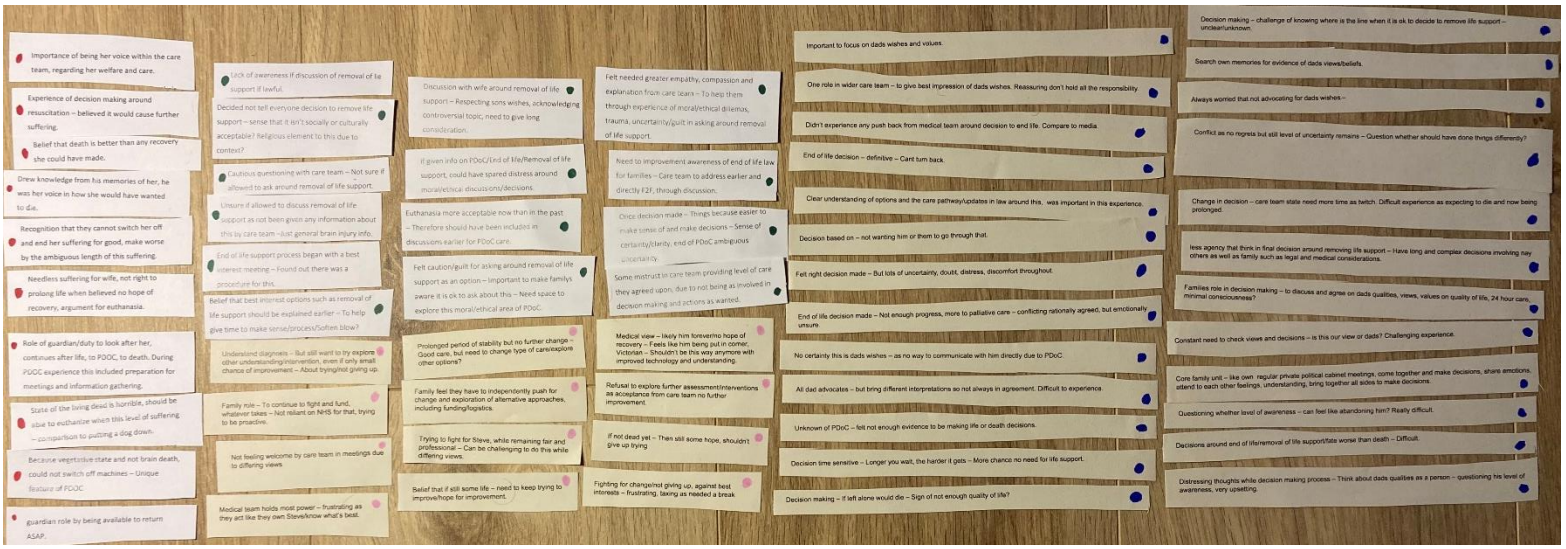



GET 3 – The Landscape of Care
"We got the personal touch" - Compassionate and Collaborative Care
You were the guardian" - Being Their Voice
Contributing PETs
Phil – Collaborating with and Receiving Care Team Support
Ross - Engaging with the care team, Positive experiences of the care team, Negative experiences of the care team
Matt - Indirect engagement with the care team
Kevin - Respect and communication in the care team, Challenges in the working relationship
Andrew - Compassionate care and the working relationship
Kyle – Care team experience
Contributing PETs
Phil – Collaborating with and Receiving Care Team Support
Matt - Making decisions in the context of PDoC
Kevin - Challenges in the working relationship
Ross - Decision making and end of life considerations

Appendix B. 12: Extract from Group Experiential Theme (GET) development – Developing 'The Landscape of Care' via visual search and clustering of experiential statement contributions from all participants

"We got the personal touch" - Compassionate and Collaborative Care

You were the guardian" - Being Their Voice



Appendix B. 13: Transcript extract to illustrate the overall analytic process from quote to GET (Example from Phil)

Quote	Exploratory Note	Experiential Statement	PET	GET sub-theme	GET
"But that was the hardest part, going out and knowing you have got an empty seat, because we went virtually everywhere together."	Hardest part, empty seat, before PDoC together all the time.	Hardest part was loss of physical presence & shared activities. Sudden change in all areas of life from together to alone.	Managing the personal impact of PDoC	"It sort of takes the person away completely" - Loss of Person	Facing the Unknown: The Emotional Journey

Paper 3: Executive Summary

Male experiences as a family member of a person in a prolonged disorder of consciousness (PDoC): A qualitative study.

