Chaos and Control: Understanding the Experiences of Healthcare Professionals and the Role of Clinical Psychology within Motor Neurone Disease Services

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A thesis submitted in partial fulfilment of the requirements for the award of Doctorate in Clinical Psychology at the University of Sheffield

The University of Sheffield

Faculty of Science

Clinical Psychology Unit, Department of Psychology

November 2024

Declaration

This thesis has been submitted for the award of Doctorate in Clinical Psychology at the University of Sheffield. It has not been submitted to any other institution, or for the purpose of obtaining any other qualifications.

Structure and Word Counts

Section One: Literature Review

Excluding references and tables:	6915
Including references and tables:	9500

Section Two: Research Report

Excluding references and tables:	8000
Including references and tables:	9700

Total Word Count: (combining lay summary, literature review and research report)

Excluding references and tables:	15212
Including references and tables:	19497

Lay Summary

Researchers have recognised the psychological impact of living with Motor Neurone Disease (MND). There is limited research exploring how healthcare professionals (HCPs) can meet the psychological needs of people living with MND (plwMND), or the role of integrated psychology within teams. Further, there is little research investigating the emotional experiences of HCPs supporting plwMND. This thesis allows for in-depth exploration of these experiences.

Literature Review

A review identified and evaluated qualitative literature regarding the emotional experiences of MND HCPs. Three databases were searched; seven studies met criteria. Thematic synthesis identified three themes. Results highlighted that HCPs experience MND work as intense, challenging, complex and unpredictable. Themes highlighted issues of power and responsibility. Protective factors such as appropriate working conditions, knowledge-sharing, positive relationships, and feelings of pride were identified. Results demonstrate the risk of HCP burnout and low wellbeing, and the importance of protective factors. Results highlight the need for awareness of threats and facilitators to HCP wellbeing, and staff support to enable high-quality care.

Empirical Project

This study explored HCP perspectives of psychology within MND-specific multi-disciplinary teams (MDT). Eight UK HCPs participated in semi-structured interviews. Thematic Analysis (TA) produced four themes. Participants perceived psychology as a limited resource, not prioritised in terms of time, staffing or funding. Participants described experiencing chaos and control related to uncertainty, and the emotive ‘diagnosis until death’ work. Participants valued psychological containment for staff, experiencing educational and reflective opportunities, and confidence in ‘good-enough’ care. Participants valued direct and indirect patient psychology support and perceived psychology as essential within MND services. Findings indicated that psychological support for MND staff is equally important as patient support. Clinicians should be

aware of the emotive and challenging work and take measures to avoid burnout. MND services could use compassionate leadership to support staff wellbeing.

Acknowledgements

Firstly, I would like to express my gratitude to the eight individuals who participated in this study; your time, willingness, and engagement made this project possible, and your openness and honesty is greatly appreciated. Thank you also to those who offered their time and guidance to help develop study materials; your expertise facilitated my learning and helped to make this research the best it could be for all those involved.

To my research supervisors, Emily Mayberry, Charlotte Wright, and Gillian Hardy – thank you for supporting me to develop this research study, sharing your passion with me, and for believing in me when I doubted my abilities. Your knowledge, guidance, and reassurance has been invaluable, and it has been a privilege to work with and learn from you all.

To my incredible partner, Tom – you are forever my best friend, and biggest cheerleader. Thank you for always encouraging my dreams, believing that I can achieve them, and being alongside me for all the ups and downs along the way. Your support is second to none, and our laughter and playfulness provides a balm for difficult times.

To my wonderful friends – thank you for giving me your presence and forgiving my absence during times of overwhelm and hyperfocus. Your reassurance, encouragement and understanding never goes unacknowledged or unappreciated.

To Mark and The Knibbs – thank you for believing in me, supporting me, and grounding me during the tough times, and being there to celebrate the happier ones.

Finally, to my lovely DClin cohort – thank you for being the respite of the last three years, and always bringing a sense of perspective, humour, and laughter to whatever was thrown our way. Laura – I feel beyond lucky to have had you as my buddy; your support, friendship and wisdom was a lifeline throughout (as were our pizza dates). Liv, Jess and Daisy – long live Backrow Babes and emergency bagels – thank you for all the hugs, venting space, kind words and solidarity along the way.

Table of Contents

Section One: Literature Review

Understanding the Emotional Experiences of Healthcare Professionals Working with People Living with Motor Neuron Disease: A Thematic Synthesis

Abstract

Objectives: Healthcare professionals (HCPs) working with people living with motor neuron disease (plwMND) within the UK are exposed to circumstances including end of life care, trauma, loss, and death. These events are likely to have an emotional impact upon providing healthcare interventions within such circumstances. Existing reviews have focused on the emotional experiences of plwMND and their carers but have ignored the emotional experiences of healthcare staff and the impact of this work on them. Therefore, this systematic review (PROSPERO: CRD42024596592) aimed to synthesise available qualitative research into the emotional experiences of HCPs working with plwMND in the UK.

Methods: A systematic search for qualitative research on the emotional experiences of HCPs working with plwMND was conducted across three databases. Seven studies were included, critically appraised, and analysed using Thomas and Harden’s (2008) thematic synthesis approach.

Results: Three superordinate themes were identified: ‘*Intensity of Work’* (Emotionally Taxing, Challenging, Complex and Unpredictable), *‘Power and Responsibility’* (Managing Hope, Balancing Act, Empowering Patients), and ‘*Protective Factors’* (Right Conditions, Knowledge and Communication, Positive Relationships, Privilege, Pride and Reward).

Conclusions: Results indicate that HCPs working within MND services experience distress, intense emotions, significant challenge, and high levels of responsibility. These factors were linked to reports of vicarious trauma, compassion fatigue (CF) and burnout, thus negatively impacting staff wellbeing. Positive and protective elements to the work were noted, including empowering patients, job satisfaction, colleague support, and staff-patient rapport. Protective elements were linked to aspects of compassion satisfaction, thus contributing to prevention or mitigation of CF and burnout.

Practitioner Points

- Further attention in practice and research should be given to acknowledging the difficulties experienced by HCPs within MND services and supporting them to care for their wellbeing.
- Utilising compassionate leadership could help to create a sense of psychological safety, enhancing staff wellbeing and promoting compassionate patient care.
- Providing psychoeducation around models such as Compassion-Focused Therapy or Dialectical Behaviour Therapy could be useful in supporting HCPs to take care of their wellbeing, and in turn provide high-quality patient care.

Keywords:

Motor Neuron Disease; Amyotrophic Lateral Sclerosis; Healthcare Professionals; Emotional Experiences; Qualitative Evidence Synthesis; Meta-Synthesis

Introduction

Motor neurone disease (MND) is a fatal, rapidly progressing disease affecting the brain and spinal cord, for which there is currently no cure (MND Association [MNDA], 2021). The significant decline in physical function, communication, thinking, behaviour and independence associated with MND (MNDA, 2021) are likely to have an emotional and psychological impact on people living with MND (plwMND), and there is evidence to suggest that plwMND experience MND-associated distress (Glennie et al., 2021; Pinto et al., 2021). Healthcare professionals (HCPs) support plwMND to manage their symptoms and are regularly exposed to challenging circumstances such as death, decline, and distress. However, the existing research investigating the emotional impact of working with plwMND upon HCPs within MND services is small.

Compassion fatigue (CF) is defined as 'the cost of caring for others in emotional pain' (Figley, 1982) and is characterised by feelings of exhaustion, irritability, and other negative physical, social, emotional, and intellectual changes (Coetzee & Klopper, 2010; Zhang et al., 2018). CF is commonly experienced by HCPs providing support to those in physical or emotional pain (Harris et al., 2015). Burnout is defined as professionals' negative attitudes or behaviours towards work in response to job strain, and is characterised by feelings of powerlessness, frustration, and inability to meet goals (Davis et al., 2013; Leiter et al., 1998). Research suggests that CF is positively correlated with burnout in nurses (Zhang et al., 2018) and can lead to high staff turnover (Halfer & Graf, 2006). Additionally, evidence suggests that CF and burnout also negatively affect patient outcomes (Cimiotti et al., 2012).

Alongside burnout, vicarious trauma[1] (VT) is also suggested to contribute to CF (Cocker & Joss, 2016). VT has been defined as the emotional residue or exposure to traumatic stories and experiences of others shared with professionals, through work, witnessing fear and pain that others have experienced (American Counselling Association, 2016). VT is common within helping

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[1] Also referred to as 'secondary trauma' or 'insidious trauma' (American Counselling Association, 2016)

professions and can arise from a ‘rescuer-caretaker’ response commonly associated with HCPs (Cocker & Joss, 2016).

The challenging nature of MND suggests that HCPs working within MND are likely to be emotionally impacted by their work. Furthermore, the existing body of research examining CF, burnout, and VT within healthcare settings suggests that HCPs working within MND may be at risk of experiencing these conditions. Further research is needed to explore this phenomenon.

This review aims to identify and synthesise the current literature exploring the emotional impact of working with plwMND on HCPs to 1) assess and critically appraise the quality of existing research and 2) enhance the understanding and support of HCPs working in MND services.

Method

This systematic review was registered on the international prospective register PROSPERO (reference: CRD42024596592) and followed the enhancing transparency in reporting the synthesis of qualitative research (ENTREQ) statement (Tong et al., 2012; Appendix A).

Search Strategy

The SPICE mnemonic (Setting, Perspective, Intervention/Interest, Comparison, Evaluation) is a recommended framework for qualitative systematic reviews (Booth, 2004) and was utilised to develop and refine the review question and search strategy (Table 1).

The search strategy, search terms (Table 2) and databases were identified in consultation with the researcher’s supervisor and a librarian. The specific term ‘trauma’ was not used due to the association with physical trauma, which skewed search results. Searches were completed in October 2024 across three databases: PsycINFO, Medline and Scopus. No restrictions were placed on date limits to ensure all relevant papers were obtained, and there have been no prior reviews. Searches were limited to peer-reviewed articles in the English language.

Table 1

SPICE Tool (Booth, 2004)

Criteria	Description
Setting	Motor Neuron Disease
Perspective	Healthcare professionals (HCPs) aged 18+
Intervention / Interest	Emotional experiences, HCPs within motor neuron disease
Comparison (if relevant)	Not applicable
Evaluation	Experiences, feelings, perspectives, perceptions, attitudes, opinions, thoughts, feelings, ideas, views captured in themes

Table 2

Search Terms

Construct	Search Terms[2]
Healthcare specialism	“motor neuron* disease*” OR mnd OR “amyotrophic lateral sclerosis”
Healthcare professionals population	“health professional*” OR “healthcare professional*” OR “health care professional*” OR “health-care professional*” OR medic OR physician* OR doctor* OR clinician* OR therapist* OR dentist* OR psychiatrist* OR surgeon* OR nurse* OR psychologist* OR 6tructured6py*
Emotional Experiences	emot* OR distress OR burnout OR “moral injury”

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[2] Individual search terms for each construct were combined with the Boolean operator ‘OR’, and broad constructs were combined with ‘AND’. Search terms were inputted into Medline and Scopus; MeSH[2] terms were inputted into PsycINFO.

Research	qualitative OR interview OR focus group OR thematic analys* OR grounded theory OR Interpretative phenomenological analys* OR discourse analys* OR Semi#stuctured OR in#depth

Study Selection

Papers identified via cross-database searches were extracted into the EndNote reference manager, and duplicates were removed. Titles and abstracts were screened against inclusion and exclusion criteria to assess relevance to the review question. Remaining papers were subjected to full-text review; papers not meeting eligibility criteria were removed. Forward and backward reference searches of included papers were performed. A secondary reviewer, a trainee clinical psychologist independent of this review, screened eight papers during full-text review to increase the reliability of the selection process.

Table 3

Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion criteria
Samples include HCPs working with plwMND aged 18+	Studies not focusing solely on professionals' experiences of service delivery. Papers which review different groups' experiences can be included if meaningful data about the HCPs' experiences can be extracted
Studies specifically focus on and explore the emotional experiences of working with plwMND	Studies which utilised solely quantitative design

Studies employed qualitative methodology and analysis, including mixed-method studies involving extractable qualitative data	Grey literature, case studies, surveys, theses, dissertation, reviews, and non-peer reviewed articles Studies that deviated from the subject by not relating to perceptions of mental health needs and desires for care.
Studies are written in the English language	Studies related to assisted suicide, which is not legal in the UK.
Studies from countries operating primarily on free or publicly-funded healthcare systems, to be most applicable to the UK NHS	Studies from countries relying on insurance-based healthcare systems, which are not applicable to the UK NHS

Data Extraction

Data relevant to the review question was extracted and accumulated including author, publication year, study country, available sample characteristics, data collection, methodology and a summary of findings or key themes (Table 4).

Quality Assessment

The quality of studies was assessed using an adaptation of the Critical Appraisal Skills Programme qualitative research checklist (CASP, 2024; Long et al., 2020; Appendix B). Long et al. (2020) adapted the CASP tool to increase its value for appraisal within qualitative evidence synthesis and suggested a supplementary question for the original checklist (CASP, 2024). A random selection of papers (28%, *N*=2) were appraised by an independent secondary reviewer. Discrepancies were identified on three of 44 checklist questions, which were resolved through discussions.

Epistemological Position

The current meta-synthesis was conducted from a social-constructionist perspective, viewing knowledge, meaning, and reality as socially and culturally produced, rather than as objective facts to be discovered (Burr, 2008). As such, the aim was not to uncover ‘universal truths’ about the topic area, but rather to elucidate the diverse narratives in which it has been understood and experienced across the included studies.

The researcher recognises that the interpretations presented in the included papers are themselves products of the individual researchers' social, historical, and institutional contexts. Therefore, within the synthesis, the author has sought to remain attuned to the contextual factors that may have shaped the constructions of meaning. Thematic synthesis was guided by the assumption that the insights produced would be partial, provisional, and shaped by the researcher’s theoretical leaning, generating plausible, contextualized understandings which honour the diversity of perspectives represented in the literature.

Reflexivity

Acknowledging the values, beliefs, assumptions and attitudes of the researcher, and the potential influence of such in the way they relate to data and others is imperative within qualitative research (Berger, 2013; Dodgson, 2019). The lead researcher identifies as white British woman who is a healthcare professional in the UK with no personal or professional experience within the field of MND. To facilitate transparency and reduce bias (Dodgson, 2019), reflective commentary (Appendix E) was conducted by the researcher throughout analysis.

Data Synthesis

Data was analysed utilising Thomas and Harden’s (2008) thematic analysis approach to meta-synthesis of qualitative research. This process involved extracting relevant findings, including descriptions, interpretations, and verbatim quotations from study results sections (Thomas &

Harden, 2008). One study included non-relevant populations; only qualitative data relating to HCPs' emotional experiences were extracted. Data was subject to line-by-line coding (Appendix C). As suggested by Thomas and Harden (2008), participant quotations and the researchers' descriptions and interpretations were included in the data. Initial codes were generated to highlight key content and meaning for each study. Codes were then clustered together via an inductive process. Theme comparison was then conducted to generate descriptive themes before further interpreting themes to initiate analytical themes, alongside a list of superordinate and subthemes (Appendix D illustrates a theme development example). Discussions between the researcher and their supervisor took place throughout the synthesis.