Word Count: 2500

"A period of limbo": The experience of being a male family member of a person in a prolonged disorder of consciousness (PDoC); an Interpretative Phenomenological Analysis

EXECUTIVE SUMMARY

This summary outlines a research project on the experiences of male family members of loved ones with Prolonged Disorder of Consciousness (PDoC) in the UK.

WHO IS THIS FOR?

1. Study Participants: Recapping their contributions and the study's outcomes.
2. Other families with loved ones experiencing PDoC: Offering insights into similar experiences.
3. Professionals working with PDoC: Enhancing understanding of family challenges and needed support.

To aid reader understanding, a table of definitions is provided below to clarify key PDoC-related terms.

WHY IS THIS RESEARCH IMPORTANT?

Severe brain injuries can happen to anyone and result in a Prolonged Disorder of Consciousness (PDoC), a condition where unconsciousness lasts for over four weeks following a brain injury, like a car accident. PDoC includes three distinct states of consciousness impairment: coma, vegetative state, and minimal conscious state.(1)

The prevalence of PDoC in the UK is uncertain due to limited data(2) and as PDoC is increasingly recognised as forming a complex spectrum of consciousness, accurate diagnosis and prognosis are challenging.(3-5)

PROLONGED DISORDER OF CONSCIOUSNESS DEFINITIONS(1)

Consciousness	The state of being awake and aware of ones' surroundings and experiences.
Prolonged Disorders of Consciousness	Conditions involving prolonged impairment of consciousness due to severe brain injury, such as from a car accident. The person's level of consciousness can range from coma to vegetative state and minimally conscious state.
Coma	A state of deep unconsciousness where the person is not awake or aware at all. The person cannot be awakened and does not respond to stimulation. Coma is not usually prolonged.
Vegetative State	A state in which a person may be awake (eyes open) but is not aware of their surroundings or able to interact consciously.
Minimally Conscious State	A state where there are minimal but clear signs of consciousness and awareness of themselves or their environment, even though it's significantly altered.

WHY IS THIS RESEARCH IMPORTANT? (CONTINUED)

Advances in brain injury treatment have improved survival rates, but long-term PDoC often leads to permanent physical and cognitive difficulties, with limited treatment options.(6-10) Due to the lack of established treatments for effective PDoC outcomes, current interventions primarily focus on specialist rehabilitation and care to prevent complications.(1)

UK clinical practice increasingly prioritises quality of life over consciousness recovery, collaborating with families in decision-making regarding life-sustaining treatments and patient best interests.(1,2,11)

Families of PDoC patients face complex emotional and social challenges that can significantly impact their well-being.(7) These include navigating unfamiliar and uncertain clinical scenarios, where their loved one lacks consciousness but remains alive. Families play a critical role in assessment, decision-making and caregiving, often dealing with clinical care teams, bioethical implications and legal contexts.(12-14) However, existing literature on family experiences in the UK is limited,(15-18) highlighting the need for comprehensive research to understand and address these unique challenges and develop tailored support.(19)

Additionally, exploring gender differences in caregiving stress is important, as men and women may use distinct coping strategies.(15,20) Therefore, understanding these experiences from the perspective of both male and female caregivers can enhance understanding and support for the entire family.

RESEARCH AIMS

1. Explore the experiences of male family members of individuals in PDoC in the UK.
2. Provide clinicians with insights to improve support and care practices for families affected by PDoC.

RESEARCH QUESTION

“What are the experiences of male family members of a loved one in a prolonged disorder of consciousness (PDoC) within the UK, and what are the clinical implications?”

WHAT WAS DONE AND WHY?

Ethical approval was obtained from Staffordshire University and NHS Trusts, ensuring the study’s safety and ethical standards.

Six adult males from the UK, all closely related to individuals with PDoC, were recruited between January 2023 and March 2024, supported by collaborating NHS professionals and brain injury organisations.

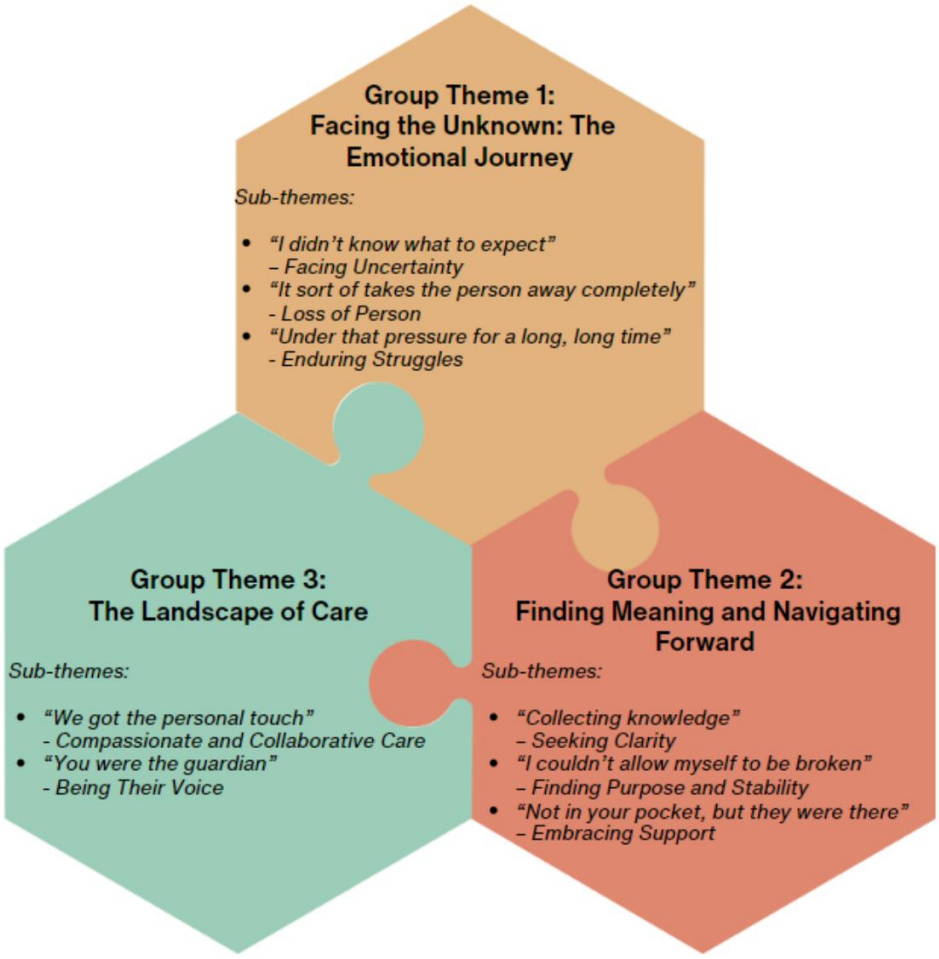
The participants represented a diverse range of PDoC experiences, resulting from various brain injuries. These experiences varied in severity and outcomes, from recovery to ongoing PDoC and, in some cases, death. This study focused on the family experience during the PDoC phase, not on the overall prognosis and outcomes.