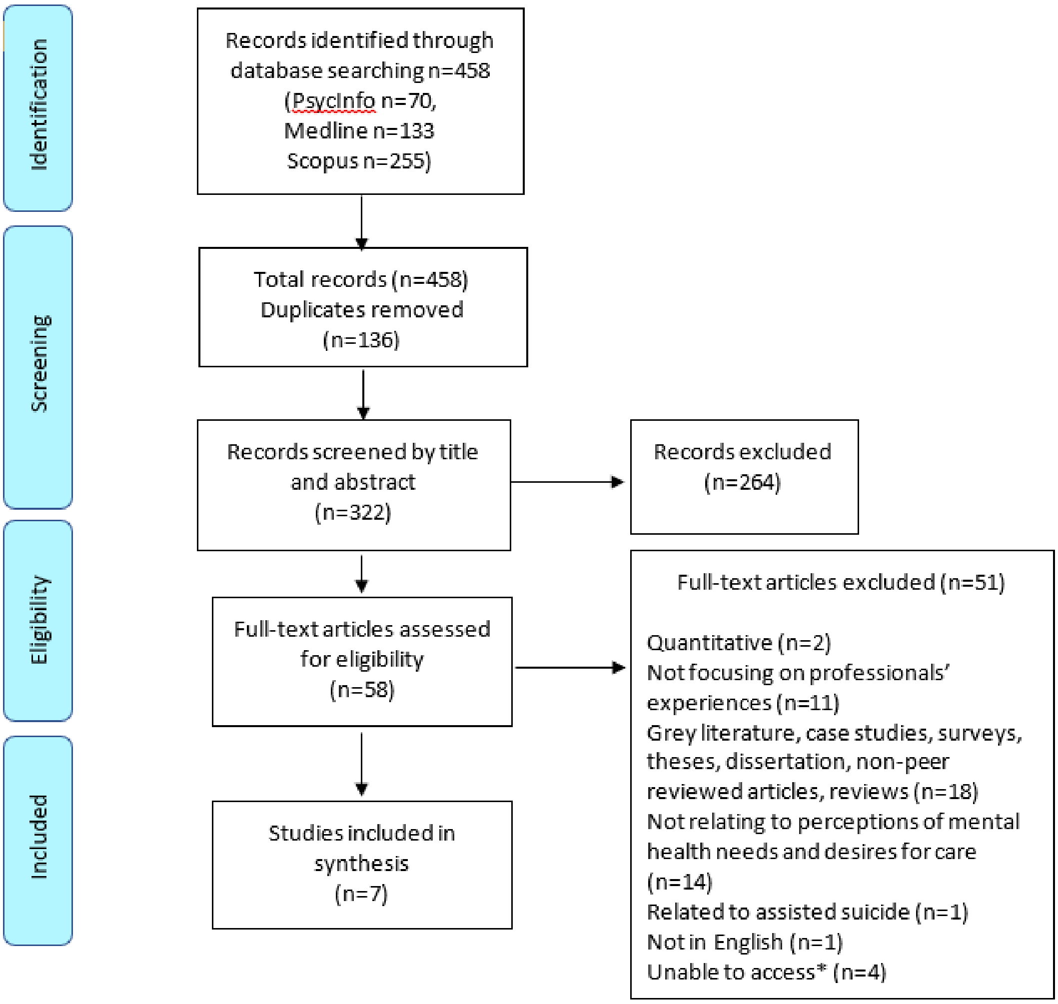
Results

Summary of Included Studies

Searches across databases yielded 322 studies, following de-duplication. A further 264 studies were eliminated following title and abstract screening, and 58 papers were subject to full-text review. Three papers were discussed in supervision regarding eligibility criteria, and a collaborative decision was made. Seven papers met inclusion criteria. The screening process is presented in the below PRISMA diagram (Figure 1; Moher et al., 2009).

Figure 1

PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) Diagram of Study Selection Process



**Note.* Contact to authors were made; however, no responses were received.*

Publication dates of studies ranged from 2017-2023 and were undertaken across the United Kingdom (UK; n=3), Denmark (n=2), Norway (n=1), and Sweden (n=1). A total of 85 HCPs participated across studies, and data was collected predominantly via semi-structured interviews (n=6 studies). Methods of analysis included thematic analysis (n=2), interpretative phenomenological analysis (n=1), content analysis (n=1), naïve reading, structural analysis and critical analysis (n=1), interpretive description (n=1) and qualitative narrative analysis (n=1). Six papers documented the experiences of exclusively HCPs whilst one paper (Olessen et al., 2022) examined HCPs and carers; only data relating to HCPs was extracted, in line with research aims. Five studies explored professionals working within MND and two studied those working within motor neurodegenerative conditions (MNDC). In studies reporting age, participants ranged from 22-64 years. Gender was reported for 77 participants; 67 females and 10 males.

Table 4

Table of Study Characteristics and Quality Appraisal Rating

Author (Year)	Country	Participant Characteristics	Recruitment	Data Collection & Methodology	Key Findings, Themes	Quality Appraisal
Anestis et al. (2022)	UK	N=19 HCPs working with MNDC Aged 28-64 (mean = 47) 17 females, 2 males 6-43 years' experience (mean = 24)	Through collaborations with NHS (National Health Service) Trusts, snowball sampling & advertisement of the study in social media.	Semi-structured interviews Thematic Analysis	Dealing with diagnostic overmath, unpacking the diagnosis, breaking bad news as a balancing act, empowering patients to regain control over their health & lives. Clinicians supported MNDC patients with negative diagnosis experience and its impact. Breaking bad news was a critical and challenging aspect of HCPs work. Formal support and specialised training could help HCPs with breaking bad news and empowering patients.	High
Anestis et al. (2023)	UK	N=8 neurologists working with MNDC Aged 38-54 (mean = 41) 6 males, 2 females 2-20 years' experience (mean = 10)	Through collaborations with NHS neurology departments & centres for MNDCs, & snowball sampling via social media advertisement.	Semi-structured interviews Interpretative Phenomenological Analysis	Meeting patients' emotional and information needs at diagnosis: a balancing act between disease, patient and organisation-related factors. Empathy makes the job harder: the emotional impact and uncovered vulnerabilities associated with breaking bad news. Breaking bad news was challenging for clinicians in terms of achieving a patient-centred approach and dealing with their own emotions during the process.	High

Beyermann et al. (2023)	Sweden	N=11 nurses working with plwMND Aged 41-61 (median = 50) 10 females, 1 male 4-21 years' experience (median = 21)	Via distribution of an invitation and information letter to randomly-selected home care units	Semi-structured interviews Content Analysis	To support in an increasingly difficult everyday life", based on the sub-categories: "Creating a trusting relationship", "Balancing between the needs of patients and their families", and "Sharing knowledge about dying to the families". To support in emotionally challenging situations, based on the sub-categories: "Harbouring family members' difficult feelings", "Providing support even though the situation is unpleasant" and "Being able to give support by receiving confirmation and support from others".	High
Cox et al. (2024)	UK	N=8 HCPs working with plwMND	Via email invitation to identified HCPs fitting inclusion criteria	Semi-structured interviews Thematic Analysis	Positive influences on staff wellbeing included: A sense of fulfilling patients' wishes, good teamwork, presence of an experience clinician, awareness of clinical guidance. Barriers to wellbeing included: Unpredictability of scenarios, moral and ethical uncertainties, external time pressures, mismatched expectations, poor communication and the emotional intensity of the work.	High
Gamskjaer et al. (2022)	Denmark	N=12 HCPs working with plwMND Aged 30-59 12 female, 0 males <5 - >10 years' experience	Via invitation to all HCPs within 2 MND teams	Semi-structured focus group interviews Naïve reading, Structural Analysis & Critical Analysis	Fundamental drive in having a meaningful job. Working conditions; self-management. Value of collegiality. Work-life balance. Work can be enriching and beneficial under the right circumstances.	High

Lerum et al. (2017)	Norway	N=18 HCPs working with plwMND 18 females, 0 male	Via telephone contact with HCPs working with plwMND	Semi-structured interviews Qualitative / Narrative Analysis (Unclear)	Key challenges: Building relationships with those giving and receiving care. Preventing caregiver burnout and breakdown. Providing tailored care. Ensuring good working conditions in patients' homes. Recruiting and retaining HCPs.	Moderate
Olesen et al. (2022)	Denmark	N=9 HCPs working with plwMND and cognitive impairment 8 females, 1 male 1 - >6 years' experience	Via contact with key leaders within health & social care, who selected HCPs meeting inclusion criteria	Focus group interview Interpretive Description	Key challenges: Collaboration as a balancing act; difficult collaborating with families and colleagues due to the severeness and complexity of the disease. Working in a home of sorrow. Coordinating threads to tie: community collaborators.	High

Quality Appraisal Results

Appendix F presents an overview of the critical appraisal. To illustrate a general reflection of study rigour, a scoring strategy was utilised. This is not a reliable statistical indicator of rigour, however, is supplemented by written analysis to indicate strengths and limitations of each study. Overall, six studies were rated as high and one as moderate quality.

All studies clearly stated the research aims and chose appropriate methods of analysis, however Lerum et al.'s (2017) analysis description and study design were vague; the qualitative and narrative elements listed seemingly fitted the aims, however the lack of clarity impacts replicability. All studies explicitly outlined ethical considerations, recruitment strategies, and data collection. Two studies failed to adequately address theoretical study underpinnings (Beyermann et al., 2023; Lerum et al., 2017). Only two studies appropriately acknowledged relationship and reflexivity (Anestis et al., 2022; Anestis et al., 2023); Cox et al. (2024) did reference a reflexivity log, however there was no available excerpt or elaboration within the main text. All studies clearly reported the findings and discussed them in relation to previous research, however three papers did not provide future research recommendations (Beyermann et al., 2023; Cox et al., 2024; Gamskjaer et al., 2022). All studies addressed limitations; however, Lerum et al. (2017) were comparatively brief. Furthermore, all but one paper (Lerum et al., 2017) provided clinical implications.

The moderate-high study ratings meant that none were excluded. This quality assessment aids the analysis and provides methodological context to support reader interpretation.

Thematic Synthesis

Study analysis identified three superordinate and nine subordinate themes (Table 5). Themes are not a total representation of experiences; they capture the primary cross-data narratives, some of which overlap between themes. Appendix G presents supplementary quotations.

Table 5

Themes and Subthemes

Theme	Subtheme
Intensity of Work	Emotionally Taxing
	Challenging, Complex and Unpredictable
Power and Responsibility	Managing Hope
	Balancing Act
	Empowering Patients
Protective Factors	Right Conditions
	Positive Relationships
	Knowledge and Communication
	Privilege, Pride and Reward

Intensity of Work

This theme encompasses the narrative that working with plwMND feels intense. Participants experienced this intensity in the emotional impact of the work, in the challenges they faced., the complexity of MND presentations and subsequent care delivery, and the unpredictability of it all.

Emotionally Taxing

Participants described the emotional consequences of their work on their wellbeing, describing the effects of holding space for patients and caregivers to express their emotions and how this impacts staff wellbeing. Staff reported having to *"bear the brunt of patients' annoyance and irritation",* being the recipient of *"anger", "mistrust" and "dissatisfaction"* (Anestis et al., 2022). Participants shared *"If they're really devastated, you can't manage it…you've just got to let them get on with it"* (Anestis et al., 2023).

Most studies described that being emotionally impacted by the work felt inevitable: *"It's impossible not to become emotional sometimes"* (Anestis et al., 2022), *"You're only human and you get affected".* Papers described the emotive nature of witnessing *"so much frustration and powerlessness"* (Gamskjaer et al., 2022) and struggling to manage their emotional responses: *"I said, I'll be back in an hour…I went to the car and cried and felt like I can't handle it"* (Beyermann et al., 2023).

Studies mentioned a sense of tiredness resulting from work: *"I find it incredibly draining…I always feel completely exhausted"* (Anestis et al., 2023), and discussed feeling traumatised: *"It was one of the most traumatic things I have ever done"* (Cox et al., 2024); *"Whenever you break bad news, it reminds you of all the others…and of your own fragility"* (Anestis et al., 2023). Participants described feeling a sense of guilt in delivering diagnoses: *"You can see the bottom drop out of somebody's life in front of you…", "You feel terribly responsible, like you've done it to them, you've given it to them"* (Anestis et al., 2023).

Studies discussed a sense of dissociating to manage the emotional nature of the work: *"I manage my emotions by going a bit numb…I'm watching myself…so you don't cry badly, you can look empathetic. The only way to not feel that upset when people are upset is to do this sort of…technique"* (Anestis et al., 2023); *"You develop some sort of immunity to the emotional impact"* (Cox et al., 2024).

Challenging, Complex and Unpredictable

Across studies, participants discussed elements of MND work as being challenging and complex, which contributed to work intensity: *"I'm having difficult conversations around advanced care planning, end of life decisions…about death and dying…it is difficult", "You do have a bit of a mess, rather than it being straightforward"* (Anestis et al., 2022). Participants described the *"immense concentration"* (Cox et al., 2024) required of them: *"It's knowing how to do it right that's the most challenging. How do you give terrible news to somebody in a way that allows them* *to absorb the information without shutting down emotionally, and without it being a challenging experience?",* and the paradox of: *"It's like punching someone so hard but you have to do it very gently to soften the blow"* (Anestis et al., 2023). Papers also discussed the energy and resilience necessary of them: *"It's like stretching a rubber band…you stretch it a little, and a little more, a little more…it's amazing how long it can get before it breaks"* (Lerum et al., 2017).

Studies mentioned the mismatch in caregiver and patient experiences to be a further challenge: *"Where I can see the patient is getting worse and the caregivers won't acknowledge it. You see the grief in the person's eyes due to being so fatally ill, and the spouse…just refuses to accept it. It's terrible to witness"* (Olesen et al., 2022). Additionally, witnessing patients' distress was cited as a challenge: *"When you have changed so radically that you have become physically and verbally aggressive…you lose your understanding of the disease…become scared of everyone around you…these are the biggest challenges I face"* (Olesen et al., 2022).

Participants discussed the unpredictability of MND and consequent challenges: *"We can't guarantee them that it won't get worse"* (Anestis et al., 2022). Chaos was referenced throughout studies: *"This is a frustration, this is a chaos"* (Beyermann et al., 2023), *"It turns into chaos"* (Lerum et al., 2017). Participants discussed being taken by surprise by aggression; *"When somebody has a violent response to diagnosis…that can be surprising and awful"* (Anestis et al., 2023), *"Sometimes I was a bit afraid of her…she could swing very quickly from being happy and thinking you're the most competent person you've ever met, to bringing you down in three seconds where you felt like the most incompetent person on earth"* (Beyermann et al., 2023) and escalation: *"The sweater gets caught in the wheelchair, he bends forward, loses his breath, then things don't happen quickly enough, he starts to cry, and his wife starts to cry, then the poor HCP is left with a very unpleasant situation".*

Power and Responsibility

This theme encapsulates the narrative that HCPs working within MND experience a sense of power and responsibility in relation to patient care. Participants discussed their priorities, struggles and feelings regarding power and responsibility.

Managing Hope

Participants mentioned hope, and the experience of giving it, withholding it, and removing it. Remaining *"realistic"* was also referenced across studies.

"I don't give any hope in MND. I think it's unfair, because they'd have an unrealistic expectation. I don't take away hope, but I don't give false hope" (Anestis et al., 2023)

"I try to encourage them to have a realistic mindset…at the same time you don't want to destroy someone's hope…it's quite a fine line" (Anestis et al., 2022).

"It's important that we are transparent with patients and not give false hope" (Anestis et al., 2022).

Managing hope was perceived as a burden: *"We get so affected by it because it is so hopeless, and the hopelessness…it becomes such a heavy burden to carry"* (Olesen et al., 2022).

Having to deliver news that patients would not be able to engage in prior work or hobbies posed a key area in hope-management: *"That was a difficult conversation to have…I obviously couldn't say, well you can't do that, but saying…oh, that might be tricky, would they have any sort of admin-type work?"* (Anestis et al., 2022).

Balancing Act

Studies referenced several domains where clinicians felt a 'balancing act'. Managing differing patient and caregiver expectations felt difficult: *""Their partner might be wanting loads of information about how to manage…the patient might be like 'I don't even want to know'…you get* *these two levels of conversations happening which can be difficult to manage"* (Anestis et al., 2022).

Balancing the perspectives of patients and stakeholders felt a further challenge: *"We try to collaborate with them"* (Lerum et al., 2017); *""I feel my energy is being drained when I'm at a multi-disciplinary meeting [with external collaborators]…I'm trying with all my presence to show that we need to be aware of this family, and then some rigid health professionals…just sit there and stare into their papers the whole time"* (Gamskjaer et al., 2022).

Papers also discussed that balancing professional and personal commitments felt difficult: *""When you've been out there listening to how difficult it is for [patients] and talk about death and how they're going to die…it's just a bit difficult to come home and sit down and have a nice family dinner"* (Gamskjaer et al., 2022).

Empowering Patients

Redistributing power to patients felt important for HCPs. Advocating for and implementing patient choice was discussed: *"The patient had chosen the location, in their own home, and died with their family around them"* (Cox et al., 2024); *"It's about reframing, isn't it? Inevitably it's sad...people will die. But it's about making sure they were able to go on that family holiday…go to that wedding...what can we put in place to make that happen?"* (Anestis et al., 2022).

The HCP and patient liaison was discussed in relation to empowerment: *"I feel what we have got to do is…empower people to self-manage. I say that with good management that comes from both the HCP and the patient who needs to take some responsibility, we can preserve a good quality of life"* (Anestis et al., 2022).

Empowering patients was cited as a paradoxical 'positive' to death: *"They had a beautiful death. They died with dignity and calmly…it is a privilege to allow a patient to have a beautiful death"* (Cox et al., 2024).

Protective Factors

This theme captures the narrative around factors which provide a buffer to the difficulties experienced within MND care. This included the impact of working environments, patient-staff and colleague relationships, desires and expectations of communication and knowledge-sharing, and clinicians' experiences of feeling privileged and proud of their work, forming a sense of reward.

Right Conditions

The right working conditions was perceived as a factor which positively influenced staff wellbeing. Autonomy contributed to this: *"I don't just get tasks assigned to me, I also have responsibility"* (Gamskjaer et al., 2022); *"To be able to shape my own working instead of going to work and having other people set the boundaries"* (Gamskjaer et al., 2022), as did having influence and an ability to delegate based on time and need: *"We have huge influence. We sit down together and decide who is best for the job…based on time and needs. The influence we have over our own work life: that means a lot in being enthusiastic about your job"* (Gamskjaer et al., 2022).

Furthermore, the right resources were described as supportive in helping staff to manage challenges and work effectively, such as training necessary to equip clinicians with skills. Participants desired training (Anestis et al., 2022) and the absence of training led to participants feeling they lacked necessary skills and knowledge (Anestis et al., 2023; Lerum et al.., 2017). HCPs were described as often experiencing sub-optimal conditions (Beyermann et al., 2023).

Positive Relationships

Participants described noticing that positive colleague relationships were helpful in managing work challenges: *""I am talking to a colleague, I had to call and vent…I calm down and I can…pick up this thread again"* (Beyermann et al., 2023). The *"shared experience"* in MND teams was described as *"lovely"* and *"positive"* and helped HCPs to feel *"connected"* (Cox et al., 2024).

Having a supportive space to share and discuss feelings or difficulties, and being listened to, was described as helpful to participants' wellbeing: *"Just the fact I can share. My colleagues don't need to say much…I can get rid of my heavy thoughts…that's a great help and important that we have opportunity for that*" (Gamskjaer et al., 2022). The knowledge that peer-support existed was perceived as helpful in itself: *"If something is tremendously difficult…I can lean on my colleagues"* (Gamskjaer et al., 2022).

Participants perceived colleagues as familial, and desired to care and nurture peer relationships: *"professionals become more akin to a version of family…there's an extended MDT family. It is important to care for, and nurture"* (Cox et al., 2024).

Participants perceived staff-patient relationships as *"long-standing and so complicated"* (Cox et al., 2024) and influential on their wellbeing. Appropriate staff disclosure was perceived as helpful in relationship-building: *"It is important that we open up a little and allow something personal into it…otherwise the person can't relate to you if you are too professional…you have to open up…bring something personal into them"* (Olesen et al., 2022). Social talk was described as another positive factor: *"You try to talk socially about other issues too…talk a little as a person with a person"* (Beyermann et al., 2023).

Knowledge and Communication

Knowledge-sharing and communication with patients felt a prominent area for HCPs, who spent time deliberating over appropriate methods and timing for patients' needs: *"Clearly it is too much information to handle all at once…it's something about taking it one step at a time"* (Lerum et al., 2017); *"…only providing it when it needs to be delivered"* (Anestis et al., 2023). Communication was perceived to help or hinder other areas of work: *"Communication is absolutely key…where communication failed, everything else failed around it"* (Cox et al., 2024).

Participants perceived transparency and honesty as paramount in care delivery: *"We need to be honest with them, make sure they are informed"* (Anestis et al., 2022). However, knowledge was also perceived as powerful, and sometimes a burden: *"Patients can't know what they don't know. You can't take away knowledge once it's given…you can't protect people from an outcome that may happen"* (Anestis et al., 2023).

Privilege, Pride and Reward

In contrast to the difficulties, participants experienced positive and satisfying elements to their work. Papers described HCPs feeling *"lucky"* (Anestis et al., 2022) and *"privileged"* in their work (Anestis et al., 2022; Cox et al., 2024), through providing patient-centred care and a 'positive' death: *"It's a privilege to allow a patient a beautiful death"* (Cox et al., 2024).

HCPs referenced feeling 'proud' of their work, which contributed to feelings of empowerment, confidence and self-worth: *"I felt proud…one of the things I've felt most proud of in my career. The experience empowered me and increased my confidence…that real sense of self-worth, and professional worth"* (Cox et al., 2024).

A specialist skillset and doing a good job led to a sense of pride, importance, and motivation: *"If I have enough experience…understanding and empathy that I do it well…it's not easy…I like to think if I've done it well, it can help the patient"* (Anestis et al., 2022); *"I've built up a specialist knowledge that not many other people have…makes me an important person…I become more motivated"* (Gamskjaer et al., 2022).

HCPs referenced feeling *"appreciated"* by patients and caregivers; feelings of gratitude and reward contributed positively to wellbeing: *"You get so much in return…you actually feel the appreciation or gratitude coming from patients or relatives"* (Gamskjaer et al., 2022); *"I strive for something that gives me something in return"* (Gamskjaer et al., 2022). Being *"A part of something significant and emotional"* (Cox et al., 2024) also provided a sense of reward and satisfaction: *"It stayed with me"* (Cox et al., 2024).

Where HCPs experienced fewer rewarding experiences, staff-retention was challenging: *"We have used up, emptied [area]. If you ask someone in the home-based services if they would like to work there, they respond 'I would rather quit'"* (Lerum et al., 2017).

Discussion

This review aimed to identify and synthesise the current literature exploring the emotional impact of working with plwMND on HCPs to 1) assess and critically appraise the quality of existing research and 2) provide clinical implications and future recommendations to enhance the understanding and support of HCPs working in MND services. Three superordinate themes were identified: *'Intensity of Work', 'Power and Responsibility', and 'Protective Factors'.*

Intensity of Work

This theme captures the narrative that MND work is intense in the emotional demand and challenges posed for HCPs. HCPs described having to bear the negative emotional responses of patients, often being the 'brunt' of difficult expressions of distress. Witnessing and absorbing patient distress felt inevitable for participants, as did the fact that their own wellbeing would be negatively impacted as a result. Negative impacts of patient distress on HCP wellbeing were described as experiencing sadness, tiredness and exhaustion, guilt about delivering traumatic diagnoses, and moral or existential dilemmas around mortality, alongside feeling traumatised by the vicarious distress. These findings indicate symptoms of CF, burnout and VT and correlate with previous literature highlighting the risk and presence of these conditions within HCPs.

Furthermore, to cope with these experiences, participants described dissociating through numbing themselves, observing themselves from afar, and becoming immune to the emotional impact of work. Dissociation and depersonalisation in response to trauma is well-documented in the face of 'overwhelming traumatic experience' (Boyer et al., 2022) as a method of 'coping with too much stress' (NHS UK, 2023) and is evidenced to interfere with functioning (Boyer et al., 2022), and thus may impact care delivery (Cimiotti et al., 2012).

Papers described MND work as challenging and complex in the intense concentration, energy, diplomacy and planning required of HCPs. These requirements felt necessary to manage the well-documented constant changes associated with MND (Pinto et al., 2021), and the difficult conversations regarding death and dying. Chaos and unpredictability posed further challenges for HCPs, who felt frustrated and surprised by the chaos and unexpected violence witnessed in MND work. The distress associated with significant and rapid changes within plwMND are evidenced in previous research (Glennie et al., 2021; Pinto et al., 2021); thus, it is not surprising that working within this environment also leads to negative experiences for HCPs.

Power and Responsibility

This theme encapsulates the dynamic of power: holding it, sharing it, and destroying it. The notion of being ‘hope managers’ was a prominent discourse which seemed an often-unwelcome position of power for HCPs. Previous literature discusses hope as being important within palliative care (Kylma et al., 2009), yet paradoxical within MND (Poppe, 2020) due to the inevitably-reduced quality of life (QoL). Hope has been proposed to involve ‘the desire for an outcome, and the belief that the outcome’s obtaining is at least possible’ (Aronson, 2015). The inevitability of an undesirable outcome within the nature of MND necessitates hope as difficult to manage.

HCPs described witnessing hopelessness as a heavy burden, perhaps unsurprisingly given the difficult position of informing patients that their QoL will decrease and having ‘dreams shuttered down’ (Selman et al., 2013). Snyder (1991) conceptualised hope as ‘the perceived capability to derive pathways to desired goals and motivate oneself to use those pathways’. The limited ability of HCPs to meet their goal of improving patient QoL suggests a possible shared hopelessness. Kern et al. (2020) criticised that Snyder’s (1991) theory lacked appreciation of the contextual and dynamic influences on thriving, suggesting that complexity requires flexibility and multi-disciplinary approaches, listening, and empathy.

Previous research recommendations indicate that literature on hope in palliative HCPs is scant and further information is needed (Kylma et al., 2009); thus, these findings are of interest.

Participants discussed navigating a balancing act between managing the needs and expectations of patients, caregivers, stakeholders, alongside their own, and that of their relatives; this posed another challenge, and felt a sense of responsibility in these many needs. Participants experienced feeling drained, and struggling to manage their personal and professional responsibilities, further suggesting evidence of CF, VT and burnout (Zhang et al., 2018; Halfer & Graf, 2006; Cimiotti et al., 2012; Cocker & Joss, 2016).

Participants described redistributing power to patients through advocacy and choice regarding sustaining QoL and preparing for death. Empowering patients was discussed through supporting self-management of symptoms, where appropriate. Empowering patients seemed a paradoxical positive for HCPs in contrast to the difficult experiences, aligned with previous literature suggesting that empowering patients via respecting patient choice and autonomy, and encouraging shared decision-making, leads to mutual satisfaction for patients and HCPs (Ippolito et al., 2020; Nimmon et al., 2016; Raina & Thawani, 2016).

Protective Factors

This theme captures the narrative that several experiences of working in MND provide buffers to the many challenges. Participants discussed how the right conditions, such as having workload-autonomy, access to training and necessary equipment, and a sense of responsibility all contributed to high-quality care-delivery, managing challenges, and work-related enthusiasm. The absence of training and resources was felt to be detrimental to participants feeling confident, skilled, and supported to do their job. Findings correlate with previous research highlighting that HCPs able to access training, upskilling and resources experience higher job satisfaction (Damery et al., 2021; Shiri et al., 2023) and can contribute to staff retention (Shiri et al., 2023; Morrow et al., 2022).

Participants discussed the value and importance of positive colleague relationships and staff-patient relationships. Space to talk, be listened to and share experiences with peers led to feelings of calm, connection, and positivity. Knowing that these opportunities were available felt containing for staff. Findings correlate with existing literature suggesting that having reflective listening spaces and common ground offers a sense of containment and psychological safety (Kline, 2002; West, 2021).

Participants described the closeness and complexity of staff-patient relationships, highlighting the importance of appropriate staff disclosure and social relationship-building. HCPs felt the need to be relatable to build rapport and trust. Knowledge and communication formed key areas in doing so; participants took care to consider what knowledge to share, and when, considering patient need. Honesty and transparency were perceived as respectful and empowering for patients yet could also feel like a burden for HCPs who experienced a sense of wanting to protect patients from undesirable outcomes. Findings further link to previous research suggesting that positive working relationships are beneficial to both staff and patient wellbeing (Ippolito et al., 2020; Nimmon et al., 2016; Raina & Thawani, 2016), alongside issues with hopelessness regarding outcomes (Aronson, 2015).

Papers discussed feelings of privilege, pride and reward in relation to aspects of their work, linking in with having empowered patients, successfully fostered positive relationships, and been a part of something significant. Participants described positive contributions to wellbeing including feeling appreciated, specialised in their skillset, confident and worthy both personally and professionally.

‘Compassion satisfaction’ (CS) is defined as the amount of pleasure derived from helping others (Stamm, 2010) and is comprised of factors such as HCPs feeling their work matters, feeling effective at work, implementing self-care strategies and receiving support (Alkema et al., 2008; Zhang et al., 2018). CS has been noted as the ‘antidote’ to CF, VT and burnout (Zhang et al., 2018; Cocker & Joss, 2016), and linked to motivation (Figley, 2002), resilience (Burnett & Wahl, 2015; Ata et al., 2020) and staff retention (Jiang & Jiang, 2024).