Participants was initially contacted via telephone to discuss study details and obtain informed consent. Participants then engaged in 1 to 2-hour semi-structured interviews, conducted in-person or via Microsoft Teams. These were recorded and transcribed for analysis.

The transcripts were analysed using Interpretive Phenomenological Analysis (IPA), a research method that explores how participants understand their experiences.(21) Key themes and sub-themes were identified. To ensure credibility, the researcher discussed the data and emerging themes through supervision, IPA workshops and peer discussions throughout the research process.

WHAT DID WE FIND?

The analysis revealed three overarching group themes that represent the participants' perceptions and understanding of having a family member with PDoC:



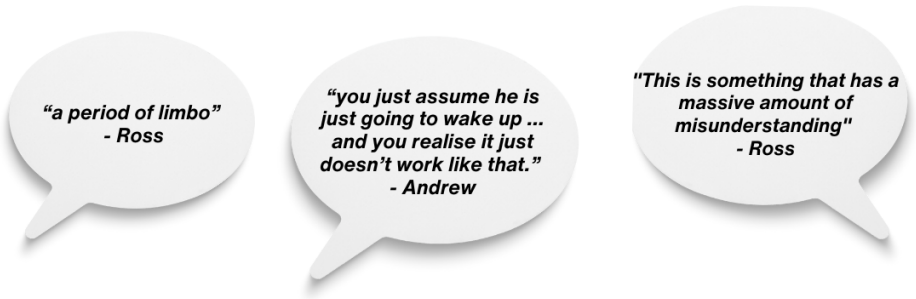
The following section outlines each theme and its sub-themes, supported by quotes. To maintain participant anonymity, pseudonyms are used, and quotes have been depersonalised.

1) FACING THE UNKNOWN: THE EMOTIONAL JOURNEY

This theme highlights the emotional and social challenges faced by participants, describing their experiences as sudden, traumatic, and emotionally burdensome.

“I didn’t know what to expect” – Facing Uncertainty

All participants faced significant uncertainty regarding their loved ones’ state, as they grappled with the unfamiliar and ambiguous nature of PDoC. Initially influenced by media portrayals of comas, they often had unrealistic expectations about the condition and recovery. This, combined with difficulties in assessing their loved ones' awareness, led to ongoing uncertainty and emotional strain.



“It sort of takes the person away completely” - Loss of Person

All participants experienced profound losses beyond physical changes, extending to core psychological aspects and relational dynamics. This led to complex grief which was often not readily acknowledged or understood by others.

"Under that pressure for a long, long time" - Enduring Struggles

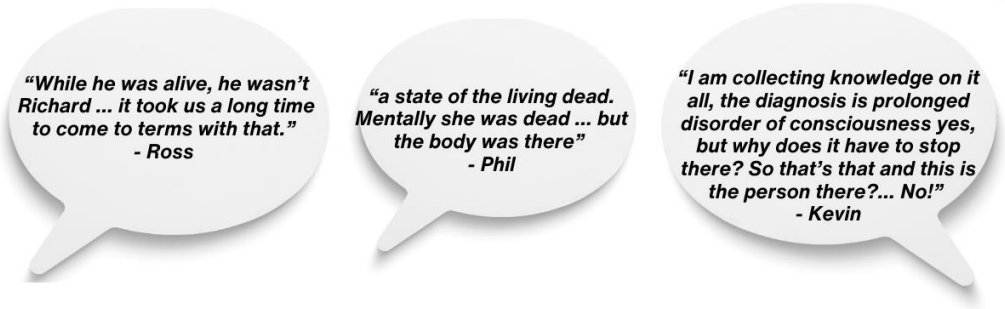
All participants highlighted the prolonged and emotionally draining nature of PDoC, describing a transition from initial hope and dynamic uncertainty, to a prolonged emotionally draining monotony. Over time this led to fatigue and burnout, impacting their well-being and ability to cope.

2) FINDING MEANING AND NAVIGATING FORWARD

This theme explores how participants sought to understand PDoC to guide their hope for improvement and how they coped with the challenges they faced.