Review findings indicate that HCPs working with plwMND experience significant and plentiful challenges, distress, and subsequent symptoms of CF, VT and burnout. Several themes indicate a need for reflective space, empathy, and support, which could contribute to CS, thus counteracting difficulties and leading to enhanced staff wellbeing and retention and consequently care delivery. Furthermore, findings indicate additional positive elements to MND work which allow staff to feel appreciated, recognised and proud, further enhancing CS.

Critique of Included Studies

Only two of the seven studies (Anestis et al., 2022; Anestis et al., 2023) appropriately acknowledged the relationship between the researcher and the participants, and adequately addressed reflexivity. Reflexivity is particularly important within qualitative research (Berger, 2013; Dodgson, 2019) to address any potential researcher bias. Thus, risk of bias is higher in studies failing to address reflexivity. Furthermore, Lerum et al. (2017) presented a vague and unclear analysis method, therefore it would be difficult to adequately replicate findings. Providing a clear analysis method would enhance robustness and guard against methodological flaws (Asendorpf, 2013). It is a strength that all other studies provided clear analysis descriptions. All studies clearly stated the research aims, ethical considerations, recruitment strategies, and data collection methods. Additionally, all studies clearly reported the findings and discussed them in relation to previous research. However, one study (Beyermann et al., 2023) failed to provide future research recommendations. Providing these recommendations would increase the usefulness of the research and encourage address of the current study limitations. Furthermore, one study (Lerum et al., 2017) did not provide clinical implications. Doing so would establish relevance to the field and demonstrate value beyond contributions to theory. At least six papers (Cox et al., 2024 is unclear) utilised multiple researchers during analysis to improve rigour and credibility, forming a significant strength of those studies.

Review Limitations and Future Directions

A key limitation of this review is the small body of research encompassed. Thus, the thematic scope is narrow and there are relatively limited perspectives explored, potentially diminishing review impact. However, this demonstrates the need for further research in the topic area, and to increase the breadth and richness of available literature. Furthermore, this review addressed a gap in literature and is the first review of its kind in the topic area, thus contributing considerably to the research on HCPs in MND; this forms a strength.

When undertaking meta-synthesis of qualitative literature, it is difficult to make direct comparisons due to the diverse methodological approaches, analytical frameworks, and sample characteristics (Thorne et al., 2004). As such, confidently integrating study findings is difficult. Further, the subjective nature of meta-synthesis allows for researcher bias. Whilst efforts have been taken to demonstrate procedural rigour and consultation of multiple researchers, some subjectivity is unavoidable. Despite these limitations, qualitative meta-synthesis allows for rich, nuanced exploration of the topic area, facilitating more contextualised understanding than purely numerical analysis might provide (Paterson et al., 2001).

This review excluded grey literature and papers not published in English. This decision was made to avoid the risk of further diluting the quality of the small existing body of research and uphold the scientific and academic rigour expected of systematic reviews. Future reviews may benefit from including grey literature to broaden the evidence base and capture perspectives not presented in peer-reviewed journals.

An adapted version of the CASP (2024) tool was utilised to assess study quality, based on its accessibility and wide use within the field. Whilst an established tool somewhat increases validity, the ‘yes/no/can’t tell’ nature of the answers could lead to inter-rater variance. A second rater was used to safeguard and increase reliability; however this was not utilised for every paper, which could have reduced the reliability of CASP ratings. Additionally, future research may benefit from using a tool with increased sensitivity to enhance quality assessment, such as the COREQ (Consolidated criteria for reporting qualitative research; Tong et al., 2007).

Finally, all included studies were conducted within the last seven years, suggesting that evidence is contemporarily relevant; a strength for clinical implications. However, due to the small body of research, only three studies were UK-based. Thus, not all findings may be generalisable to UK healthcare settings.

Clinical Implications

This review highlights the importance of clinicians working in MND, and their managers, to be aware of the impact of this work and challenges faced. A recognition of the risks of CF, VT and burnout is imperative, alongside acknowledging the importance of CS in guarding against these conditions. Equipping staff with the skills and support necessary to care for their own wellbeing, and in turn that of their patients, is essential in ensuring health staff teams and high-quality patient care.

Compassionate Leadership (CL) encompasses many key areas identified within review findings as contributing positively to staff wellbeing, for example providing staff with the necessary training and resources (Atkins & Parker, 2012; McCauley & Fick-Cooper, 2020), focusing on relationships via listening, understanding, empathising and supporting staff to feel valued and able (West, 2021), removing obstacles hindering effective working, and leaders collaborating, not imposing their own ideas (Gallo, 2017). Thus, utilising CL approaches within MND services could enhance staff wellbeing, retention, and consequently patient outcomes (De Hert, 2020).

Compassion-Focused Therapy (CFT) helps individuals to learn key skills related to nurturing core aspects of compassion, including caring for wellbeing, sensitivity, distress tolerance, empathy, and non-judgment (Gilbert, 2009). CFT emphasises three brain systems; ‘threat’, activated when we are feeling threatened or trying to rescue, ‘drive’, focused on problem-solving and achieving, and ‘soothe’, focused on being present, connection, and kindness (Gilbert, 2009). When exposed to the reported distress, challenge, responsibility and expectations associated with MND care, it is likely that HCPs are over-activating their threat and drive systems, interacting by increasing the sense of threat and being on-the-go. In order to balance this sense of threat and constant ‘doing’, it is necessary to activate the soothe system, thus bringing the other systems back into balance (Gilbert, 2009). Thus, providing CFT psychoeducation to HCPs could assist in promoting a sense of safety, care, and connection, shown to increase compassion for self and others (Gilbert, 2009), enhancing staff wellbeing and improving care-delivery.

Another helpful support method for HCPs could be Dialectical Behaviour Therapy (DBT), a therapy aiming to support with intense emotions, distress tolerance, emotional regulation, and interpersonal effectiveness (Linehan, 2014). DBT discussed a ‘rational mind’, focused on problem-solving and fixing, an ‘emotional mind’, where strong emotions dictate over logic, and a ‘wise mind’ where the individual can connect with emotions of self and others, alongside logic (Linehan, 2014). Within MND work, over-focusing on the rational mind and ignoring emotions in situations the HCP is unable to ‘fix’, could contribute to burnout and CF. Similarly, over-connecting with the emotional mind in a rescuer-caretaker response could make it harder to take effective action, and contribute to VT. All these factors are likely to negatively impact HCP wellbeing and patient care. Thus, teaching clinicians DBT skills could be useful to encourage identifying with the ‘wise mind’ and connecting with both the logic necessary for care-planning, effective decision-making and problem solving, and also the emotional attributes such as empathy and compassion necessary to manage caring for self and others (Linehan, 2014).

Conclusion

The results of this synthesis indicate that HCPs working within MND services experience distress, intense emotions, significant challenge, and high levels of responsibility. These factors were linked to reports of VT, CF and burnout, thus negatively impacting staff wellbeing. Positive and protective elements to the work were noted, including empowering patients, job satisfaction, colleague support, and staff-patient rapport. Protective elements were linked to aspects of CS, thus contributing to prevention or mitigation of CF and burnout. Further attention in practice and research should be given to acknowledging the difficulties experienced by HCPs within MND services and supporting them to care for their wellbeing. Utilising CL and providing psychoeducation around models such as CFT or DBT could be useful in supporting HCPs to take care of their wellbeing, and in turn provide high-quality patient care.

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Appendices

Appendix A

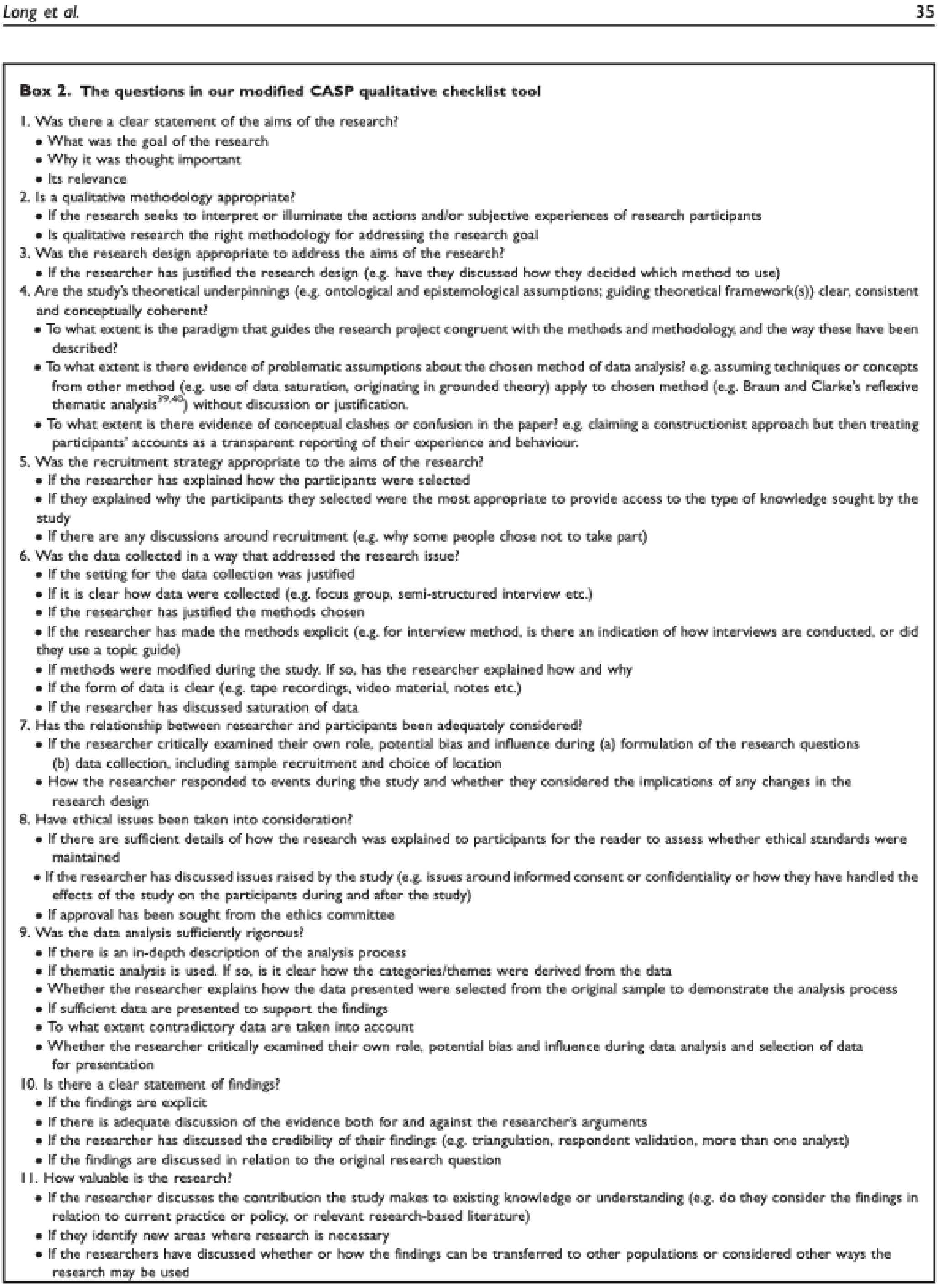
Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) Guidelines (Tong et al., 2012)

No.	Item	Guide and Description	Page Number
1	Aim	State the research question the synthesis addresses	pp.5
2	Synthesis methodology	Identify the synthesis methodology or theoretical framework which underpins the synthesis and describe the rationale for choice of methodology (e.g., meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis).	pp.5,8,9
3	Approach to searching	Indicate whether the search was pre-planned (comprehensive search strategies to seek all available studies) or iterative (to seek all available concepts until they theoretical saturation is achieved).	pp.5
4	Inclusion criteria	Specify the inclusion/exclusion criteria (e.g., in terms of population, language, year limits, type of publication, study type).	pp.7
5	Data sources	Describe the information sources used (e.g., electronic databases (MEDLINE, EMBASE, CINAHL, psycINFO, Econlit), grey literature databases (digital thesis, policy reports), relevant organisational websites, experts, information specialists, generic web searches (Google Scholar) hand searching, reference lists) and when the searches conducted; provide the rationale for using the data sources.	pp.5,6
6	Electronic search strategy	Describe the literature search (e.g., provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research, and search limits).	pp.6
7	Study screening methods	Describe the process of study screening and sifting (e.g., title, abstract and full text review, number of independent reviewers who screened studies).	pp.7,10
8	Study characteristics	Present the characteristics of the included studies (e.g., year of publication, country, population, number of participants, data collection, methodology, analysis, research questions).	pp.10-14
9	Study selection results	Identify the number of studies screened and provide reasons for study exclusion (e.g., for comprehensive searching, provide numbers of studies screened and reasons for exclusion indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion based on modifications t the research question and/or contribution to theory development).	pp.7,10

10	Rationale for appraisal	Describe the rationale and approach used to appraise the included studies or selected findings (e.g. assessment of conduct (validity and robustness), assessment of reporting (transparency), assessment of content and utility of the findings).	pp.5,8
11	Appraisal items	State the tools, frameworks and criteria used to appraise the studies or selected findings (e.g. Existing tools: CASP, QARI, COREQ, Mays and Pope [25]; reviewer developed tools; describe the domains assessed: research team, study design, data analysis and interpretations, reporting).	pp.8
12	Appraisal process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required.	pp.8
13	Appraisal results	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale.	pp.12-15
14	Data extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies? (e.g. all text under the headings "results /conclusions" were extracted electronically and entered into a computer software).	pp.7
15	Software	State the computer software used, if any.	pp.7
16	Number of reviewers	Identify who was involved in coding and analysis.	pp.9
17	Coding	Describe the process for coding of data (e.g. line by line coding to search for concepts)	pp.9, Appendix C, D
18	Study comparison	Describe how were comparisons made within and across studies (e.g. subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary).	pp.9
19	Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive.	pp.9
20	Quotations	Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations of the author's interpretation	pp.16-24, Appendix G
21	Synthesis output	Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g. new interpretation, models of evidence, conceptual models, analytical framework, development of a new theory or construct).	pp.15-28

Appendix B

Adapted CASP Qualitative Research Checklist (Long et al., 2020)



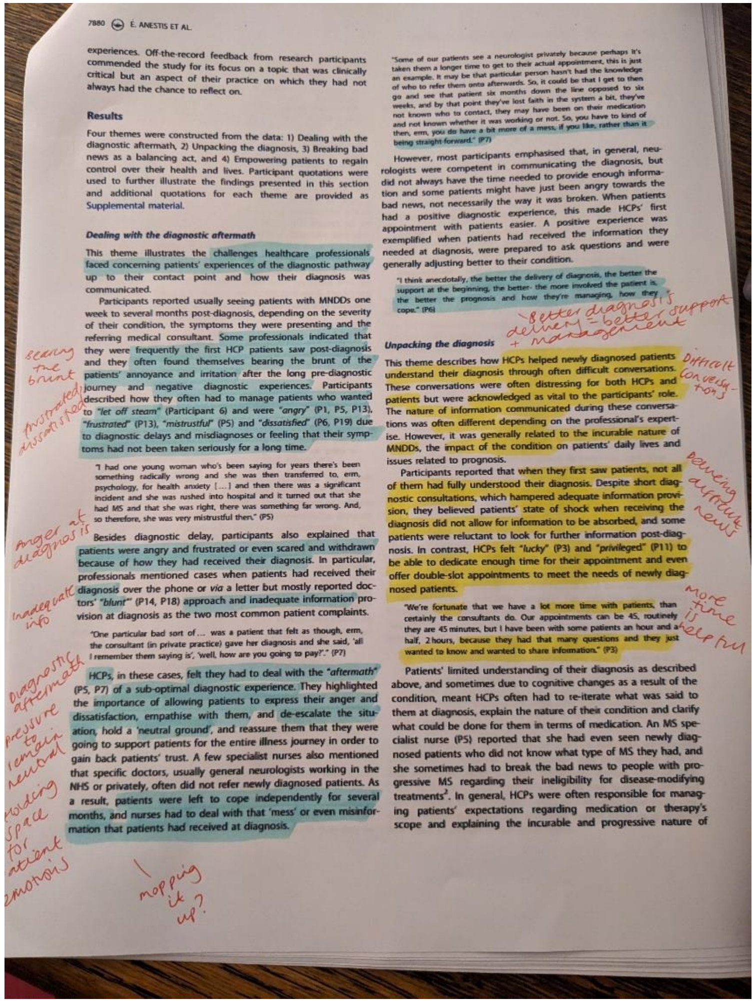
Long et al. 35

Box 2. The questions in our modified CASP qualitative checklist tool

1. Was there a clear statement of the aims of the research?
   - What was the goal of the research
   - Why it was thought important
   - Its relevance
2. Is a qualitative methodology appropriate?
   - If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
   - Is qualitative research the right methodology for addressing the research goal
3. Was the research design appropriate to address the aims of the research?
   - If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)
4. Are the study's theoretical underpinnings (e.g. ontological and epistemological assumptions; guiding theoretical framework(s)) clear, consistent and conceptually coherent?
   - To what extent is the paradigm that guides the research project congruent with the methods and methodology, and the way these have been described?
   - To what extent is there evidence of problematic assumptions about the chosen method of data analysis? e.g. assuming techniques or concepts from other method (e.g. use of data saturation, originating in grounded theory) apply to chosen method (e.g. Braun and Clarke's reflexive thematic analysis[39,40]) without discussion or justification.
   - To what extent is there evidence of conceptual clashes or confusion in the paper? e.g. claiming a constructionist approach but then treating participants' accounts as a transparent reporting of their experience and behaviour.
5. Was the recruitment strategy appropriate to the aims of the research?
   - If the researcher has explained how the participants were selected
   - If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
   - If there are any discussions around recruitment (e.g. why some people chose not to take part)
6. Was the data collected in a way that addressed the research issue?
   - If the setting for the data collection was justified
   - If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
   - If the researcher has justified the methods chosen
   - If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
   - If methods were modified during the study. If so, has the researcher explained how and why
   - If the form of data is clear (e.g. tape recordings, video material, notes etc.)
   - If the researcher has discussed saturation of data
7. Has the relationship between researcher and participants been adequately considered?
   - If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
   - How the researcher responded to events during the study and whether they considered the implications of any changes in the research design
8. Have ethical issues been taken into consideration?
   - If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
   - If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
   - If approval has been sought from the ethics committee
9. Was the data analysis sufficiently rigorous?
   - If there is an in-depth description of the analysis process
   - If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
   - Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
   - If sufficient data are presented to support the findings
   - To what extent contradictory data are taken into account
   - Whether the researcher critically examined their own role, potential bias and influence during data analysis and selection of data for presentation
10. Is there a clear statement of findings?
    - If the findings are explicit
    - If there is adequate discussion of the evidence both for and against the researcher's arguments
    - If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
    - If the findings are discussed in relation to the original research question
11. How valuable is the research?
    - If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature)
    - If they identify new areas where research is necessary
    - If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Appendix C

Initial Coding Example



7880 É. ANESTIS ET AL.

experiences. Off-the-record feedback from research participants commended the study for its focus on a topic that was clinically critical but an aspect of their practice on which they had not always had the chance to reflect on.

Results

Four themes were constructed from the data: 1) Dealing with the diagnostic aftermath, 2) Unpacking the diagnosis, 3) Breaking bad news as a balancing act, and 4) Empowering patients to regain control over their health and lives. Participant quotations were used to further illustrate the findings presented in this section and additional quotations for each theme are provided as Supplemental material.

Dealing with the diagnostic aftermath

This theme illustrates the challenges healthcare professionals faced concerning patients' experiences of the diagnostic pathway up to their contact point and how their diagnosis was communicated.

Participants reported usually seeing patients with MNDDs one week to several months post-diagnosis, depending on the severity of their condition, the symptoms they were presenting and the referring medical consultant. Some professionals indicated that they were frequently the first HCP patients saw post-diagnosis and they often found themselves bearing the brunt of the patients' annoyance and irritation after the long pre-diagnostic journey and negative diagnostic experiences. Participants described how they often had to manage patients who wanted to *"let off steam"* (Participant 6) and were *"angry"* (P1, P5, P13), *"frustrated"* (P13), *"mistrustful"* (P5) and *"dissatisfied"* (P6, P19) due to diagnostic delays and misdiagnoses or feeling that their symptoms had not been taken seriously for a long time.

bearing the brunt

frustrated, dissatisfied

> "I had one young woman who's been saying for years there's been something radically wrong and she was then transferred to, erm, psychology, for health anxiety [...] and then there was a significant incident and she was rushed into hospital and it turned out that she had MS and that she was right, there was something far wrong. And, so therefore, she was very mistrustful then." (P5)

Besides diagnostic delay, participants also explained that patients were angry and frustrated or even scared and withdrawn because of how they had received their diagnosis. In particular, professionals mentioned cases when patients had received their diagnosis over the phone or *via* a letter but mostly reported doctors' *"blunt"* (P14, P18) approach and inadequate information provision at diagnosis as the two most common patient complaints.

Anger at diagnosis

Inadequate info

> "One particular bad sort of… was a patient that felt as though, erm, the consultant (in private practice) gave her diagnosis and she said, 'all I remember them saying is', 'well, how are you going to pay?'." (P7)

HCPs, in these cases, felt they had to deal with the *"aftermath"* (P5, P7) of a sub-optimal diagnostic experience. They highlighted the importance of allowing patients to express their anger and dissatisfaction, empathise with them, and de-escalate the situation, hold a 'neutral ground', and reassure them that they were going to support patients for the entire illness journey in order to gain back patients' trust. A few specialist nurses also mentioned that specific doctors, usually general neurologists working in the NHS or privately, often did not refer newly diagnosed patients. As a result, patients were left to cope independently for several months, and nurses had to deal with that 'mess' or even misinformation that patients had received at diagnosis.

Diagnostic aftermath

pressure to remain neutral

holding space for patient emotions

mopping it up?

> "Some of our patients see a neurologist privately because perhaps it's taken them a longer time to get to their actual appointment, this is just an example. It may be that particular person hasn't had the knowledge of who to refer them onto afterwards. So, it could be that I get to then go and see that patient six months down the line opposed to six weeks, and by that point they've lost faith in the system a bit, they've not known who to contact, they may have been on their medication and not known whether it was working or not. So, you have to kind of then, erm, you do have a bit more of a mess, if you like, rather than it being straight-forward." (P7)

However, most participants emphasised that, in general, neurologists were competent in communicating the diagnosis, but did not always have the time needed to provide enough information and some patients might have just been angry towards the bad news, not necessarily the way it was broken. When patients had a positive diagnostic experience, this made HCPs' first appointment with patients easier. A positive experience was exemplified when patients had received the information they needed at diagnosis, were prepared to ask questions and were generally adjusting better to their condition.

> "I think anecdotally, the better the delivery of diagnosis, the better the support at the beginning, the better- the more involved the patient is, the better the prognosis and how they're managing, how they cope." (P6)

Better diagnosis delivery = better support + management

Unpacking the diagnosis

This theme describes how HCPs helped newly diagnosed patients understand their diagnosis through often difficult conversations. These conversations were often distressing for both HCPs and patients but were acknowledged as vital to the participants' role. The nature of information communicated during these conversations was often different depending on the professional's expertise. However, it was generally related to the incurable nature of MNDDs, the impact of the condition on patients' daily lives and issues related to prognosis.

Difficult conversations

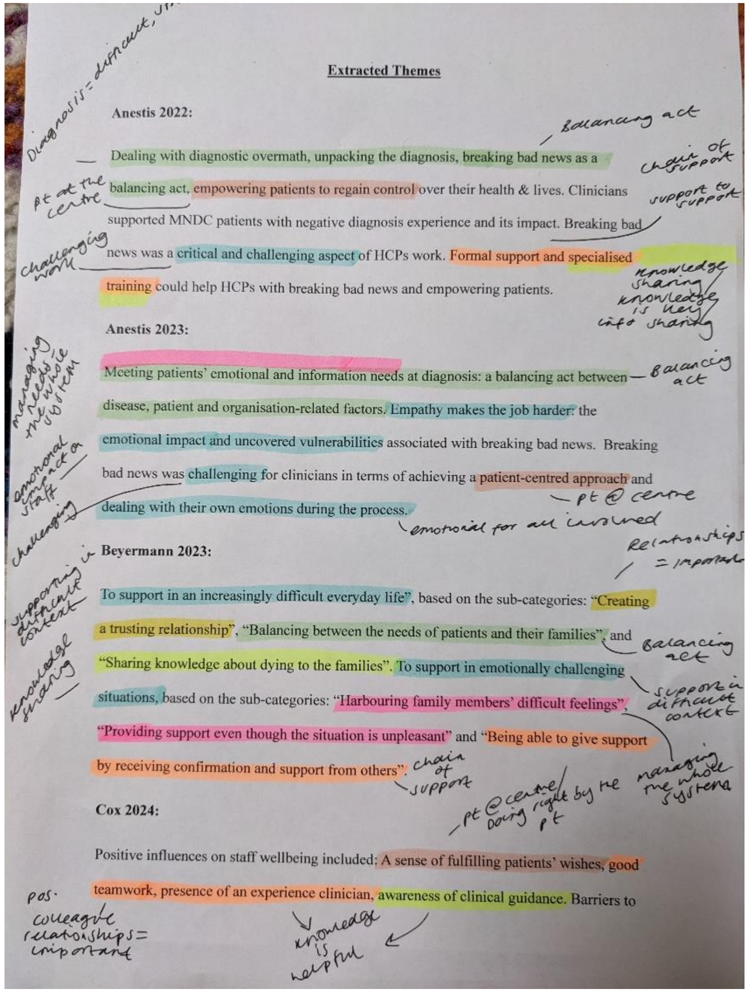
Participants reported that when they first saw patients, not all of them had fully understood their diagnosis. Despite short diagnostic consultations, which hampered adequate information provision, they believed patients' state of shock when receiving the diagnosis did not allow for information to be absorbed, and some patients were reluctant to look for further information post-diagnosis. In contrast, HCPs felt *"lucky"* (P3) and *"privileged"* (P11) to be able to dedicate enough time for their appointment and even offer double-slot appointments to meet the needs of newly diagnosed patients.

Delivering difficult news

> "We're fortunate that we have a lot more time with patients, than certainly the consultants do. Our appointments can be 45, routinely they are 45 minutes, but I have been with some patients an hour and a half, 2 hours, because they had that many questions and they just wanted to know and wanted to share information." (P3)

More time is helpful

Patients' limited understanding of their diagnosis as described above, and sometimes due to cognitive changes as a result of the condition, meant HCPs often had to re-iterate what was said to them at diagnosis, explain the nature of their condition and clarify what could be done for them in terms of medication. An MS specialist nurse (P5) reported that she had even seen newly diagnosed patients who did not know what type of MS they had, and she sometimes had to break the bad news to people with progressive MS regarding their ineligibility for disease-modifying treatments[2]. In general, HCPs were often responsible for managing patients' expectations regarding medication or therapy's scope and explaining the incurable and progressive nature of



Diagnosis = difficult,

Extracted Themes

Anestis 2022:

Dealing with diagnostic overmath, unpacking the diagnosis, breaking bad news as a balancing act, empowering patients to regain control over their health & lives. Clinicians supported MNDC patients with negative diagnosis experience and its impact. Breaking bad news was a critical and challenging aspect of HCPs work. Formal support and specialised training could help HCPs with breaking bad news and empowering patients.

Balancing act

Pt at the centre

Chain of support

support to support

challenging work

knowledge sharing / knowledge is key

info sharing

Anestis 2023:

Meeting patients' emotional and information needs at diagnosis: a balancing act between disease, patient and organisation-related factors. Empathy makes the job harder: the emotional impact and uncovered vulnerabilities associated with breaking bad news. Breaking bad news was challenging for clinicians in terms of achieving a patient-centred approach and dealing with their own emotions during the process.

Balancing act

managing needs in the whole system

emotional impact on staff

challenging

pt @ centre

emotional for all involved

Beyermann 2023:

To support in an increasingly difficult everyday life", based on the sub-categories: "Creating a trusting relationship", "Balancing between the needs of patients and their families", and "Sharing knowledge about dying to the families". To support in emotionally challenging situations, based on the sub-categories: "Harbouring family members' difficult feelings", "Providing support even though the situation is unpleasant" and "Being able to give support by receiving confirmation and support from others".