"Collecting knowledge" – Seeking Clarity

Five participants expressed trying to understand consciousness in the context of PDoC by gathering information from medical professionals and adjusting their expectations over time. Medical explanations provided some clarity, however some participants also sought to integrate their own personal and spiritual beliefs with medical perspectives, to maintain a sense of hope regarding their loved ones' conditions.

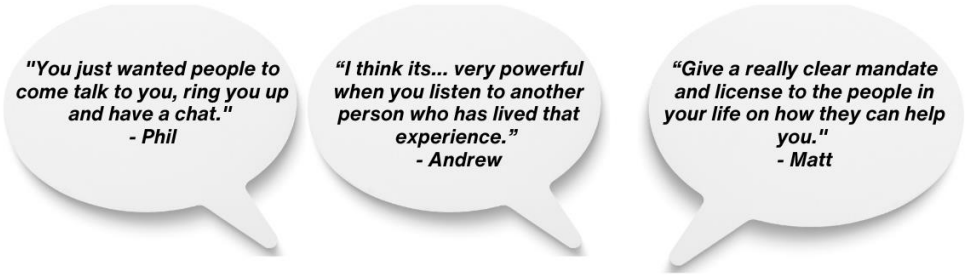


“I couldn’t allow myself to be broken” – Finding Purpose and Stability

All participants derived purpose and stability from their familial and personal values, which nurtured resilience, acceptance, and hope. They emphasised staying strong for loved ones, fulfilling family roles, and, for some, drawing on positivity and spirituality. This approach bolstered resilience and, for some, sustained hope. However, participants also faced challenges balancing family responsibilities with personal well-being, often struggling with shifting roles and neglecting their own needs.

“Not in your pocket, but they were there” – Embracing Support

Five participants emphasised the crucial role of social support in navigating PDoC, appreciating the presence, compassionate support and practical assistance from friends, family, and neighbours. They valued genuine connections, flexible support, and clear communication, finding comfort in being treated as individuals and connecting with others facing similar experiences.



3) THE LANDSCAPE OF CARE

This theme explores participants' interactions with care teams, focusing on the care provided to them and their loved ones, their partnership with the team, and their role as advocates, making critical decisions about treatment and quality of life.

“We got the personal touch” - Compassionate and Collaborative Care

All participants emphasised the need for compassionate, personalised care and effective collaboration with care teams. They stressed the importance of respecting their loved ones' identity and the family's emotional needs, balanced alongside clear and honest communication. Participants expressed frustration with impersonal treatment and power imbalances and suggested better support through family liaison officers and resources for family experiences.

It’s not like we are right you are wrong, let’s just have a bit more positivity”
- Kevin

“They had got to know Jane and they had got to know me...the fact that we got the personal touch between them, and me, was great”
- Phil

“It probably took, 8 months before anyone asked me, how are you? How are you coping? ... I was falling apart at that point”
- Andrew

“You were the guardian” - Being Their Voice

Four participants emphasised their role as advocates, interpreting their loved ones' wishes in complex treatment decisions. They prioritised respecting pre-injury values and making decisions based on shared memories and family discussions. This process often involved navigating tensions between family and medical perspectives and addressing emotional and ethical dilemmas, particularly concerning life-sustaining treatments and quality of life.

"Whether she was breathing and living, or in that state, I still had to look after her."
- Phil

"It feels too tenuous to make a life and death decision."
- Matt

“Doctors and things, you don’t own him, he is a part of us, and that’s where the frustration lies”
- Kevin

WHAT DID WE LEARN ABOUT MALE FAMILY MEMBER EXPERIENCES OF PDOC?