Relationships = important

supporting in difficult context

knowledge sharing

Balancing act

support in difficult context

managing the whole systems

chain of support

pt @ centre / Doing right by the pt

Cox 2024:

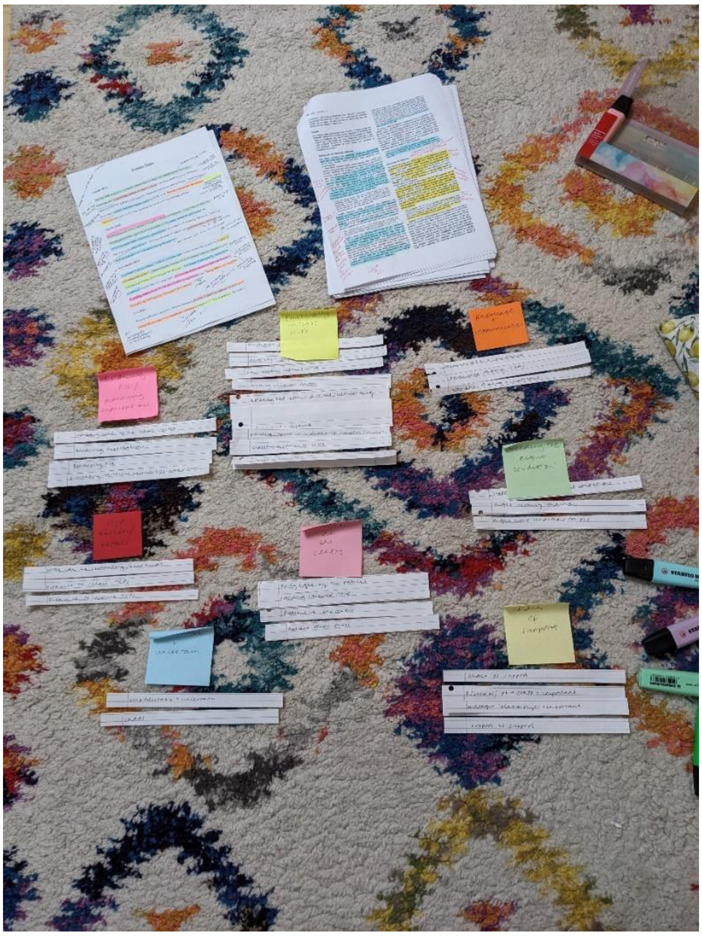
Positive influences on staff wellbeing included: A sense of fulfilling patients' wishes, good teamwork, presence of an experience clinician, awareness of clinical guidance. Barriers to

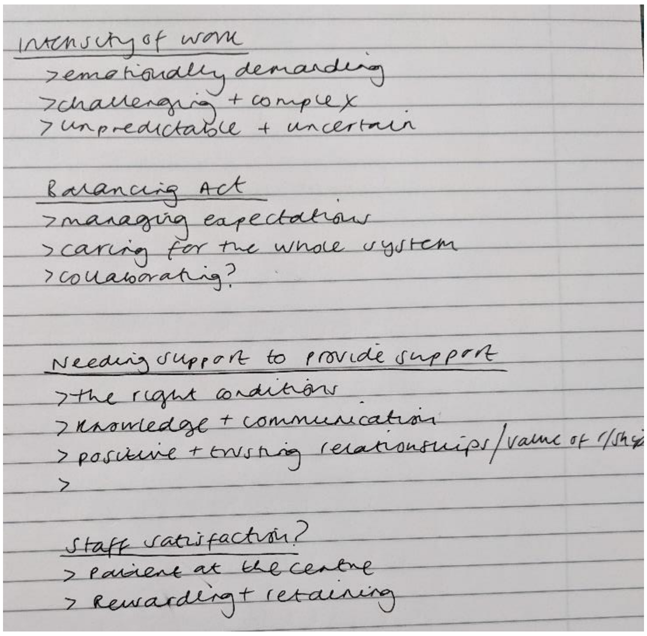
pos. colleague relationships = important

knowledge is helpful

Appendix D

Example of Theme Development



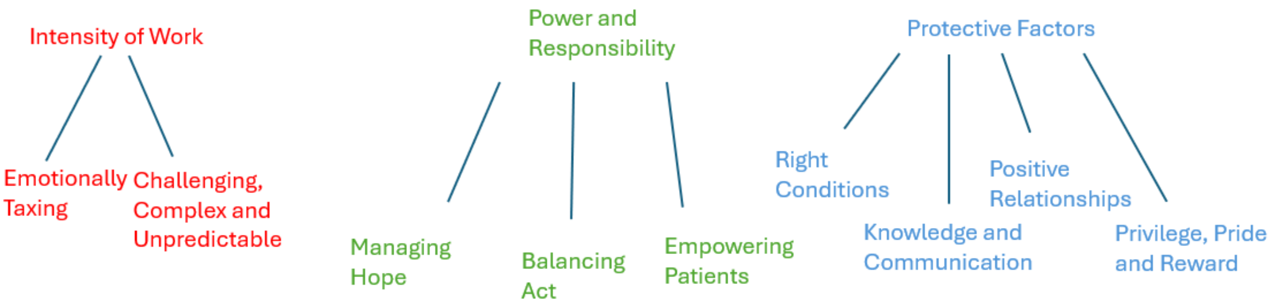


Intensity of work
>emotionally demanding
>challenging + complex
>unpredictable + uncertain

Balancing Act
>managing expectations
>caring for the whole system
>collaborating?

Needing support to provide support
>the right conditions
>knowledge + communication
>positive + trusting relationships/value of r/sh
>

Staff satisfaction?
> patient at the centre
> Rewarding + retaining



Appendix E

Reflective Commentary Excerpt

Reading the papers discussing balancing the many demands which come with being a HCP in MND services is making me feel overwhelmed just to hear about. Working in such a complex, chaotic setting… having to manage your own emotional wellbeing, and that of your patients, is difficult enough, but hearing about the consideration and collaboration necessary to also take care of yourself, the patient, their family or caregivers…it really does sound tiring, overwhelming, and difficult to manage everything.

I'm really interested in the literature documenting what staff find contributes positively to their wellbeing in the workplace. I feel passionate about compassionate leadership, and noticing the thread of support which participants are mentioning I think is interesting with that in mind. Needing support in order to give support to others? Sort of fill your own cup first…which must feel incredibly difficult when working within this setting. I'm finding myself reflecting on the elements impacting how staff can support themselves, and how this might link in with compassionate leadership. The value of relationships, colleague support, training and the right workplace conditions do all seem reminiscent of compassionate leadership. I'm wondering about this linking in with the literature around compassion satisfaction perhaps being part of the antidote to compassion fatigue / burnout? Which is easier said than done – I certainly think that systemic elements can help or hinder looking after your own wellbeing.

Appendix F

Quality Appraisal Results

Author (Year)	**Clear aims**	**Qualitative methodology**	**Research design**	**Theoretical underpinnings**[a]	**Recruitment strategy**	**Data collection**	**Relationship & reflexivity**	**Ethical issues**	**Rigorous data analysis**	**Clear statement of findings**	**Value of research**	**Quality rating**
Anestis et al. (2022)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Findings discussed in relation to previous research. Limitations discussed. Future research discussed. Clinical implications discussed.	High
Anestis et al. (2023)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Findings discussed in relation to previous research. Limitations discussed. Future research discussed. Clinical implications discussed.	High
Beyermann et al. (2023)	Yes	Yes	Yes	No	Yes	Yes	No	Yes	Yes	Yes	Findings discussed in relation to previous research. Limitations discussed. No recommendations for future research discussed. Clinical implications discussed.	High
Cox et al. (2024)	Yes	Yes	Yes	Yes	Yes	Yes	Can’t tell	Yes	Yes	Yes	Findings discussed in relation to previous research. Limitations discussed. Recommendations for future research not discussed. Clinical implications discussed. Author referenced a reflexive journal, however not available in main text, and no reference of author’s position in main body.	High
Gamskjaer et al. (2022)	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Findings discussed in relation to previous research. Limitations discussed. Recommendations for future research not discussed. Clinical implications discussed. No acknowledgement of reflexivity.	High

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[a] Long et al. (2020) added question: are the study’s theoretical underpinnings (e.g. ontological and epistemological assumptions; guiding theoretical framework(s)) clear, consistent and conceptually coherent?

Note. The researcher implemented a scoring template. Scoring strategy: ‘No’ = 0, ‘Can’t tell’ = 0, ‘Yes’ = 1. Total score ratings: <3 = poor quality; 4-6 = moderate quality; 7-11 = high quality

Lerum et al. (2017)	Yes	Yes	Can’t Tell	No	Yes	Yes	No	Yes	Can’t Tell	Yes	Findings discussed in relation to previous research. Limitations briefly discussed. Future research discussed. Clinical implications not discussed. Vague design and data analysis description. No reflexivity statement.	Moderate
Olesen et al. (2022)	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Findings discussed in relation to previous research. Limitations discussed. Future research discussed. Clinical implications discussed. No reflexivity statement.	High

Appendix G

Additional Supporting Quotations by Theme

Theme	Subtheme	Additional Supporting Quotes
Intensity of Work	**Emotionally Taxing**	“Bearing the brunt of patients’ annoyance and irritation”, “let off steam”, “angry”, “mistrustful”, “dissatisfied” (Anestis et al., 2022) “If they’re really devastated, you can’t manage it…you’ve just got to let them get on with it” (Anestis et al., 2023) “There’s always a moment, just before you say the name of the disease, where you feel terribly responsible. Like you’ve done it to them, that you’ve given it to them…that’s very sad” (Anestis et al., 2023) “You can see the bottom drop out of somebody’s life in front of you…that’s not nice” (Anestis et al., 2023) “Afterwards, I find it incredibly draining…I always feel completely exhausted…I replay the consultation in my head” (Anestis et al., 2023) “It’s impossible not to become emotional sometimes…it’s hard to get your brain back on track” (Anestis et al., 2023) “You’re only human and you get affected” (Anestis et al., 2023) “I probably manage by emotions by going a bit numb…I’m watching myself give bad news, rather than giving bad news…so you don’t cry badly, you can look empathetic…but the only way to not feel that upset when people are upset is to do this sort of…technique” (Anestis et al., 2023) “Whenever you break bad news, it…reminds you of all the others…and of your own fragility. It is existential angst” (Anestis et al., 2023) “There are no words I can say to take this away” (Beyermann et al., 2023)

	“I said…I’ll be back in an hour…I went to the car and cried and felt like I can’t handle it” (Beyermann et al., 2023) “You do develop some sort of immunity to the emotional impact” (Cox et al., 2024) “It was one of the most traumatic things I have ever done” (Cox et al., 2024) “The experience and responsibility isn’t just a privilege. It’s a burden as well…I feel emotionally and physically tired” (Cox et al., 2024) “Allowing them to bed sad and think that life is really unfair…you make room for those feelings” (Gamskjaer et al., 2022) “It can often be emotional to be a part of, because there is so much frustration and powerlessness” (Gamskjaer et al., 2022)
Challenging, Complex and Unpredictable	“You do have a bit of a mess, if you like, rather than it being straightforward” (Anestis et al., 2022) “I’ve been in that position, I’ve been the one who has to say, there is no magic pill” (Anestis et al., 2022) “I’m having conversations around advanced care planning, end of life decisions…about death and dying…it is difficult” (Anestis et al., 2022) “It’s knowing how to do it right, that’s the most challenging. How do you give terrible news to somebody in a way that allows them to absorb the information without shutting down emotionally and without it being a challenging experience?” (Anestis et al., 2023) “It’s like punching someone so hard but you have to do it very gently…”, “Soften the blow” (Anestis et al., 2023) “The concentration is immense” (Cox et al., 2024) “It’s like stretching a rubber band…you stretch it a little, and a little more, and a little more…it is amazing how long that rubber band can get before it breaks” (Lerum et al., 2017)

“When you have changed so radically that you become physically and verbally aggressive or without inhibitions. And you lose your understanding of the disease and try to stand up, and become scared of everyone around you because they don’t help you. It’s really difficult. These are the biggest challenges I face” (Olesen, 2022)

“I feel most challenged where I can see that the patient is simply getting worse and worse and the caregivers in the family won’t acknowledge it. You see the grief in the person’s eyes due to being so fatally ill, and the spouse doesn’t understand that the person has become this ill or refuses to accept it . . . I think that is so terrible to witness” (Olesen, 2022)

“There is a lot of discussion around prognosis – how long will I be able to do this? What happens if I’m no longer able to do that? Will I be able to stay in work…see my children grow up?” (Anestis et al., 2022)

“You can’t necessarily reassure them that it won’t, we can’t guarantee that…it won’t get worse” (Anestis et al., 2022)

“When somebody has quite a violent response to a diagnosis…that can be quite surprising for you and that’s awful” (Anestis et al., 2023)

“This is a frustration, this is chaos” (Beyermann et al., 2023)

“Sometimes I was actually a bit afraid of her…she could swing incredibly quickly from being happy…and thinking you’re the most competent person you’ve ever met, to bringing you down in three seconds where you felt like the most incompetent person on earth” (Beyermann et al., 2023)

“The sweater gets caught in there wheelchair, he bends forward, then loses his breath…then things did not happen quickly enough, and he starts to cry, and his wife starts to cry, and then the poor [HCP] is left with a very unpleasant situation” (Lerum et al., 2017)

“It requires a high level of skill and you have to feel confident… If there is much uncertainty and insecurity then it does not work out…then it turns into chaos” (Lerum et al., 2017)

Power and Responsibility	**Managing Hope**	“That was a difficult conversation to have, ‘cause obviously I couldn’t say well you can’t do that, but saying…oh that might be tricky, would they have any more sort of admin type work?” (Anestis et al., 2022) “I try to encourage them to have a realistic mindset…at the same time you don’t want to destroy someone’s hope…I think it’s quite a fine line” (Anestis et al., 2022) “No, I don’t give any hope in MND. I think it’s unfair, because then they’d have an unrealistic expectation. I don’t take away hope, but I don’t give false hope” (Anestis et al., 2023) “We get so affected by it because it is so hopeless, and the hopelessness . . . it becomes such a heavy burden to carry” (Olesen, 2022) “It can often be emotional to be a part of, because there is so much frustration and powerlessness” (Gamskjaer et al., 2022) “I’ve been in that position, I’ve been the one who has to say, there is no magic pill” (Anestis et al., 2022) “It’s important that we are transparent with patients and not give them false hope” (Anestis et al., 2022)
	Balancing Act	“When you’ve been out there listening to how difficult it is for [patients] and talk about death and how they’re going to die…it’s just a bit difficult to come home and sit down and have a nice family dinner” (Gamskjaer et al., 2022) “I feel my energy is being drained when I’m at a multi-disciplinary meeting [with external collaborators] …I’m trying with all my presence to show that we need to be aware of this family, and then some rigid health professionals…just sit there and stare into their papers the whole time” “We have huge influence. We sit down together and decide who is best for the job…based on time and needs. The influence we have over our own work life: that means a lot in being enthusiastic about your job” (Gamskjaer et al., 2022) “We try to collaborate with them [other healthcare institutions]” (Lerum et al., 2017) “When you have these collaborative meetings where both patient and caregivers are present, and you represent a professional skill, that it can calm down these families, because then they know that everyone has heard the same

		thing. And if there is a relative who is so frustrated and would like to split the professionals, then you can say, 'Well, at the meeting where we were all present, so and so and so" (Olesen, 2022) "Their partner might be wanting loads of information about how to manage…the patient might be like 'I don't even want to know'…you get these two levels of conversations happening which can be difficult to manage" (Anestis et al., 2022) "It's about reframing, isn't it? Inevitably it's sad…people will die. But it's about making sure they were able to go on that family holiday…go to that wedding…what can we put in place to make that happen?" (Anestis et al., 2022)
	Empowering Patients	"It's about reframing, isn't it? Inevitably it's sad…people will die. But it's about making sure they were able to go on that family holiday…go to that wedding…what can we put in place to make that happen?" (Anestis et al., 2022) "The patient had chosen the location, in their own home, and died with their family around them" (Cox et al., 2024) "They had a beautiful death. They died with dignity and calmly…it is a privilege to allow a patient to have a beautiful death" (Cox et al., 2024) "I feel [what] we [have] also got to do is give people, empower people to self-manage. […] I say that with good management that comes from both the healthcare professional and the patient who needs to take some responsibility, we can, we can preserve a good quality of life" (Anestis et al., 2022).
Protective Factors	**Right Conditions**	"I don't just get tasks assigned to me, I also have responsibility" (Gamskjaer et al., 2022) "To be able to shape my own working instead of going to work and having other people set the boundaries" (Gamskjaer et al., 2022) "We have huge influence. We sit down together and decide who is best for the job…based on time and needs. The influence we have over our own work life: that means a lot in being enthusiastic about your job" (Gamskjaer et al., 2022)

	“For us it is a workplace that must be able to function as such, and for them it is a home and must be able to function as such as well, so I sometimes have to compromise, and sometimes they have to be able to compromise” (Olesen, 2022)
Knowledge and Communication	“They had that many questions and they just wanted to know and to share information” (Anestis et al., 2022) “We need to be honest with them, make sure they are informed” (Anestis et al., 2022) “Patients can’t know what they don’t know. You can’t take away knowledge once it’s given…you can’t protect people from an outcome that may happen…only providing it when it needs to be delivered” (Anestis et al., 2023) “There’s also information, that you inform the family about…the challenge is that you bring information all the time and preferably as clearly as possible” (Beyermann et al., 2023) “I think communication is absolutely key…where communication failed, everything else failed around it” (Cox et al., 2024) “Clearly it is too much information to handle all at once…it’s something about taking it one step at a time” (Lerum et al., 2017)
Positive Relationships	“I went away thinking…I’ve done the wrong thing really…because it stifled my relationship with her” (Anestis et al., 2022) “You try to talk socially about other issues too…talk a little as a person with a person, not just as a nurse” (Beyermann et al., 2023) “I am talking to a colleague, I had to call and vent…I calm down and I can talk to my colleague, then pick up this thread again” (Beyermann et al., 2023) “Sometimes relationships with…this cohort of patient are so long-standing and…so complicated. The professionals become more akin to a version oof family…there’s an extended MDT family- it is important to care for and nurture” (Cox et al., 2024)

		“The teamwork was really positive…something really lovely about it. I felt connected…there is a kind of bond because of that shared experience, and I think that’s a really positive experience” (Cox et al., 2024) “We can talk to each other about what didn’t go as planned…what went well…that means a lot in our field of work” “We have huge influence. We sit down together and decide who is best for the job…based on time and needs. The influence we have over our own work life: that means a lot in being enthusiastic about your job” (Gamskjaer et al., 2022) “Just the fact I can share. My colleagues don’t need to say much, just the fact that I can get rid of my heavy thoughts…that’s a great help and really important that we have opportunity to do that” (Gamskjaer et al., 2022) “If something is tremendously difficult…I can lean on my colleagues” (Gamskjaer et al., 2022) “Never any talk, never sitting down and sharing a cup of coffee…there is very little of that generally in the services…maybe they have realised we don’t have the time” (Lerum et al., 2017) “But it is also important that we sometimes open up a little and allow something personal into it [the relationship], because otherwise the person you face can’t relate to you if you are too professional, then you have to open up for some things and bring something personal into them” (Olesen, 2022) “That’s where the collaboration works really well with caregivers and with the home care, that’s a good support, indeed! Then you experience that, yes, that there is a unified whole and we share common ground, and we can see that we can do this together. We can deliver good support and care for the family, despite all things.” (Olesen, 2022)
	Privilege, Pride, and Reward	“It is a privilege to allow a patient to have a beautiful death” (Cox et al., 2024) “Lucky and privileged” (Anestis et al., 2022) “I feel that…if it’s done properly, it can help the patient…I think if I have enough experience…understanding and empathy that I do it well, and it’s not easy…but I like to think if I’ve done it well, it can help the patient” (Anestis et al., 2022)

"It is a privilege to allow a patient to have a beautiful death" (Cox et al., 2024)

"I felt really proud…one of the things I've felt most proud of in my career. The experience empowered me, and increased my confidence…that real sense of self-worth, and professional worth" (Cox et al., 2024)

"That sense of being part of something that was very significant and emotional stayed with me" (Cox et al., 2024)

"You get so much in return…you actually feel the appreciation or gratitude coming from patients or relatives" (Gamskjaer et al., 2022)

"I've built up a specialist knowledge that not many other people have…makes me an important person…I become more motivated" (Gamskjaer et al., 2022)

"I strive for something that gives me something in return" (Gamskjaer et al., 2022)

"We have huge influence. We sit down together and decide who is best for the job…based on time and needs. The influence we have over our own work life: that means a lot in being enthusiastic about your job" (Gamskjaer et al., 2022)

"We have used up, emptied [area]. If you ask someone in the home-based services if they would like to work there, they respond 'I would rather quit'" (Lerum et al., 2017)

Section Two: Empirical Study

Chaos and Control: Exploring the Role of Clinical Psychology within a Multi-Disciplinary Team in the Context of Motor Neurone Disease: A Thematic Analysis

Abstract

Objectives: There is growing evidence of the psychological impact of motor neurone disease (MND), yet limited research into how professionals can meet the psychological needs of people living with MND (plwMND). This study explored National Health Service (NHS) staff members' perspectives of direct and indirect integrated psychology support within an MND multi-disciplinary team (MDT).

Design and Method: Thematic Analysis (TA) was used to investigate the experiences of clinicians within an MND MDT with integrated psychology. Eight clinicians working within non-psychology disciplines participated in semi-structured interviews.

Results: Four themes were identified: 'Limited Resource', 'Chaos and Control', 'Staff Psychological Containment' and 'Value of Psychology to Service-users'. Theory and practice links were made between MND services and the value of compassionate leadership (CL). Benefits of CL were highlighted on staff, organisational, and patient levels.

Conclusion: The chaos, complexities, and desire for control within MND services was experienced as a parallel process between patients and clinicians. Psychology support was deemed essential and necessary to provide good-quality patient care, yet clinicians felt frustrated at the lack of both funding and staffing for psychology as a discipline, and for MND services generally. Clinicians shared a sense of psychology not being as equally prioritised as other MDT disciplines. Barriers to accessing psychology were highlighted, alongside the benefits and value of MND-specific psychology.

Practitioner Points

- Integrated psychology is needed within MDTs when setting up MND services. Psychology provision should be equally valued as other core roles.
- Psychological staff support is of equal importance as psychological support for patients within MND services.
- MND clinicians should be aware of the emotive impact and challenging nature associated with their service and take measures to support with this to avoid burnout and compassion fatigue.
- Psychology provision requires a commitment to supporting staff with the emotive nature and cognitive demands of working within MND services.
- MND services would benefit from implementing compassionate leadership approaches.

Keywords

Motor Neurone Disease, Motor Neuron Disease, Psychologically Informed Care, Qualitative Research, Thematic Analysis

Introduction

Motor neurone disease (MND) is a fatal, rapidly progressing disease affecting the brain and spinal cord (MND Association [MNDA], 2021). There is currently no cure for MND. Health and social care professionals focus on supporting people living with MND (plwMND) to manage symptoms and live as well as possible with their condition; they also often indirectly support MND carers.

PlwMND experience significant changes in their physical function, communication, thinking and behaviour, alongside a loss of independence (MNDA, 2021). These factors are likely to negatively impact a person's emotional and psychological wellbeing (Glennie et al., 2021; Pinto et al., 2021).

There is growing evidence of the broader psychological impact of MND, yet very limited research focused on the specific psychological needs of plwMND and how professionals can best meet them. Existing research in the area demonstrates that the loss of physical function, challenge of keeping up with 'constant changes', and a threatened future due to poor prognosis leads to emotional distress (Pinto et al., 2021). The COMMEND project (MNDA) highlighted that 62% of people diagnosed with MND experience anxiety or depression, but do not routinely get help to deal with the mental health impact of the disease. Likewise, plwMND have described feeling 'unsupported by the healthcare system' which reportedly increased emotional distress (Pinto et al., 2021). Pinto's (2021) findings indicate that 'hope and positivity, exerting some control, being kinder to oneself and experiencing support from others' were key strategies which plwMND would find helpful in promoting emotional well-being; additionally, these are all key areas of focus within psychological interventions (National Institute of Clinical Excellence; 2019).

Woods (2019) conducted research into MDT perspectives of psychology within a psychiatric inpatient setting, finding that psychology was seen as a 'valuable role', but staff understanding of what psychology could offer was limited. Woods (2019) found that psychology was 'valued, but not a first-line treatment'. Suggested recommendations from Woods's (2019) research encourage psychologists to ‘better integrate’ their role within an MDT, and to clarify what an MDT would find most useful in terms of both psychological treatments for clients and staff training. These recommendations informed the interview schedule to sufficiently explore clinicians’ understanding and value of integrated psychology, and desire for psychological upskilling, within MND-specific MDTs. Woods’ research supports previous findings from Christofides et al (2012), which highlighted the importance of integrating clinical psychologists into the MDT to improve delivery of psychological support.

Giebel et al. (2019) conducted a study investigating how educating multi-disciplinary teams (MDT’s) about the psychosocial wellbeing of plwMND could change approaches to working with plwMND. This study utilised semi-structured interviews with MDT staff before and after attending a workshop on the quality of life in plwMND, alongside a 2-month follow-up interview. Findings indicated that staff showed increased awareness of the topic and identified barriers to communication in staff working within MND. Clinical implications included: collaborative working, raising awareness of psychological and emotional issues in MND, and exploring service access barriers.

The MNDA (2021) emphasises professionals working with plwMND adopting a ‘palliative care approach’, acknowledging that plwMND have ‘particularly complex care and support needs, especially towards the end of life’. Additionally, Cramond et al. (2020) stated that compassion fatigue is ‘inconsistent’ for staff working in palliative care, and that professionals should be ‘supported to reflect on their experiences of compassion and resilience’, and that ‘services should provide resources that facilitate staff to maintain their wellbeing’ particularly as physician burnout has been linked to ‘suboptimal patient care’ (De Hert, 2020).

Based on the existing literature, it seems clear that plwMND have significant psychological needs, and clinicians supporting plwMND may require support to meet these needs. Further, MDT clinical psychology could help to support clinicians and plwMND, leading to improved care, support, and wellbeing – further research is required to explore this. The current study aims to explore clinicians’ experiences of supporting plwMND, and perspectives surrounding integrated psychology. More specifically, it seeks to explore psychological needs, and the role and impact of psychology. Thematic Analysis (TA; Braun & Clarke, 2006; 2019) will be utilised.

Method

Design

TA is widely used to identify, analyse and report themes within qualitative data, organizing and describing data in rich detail (Braun & Clarke, 2006). TA usefully summarises key features of a dataset allowing for both social and psychological interpretations of data, making it well-suited for policy-development and guiding healthcare practice (Braun & Clarke, 2006).

TA is more aligned with meeting the research aims than other methods; for example, Interpretative Phenomenological Analysis prioritises a focus on individuals' unique characteristics over establishing patterns and themes within a largely heterogeneous group (Smith et al., 2009; Braun & Clark, 2020), and Grounded Theory and Framework Analysis allow greater room for researcher-induced bias (Saunders et al., 2012).

Inductive (as opposed to theoretical) thematic analysis was utilised to guard against the researcher's topic interest influencing the identified themes. Data was coded without attempting to fit a pre-existing framework or researcher preconceptions, allowing the analysis and emergent themes to be data-driven (Braun & Clark, 2006). Data was analysed at a semantic level; organised to demonstrate patterns in semantic content, then interpreted to theorise the significance, broader meanings and implications of these patterns (Braun & Clark, 2006; Patton, 1990).

Ethics

Ethical approval was obtained via the University of Sheffield (UoS) Research Ethics Approval system (Appendix A) and the Health Research Association (Appendix B).

Participants

Convenience sampling was utilised to recruit eight clinicians with a range of experience and expertise from four UK-wide NHS trusts. Participants were recruited if they met inclusion criteria (Table 1). Relevant demographic information was collected (Table 2). Clinical roles included nurse, occupational therapist, care-coordinator, dietician, neurologist and physiotherapist. Current role experience ranged from 1-6 years, and experience working with plwMND ranged from 6-23 years.

Table 1

Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
NHS Clinicians	
18+ years old	Employment is/was in a psychology role
Based in the UK	Working/worked in a service that is either not focused on MND or where there is not a clinical psychologist integrated within the MND team
Employed in a non-psychology discipline and providing care for people living with MND within an NHS setting	
Working within an MND MDT where there is (or has recently been) a clinical psychologist integrated in the MND team, within the last 24 months	Not fluent in English

Table 2

Demographic Information

Occupation[4]	Time in team (years)	Time working with plwMND (years)	Setting (inpatient/outpatient/community)
Nurse	2	11	Inpatient and Community
Dietician	2.5	23	Outpatient
Neurologist	4	12	Inpatient and Outpatient
Care-coordinator	2	12	Inpatient and Outpatient
Occupational Therapist	2	18	Outpatient and Community
Physiotherapist	6	6	Inpatient, Community and Outpatient
Occupational Therapist	1	10	Outpatient
Nurse Consultant	23	23	Outpatient

P: Participant; plwMND: People living with motor neurone disease

Braun and Clarke (2019) suggest a sample size of 10 participants for doctoral-level thematic analysis. Whilst it is generally agreed that ‘there are no rules for sample size in qualitative inquiry’ (Patton, 2002: 244), and considering the recent critique of the concept of ‘saturation’ being ‘inconsistently applied’ when determining sample size in qualitative research (Braun & Clarke, 2021), this study was guided by recommendations for doctoral-level research, and the concept of ‘information power’ (Malterud et al., 2016).

Malterud et al. (2016) proposed a five-step model examining (a) study aims, (b) sample specificity, (c) use of established theory, (d) quality of dialogue, and (e) analysis strategy, to ‘guide adequate sample size’ within qualitative projects. The research aims were deliberately broad, yet the sampling method deliberately specific; there was some established theory, yet a desire to refrain from influencing emergent data; the researcher has previous experience of conducting interviews, yet no experience within MND. These factors led to a proposed sample size of 12 participants to ensure sufficient relevant data was collected. However, Braun and Clarke (2021) note that judgements about how much data collection is enough ‘cannot be wholly determined in advance of

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[4] Participants are not linked to demographic data to further preserve anonymity

analysis'; Malterud et al (2016) agree, stating that 'whilst an initial approximation of sample size is necessary for planning, the adequacy of the final sample size must be evaluated continuously during the research process', concluding that the interpretation of data, and final results, will ultimately demonstrate whether the sample size did hold adequate information power to 'develop new knowledge' regarding the research aims. Recruitment issues led to eight participants being recruited.

Materials

Interview Schedule

A semi-structured interview schedule (Appendix C) was collaboratively created with the researcher's supervisors, considering the research aims and a previously established interview schedule (Woods, 2019).

Service User Consultation

Clinicians within an MND research team provided feedback on the content, phrasing, and structure of questions in the interview schedule, and amendments made. (see Appendix D for an audit of changes).

Procedure

A poster (Appendix E) and information sheet (Appendix F) were distributed via email to identified points of contact to each team., Additionally, the poster was advertised via social media by the researcher and the MNDA.

Interested clinicians contacted the researcher via email and received a copy of the information sheet and consent form (Appendix G), which were returned signed prior to arranging interviews.