Facing the Unknown: The Emotional Journey

Male family members face profound emotional challenges, often characterised by a sudden, traumatic and uncertain situation. Families were generally unprepared for the unfamiliar and ambiguous nature of PDoC, leading to unrealistic assumptions and widespread misunderstanding. This often entails profound loss and traumatic grief, resulting in care fatigue and burnout as hopes for improvement shift to the harsh realisation of a prolonged, indefinite condition. These emotional challenges align with existing literature(13,15,16,19,22) and distinguish PDoC from general caregiving experiences.(2,7,12)

Finding Meaning and Navigating Forward

Male family members undergo a dynamic process of understanding and adjustment, balancing hope for improvement with acceptance of their loved ones' condition. They often rely on medical perspectives, seeing PDoC as a state of physical survival with diminished mental awareness, sometimes seeking to incorporate rare recovery cases and spiritual beliefs. They demonstrate resilience through personal and familial values, maintaining roles, and engaging with supportive networks. This aligns with research on male caregiver coping strategies and resilience frameworks, which emphasise balancing hope and acceptance, and reconstructing family dynamics and social connections amidst these challenges.(23, 24)

The Landscape of Care

These findings highlight the need for compassionate, personalised and family-orientated approaches that respect both patient and family needs, including diverse values and beliefs. Active involvement of families in assessment, decision-making, and caregiving is crucial, as they advocate for their loved ones, ensuring patients' wishes are honoured and making critical treatment decisions. This study emphasises the importance of understanding family dynamics, establishing effective communication, and addressing complex ethical dilemmas, such as end-of-life decisions and the quality of life. These insights underscore the vital role families play within the care team.(13,17)

WHAT ARE THE RECOMMENDATIONS?

Enhance Clinician Understanding

- Provide specialised training to educate staff beyond medical aspects, on the emotional and social challenges families face, including enduring uncertainty, ambiguous loss and disenfranchised grief.

Provide Specialised Information

- Offer families clear clinical information about PDoC and the care pathway.
- Offer families access to other families' lived experiences.

Provide Specialised Psychological Support

- Offer a range of psychological support options for building resilience and coping with ambiguity, complex loss and grief.(24)
- Develop PDoC peer support networks.

Adopt a Family-Orientated Approach

- Shift to a family-oriented care model that respects individual and family values, beliefs, roles, and identities.
- Collaborate with families to help them understand the clinical perspective in a way that is helpful to them, without requiring agreement or conformity, reducing tension from differing views.

Integrate Families as Partners in Care

- Involve family members in care, ensuring they know their rights to participate in decision-making.(25)
- Foster trust and understanding by encouraging meaningful family involvement and open dialogue for expressing concerns.(26)

Guide Ethical Decisions and End-of-Life Discussions

- Provide guidance on complex ethical and legal decisions.(27)
- Facilitate open discussions about end-of-life care to improve preparedness and reduce discomfort.(28)

WHAT WERE THE RESEARCH STRENGTHS AND LIMITATIONS?

Strengths

- Provides original and clinically relevant insights.
- Uses a rigorous approach to broaden understanding of family PDoC experiences.

Limitations

- Small sample size limits the transferability of findings; recruitment challenges highlight the need for a national PDoC database and broader engagement.
- Exclusive focus on NHS care in the UK may limit the applicability to other healthcare settings.
- Data collected during the COVID-19 pandemic may affect the transferability of findings.
- Does not explore variations in family roles, post-injury durations, causes, outcomes, and specific states of consciousness impairment.
- Lacks formal collection of ethnicity data, with predominantly white British participants, indicating a need for greater diversity in research to explore varied cultural perspectives on PDoC experiences.

HOW WILL THIS RESEARCH BE SHARED?

Clinical Psychology Doctorate

- The full research paper will contribute to the researcher's qualification.

Submission for Publication

- Targeting academic journals to reach clinical and research communities.

Internal Sharing

- Sharing with clinical research supervisors and the Research and Development departments within the associated NHS Trusts.

External Sharing

- Fulfilling requests to share findings with brain injury organisations.

Participant Engagement

- Informing participants who opted in about the outcomes and their contributions.

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