Online interviews occurred between 19th March and 25th September 2024. At the beginning of each interview, confidentiality limits were discussed, the research aims explained and consent re-established. Interviews were recorded via MS Teams audio. Interviews lasted between 43-68 minutes (mean = 55). Post-interview debriefs took place to ascertain wellbeing, explain next steps, and reiterate the withdrawal time limit. Interviews were transcribed verbatim, adhering to standard guidelines.

Interview recordings and transcriptions were password-protected and shared via a secure drive between the researcher and the transcriber and deleted once completed. Data was stored electronically on a secure Google drive, accessed only by the researchers. Data contained no identifying information outside of consent forms, which were stored in an encrypted, password-protected folder and deleted after two weeks. Password-protected files were named 'Participant 1, 2' et cetera.

Reflexivity

Braun & Clarke (2019) describe reflexive TA as 'a reflection of the researcher's interpretive analysis of data conducted at the intersection of: (1) the dataset; (2) theoretical assumptions of the analysis, and (3) the analytical skills/resources of the researcher'. Reflexive TA researchers are discouraged from pursuing consensus amongst multiple-coders (Byrne, 2021); within this approach, it is not expected that any two researchers would necessarily produce the same codes, preferring to focus on 'the researcher's reflective and thoughtful engagement with data and reflexive, thoughtful engagement with the analytic process" (Braun and Clarke 2019, p. 594).

Acknowledging the values, attitudes and beliefs of the researcher, alongside the potential impact of such on the research, is essential within qualitative research (Berger, 2013; Dodgson, 2019). To maintain awareness of biases, the researcher kept a reflexivity log throughout, noting any preconceptions or personal influences in data interpretation (Appendix H). The author identifies as a white British woman with no personal or professional experience within MND, but with prior experience in conducting interviews and TA. A full reflective statement is presented in Appendix I.

Analysis

Data was analysed using by Braun and Clarke's (2006; Appendix J) six steps. Firstly, transcripts were read alongside the audio recordings, to check accuracy and consider context. Meanwhile, familiarisation notes (Appendix K) were made to highlight points of interest and patterns in the text.

Line-by-line annotation was then conducted, noting semantic meaning, conceptual and linguistic data elements, and assigning codes. Coding occurred multiple times in multiple orders, developing and modifying codes appropriately. Codes were reviewed for similarities and contrast; areas of interest or significance generated preliminary themes, which were diagrammatically mapped (Appendix L). Themes were reviewed, utilising supervision to discuss amongst the researchers, allowing definition, refinement and naming of themes. Finally, a narrative was created to describe the analysis and theme development, furthering refinement. Whilst Braun and Clarke's (2006) steps are presented linearly, analysis is a fluid process; thus, the researcher iterated between phases as needed.

Quality and Rigour

The researcher endeavoured to provide as much structure as possible through utilising the validated six TA steps (Braun & Clarke, 2006; Appendix J). Additionally, Yardley's (2000; 2008) four principles for assessing the quality of qualitative research (Table 3) were upheld throughout the study, alongside considering Braun and Clarke's (2021) evaluative tool for reflexive TA quality (Appendix M) to enable quality control and independent review of the process. Furthermore, a documentation and data audit trail were maintained throughout.

Table 3

Quality Control

Guideline	Study Application
Sensitivity to context	The researcher recognised and reflected on their position, assumptions, thoughts and biases through a reflexive log (Appendix H). Relevant participant demographic data helped to situate findings, whilst protecting anonymity. The researcher remained aware of the specific emotional impact on clinicians who may have discussed distressing or provocative events (e.g., debrief and wellbeing checks).
Commitment and rigour	Verbatim extracts are included within the results, alongside clear documentation of themes to facilitate understanding of interpretations An audit trail for all documents was kept throughout the entire process to enable high-standard rigour.
Transparency and coherence	Analysis methods are presented, alongside the progression from themes to subthemes (Appendix L). A clear, concise summary of findings is presented within the results section, alongside a table of themes.
Impact and importance	Gaps within the literature are clearly identified and discussed, alongside the practical and clinical implications and potential facilitation of meaningful change within clinical services for plwMND and the clinicians supporting them. The aforementioned are furthermore reflected on within the discussion.

Results

Reflexive thematic analysis identified four themes and 10 subthemes. Verbatim participant quotes are presented to illustrate themes; themes provide an interpretation of prominent discourse rather than a comprehensive narration of experiences. Table 4 presents themes and participant contributions alongside further supporting quotations in Appendix N.

Table 4

Participant Contribution to Themes

	P1	P2	P3	P4	P5	P6	P7	P8
Limited resource	√	√	√	√	√	√	√	√
Not contained	√	√		√	√	√	√	√
Protective	√	√	√	√	√	√	√	√
Chaos and control	√	√	√	√	√	√	√	√
Uncertainty	√	√	√	√	√	√	√	√
Diagnosis to death	√	√	√	√	√	√	√	√
Emotive nature of work	√	√	√	√	√	√	√	√
Staff psychological containment	√	√	√	√	√	√	√	√
Psychological frame	√	√	√	√	√	√	√	√
Confidence and ‘good enough’ care	√	√	√	√		√		√
Psychological safety	√	√	√	√	√	√	√	√
Value of psychology to service users	√	√	√	√	√	√	√	√
Measuring impact	√	√	√	√	√	√	√	√
Embedded psychological care	√	√	√	√	√	√	√	√

Limited Resource

This theme encapsulates participants' accounts of psychology being a limited resource, regarding time, funding, presence, availability and accessibility.

Not Contained

Participants discussed a lack of psychologists within MND services, influenced by the lack of funding, with psychology availability seen as an ideal.

The best gold standard would be having a psychologist see someone whenever we felt that was needed…I accept this is the real world and it won't happen…because the money's not there," (P2)

Clinicians discussed not feeling prioritised regarding funding, commissioning, and acknowledging the value of psychology both within their service and MDT roles. Clinicians felt that psychology was less prioritised than other MND MDT disciplines and indicated frustration regarding this.

"Psychology should come above, you know, you shouldn't have a pecking order, but it should come above a lot of the core MDT that we already get, that you get in every single MND centre, but you don't get psychologists, and I just don't, I don't get that." (P2)

Clinicians indicated that the feeling of not being a priority was reflected in patients as well as staff, suggesting cross-systemic similarities.

"Patients were outraged when she left, there was no one to follow them up" (P4)

Protective

Every interviewee noted that their experience of MDT psychologists was of part-time employment, with most clinicians highlighting that this was not enough.

"It's tricky because funding…the majority of conversations I have are surrounding the psychologist not having capacity" (P7)

Clinicians reported a sense of wanting to almost protect the psychologist from the influx of patients, which sometimes proved a barrier to referrals.

"If we bombarded them with every single person at every point then they would be overwhelmed, so there has to be an element of prioritisation" (P3)

Interestingly, staff perceived the psychologists as willing to see patients and take on referrals, yet still voiced reluctance.

"Our psychologist is incredibly open to referrals, there are no barriers there…I suppose I'm conscious of not wanting to completely overwhelm and swamp her" (P5)

Chaos and Control

Participants spoke about a sense of chaos and need for control, citing uncertainty, complexities, and a need for speed. There was a parallel between patient and clinician experiences.

Uncertainty

Clinicians discussed the many sudden and significant uncertainties and needs associated with MND that impacted on them, patients and the staff team.

"With MND, nobody really knows timelines, how quick or slow that progression will be…we can't promise anything, it feels very fragile, very chaotic because you can't pin anything down, so people feel like they're out of control with this condition, and that's one of the main psychological things." (P4)

Most clinicians discussed the cognitive demand of their work, regarding staying updated with relevant policies and literature, managing emotional lability in patients, crisis management, and future planning. Staff cited the cognitive load impacting both inside and outside of work.

"You're dealing with crisis management, thinking about advanced care planning, guidelines, there's a lot…going on in your head, in and outside of the consultation room that patients might not necessarily appreciate" (P3)

Participants discussed finding psychology support helpful in managing this cognitive load, through joint-working, conversations, and sharing responsibilities.

"Having somebody there with you in clinic…I used to go home and want to lie in a darkened room, but now having somebody there with you…I don't feel quite so head-spinning as I leave. You've shared, you've worked together and it's a different feeling, it feels good" (P8)

"It does affect you mentally, so I find speaking to [the psychologist], there's a lot of value in that for me" (P1)

Diagnosis to Death

All clinicians discussed the nature of working with patients from 'diagnosis to death', a direct quote from several participants. This theme illustrates the intensity felt by staff in their work, in terms of uncertainty, short prognosis, and unpredictability. Clinicians talked about the nature of difficult conversations associated with this, including responses to diagnosis, and discussing death as an inevitability.

"I think it's an adjustment to being diagnosed with MND to feeling overwhelmed … and they're thinking of all the different ways they're going to die, (P4)

Some participants noted feeling that death seemed taboo within their team, and worried about this impacting patient conversations.

"Death, I think that could be a conversation that feels less taboo within the MDT, it trickles down to patients if that feels challenging as a team. We should be a team where that's flowing off the tongue…the sticky taboo topic of when and how you're gonna die" (P7)

Most clinicians felt that psychology support was useful at the point of diagnosis, in terms of supporting patient acceptance and responses, and supporting staff to deliver the news.

Emotive Nature of Work

Staff acknowledged the emotive nature of working with MND, regarding facing challenging patient behaviour associated with symptoms, delivering upsetting and life-changing news and managing emotional reactions.

"We often have numerous phone calls with a number of people crying down the phone, screaming down the phone in anger that things aren't being done quick enough" (P4)

Clinicians found the aspect of building a relationship with a patient knowing that they are dying, and facing the grief associated with losing patients, to impact them emotionally.

"It's a really emotive job, all the patients we see you know, unfortunately die, some within quite a short time frame, two years…that's, you know, it's hard when you meet a patient, and you know they're gonna die" (P1)

Clinicians discussed feeling that psychology had a role in supporting staff with the emotive nature of the work.

"It's helpful to share that kind of intensity [with a psychologist]…you see four people, one after the other after that huge emotional reaction…life-changing news, you're trying to support them in that moment but you know it's like, 45 minutes of that and then let's do it again, and again…(P5)

Staff Psychological Containment

This theme encapsulates the psychological containment experienced by staff within the MDT.

Psychological Frame

Staff perceived psychology as an educational resource and a learning opportunity. Most clinicians felt like all disciplines required psychological training to meaningfully engage with and care for patients.

"It should be expected that they complete some training around the psychological management of people with MND and how they can contribute outside of what the psychologist does" (P2)

Clinicians highlighted an absence of psychological training in both their educational and clinical backgrounds and sought to change this.

"I feel that's the one thing missing in our education, a bit about psychology…in a job like this it's really important" (P1)

All clinicians acknowledged the lack of funding and resourcing for psychology. Many suggested that upskilling staff and providing psychological education could bridge the gap in patient psychological provision.

"The psychologist may only see that patient once, whereas if I've got tools and skills to deliver psychological care at a basic level then that's very helpful" (P3)

Clinicians discussed a key value of psychology staff facilitating staff to develop new perspectives and alternative thinking to staff both individually and within the MDT more broadly.

"The value is in where it helps bring that level of detail, things we won't have thought about. The psychologist guiding the MDT discussions is valuable because we can get very procedural-driven and forget the psychological impact of interventions or thinking about the future…." (P2)

Clinicians described valuing a shared psychological understanding of patients, which helped them to better support patients.

"Having the psychologist involved…enabling us to deal with situations and see how we can best support, better understand somebody and their behaviour, situation, and explain it to the family" (P8)

Most interviewees discussed the need for transparency and communication around psychology patient input. Clinicians who had experienced positive examples of this found it useful for their learning and understanding of psychology and ensuring a 'united approach' to care.

Conversely, yet similarly, clinicians who experienced restricted access to psychology, through being unable to view notes and letters for example, voiced frustration at 'information gatekeeping'. They believed psychology had a responsibility to inform staff about psychological input, to promote efficient and effective MDT liaison and care.

"We don't have access to psychology notes…I can see what other disciplines have written but not psychology, we don't have access to them. I can't read the letters, I can't learn from them (P1)

"They have a responsibility to share information with the MDT, make sure we're aware of assessments, advice, not only that they're giving to patients but what advice have they got for the MDT about how to incorporate it? Effective communication to the MDT is important" (P2)

Confidence and 'Good-Enough' Care

A key element of perceived value of MDT psychology input was that clinicians felt it had enhanced their confidence in various ways, such as feeling better-equipped to have difficult conversations with patients, implement boundaries, and work within the scope of their roles. One element was the sense of 'permission-giving'.

"You want to help people don't you, the expectation on us is so high nowadays, we want to be giving more... She helped us create boundaries, gave us permission to have boundaries in place. Having support from psychology is massive. It's a place where you can go for permission to grieve, talk and listen" (P4)

Clinicians who had experienced training provided by MDT psychologists cited that the skills and knowledge helped to increase their confidence.

"The psychologist provided us with training because none of us felt particularly confident to explore that area and the risk [suicide]…I felt more confident, obviously it was still difficult, but I felt able to explore that…I had slightly more skills and confidence" (P6)

Another aspect cited by several clinicians was the concept of 'good-enough care'; staff shared that through psychology support, they had been able to reframe their thinking, resulting in increased confidence and feelings of self-worth.

"I felt like I wasn't meeting his expectations all the time and she said that's who he is, no matter what you do you'll never actually meet them…that helped because I was getting stressed about, erm feeling like I wasn't good enough …she helped me understand that and see'okay, it's not me, he's angry because he's been diagnosed with MND, it's not aimed at you" (P1)

Psychological Safety

"We forget about our own psychological needs… the impact on us…our psychologist is incredible at supporting the MDT to consider these…the psychological support creates a sense of safety" (P7)

A key area of psychological input which all clinicians voiced having valued was around staff wellbeing. Clinicians across different teams experienced varied elements of psychological support, including group or peer supervision, reflective practice, 1:1 supervision, and informal conversations with the psychologist. The feeling amongst staff was having found a sense of containment and reassurance within these spaces, having valued the opportunity to talk with their colleagues, with the psychological oversight to facilitate conversations in an appropriate and meaningful way.

"The psychologist would run the supervision, ask us how we had been doing… it was chance to really sit down and tell each other, led by her appropriately, how we were doing. …. …a role model who knows what they're doing, the implications of blurred boundaries, going above and beyond, burnout, compassion fatigue, not looking after yourself and all that stuff. Just to reflect on what's important… acknowledge and sit with the difficult emotions." (P4)

Clinicians reflected that they felt reassured and contained about patient wellbeing through psychological input such as risk assessment, which consequently led to increased feelings of wellbeing.

"Managing that risk of the patient, psychologically, and having that reassurance that it's been assessed and is being monitored accordingly" (P5)

Value of Psychology to Service-Users

This theme captures the perceived value of MDT psychology to the service-users supported by participants. There was a sense that the psychological input or benefit to patients was not always direct or formal, and clinicians found it difficult to 'prove' the concrete value of it. Additionally, clinicians felt strongly that integrated MND-specific psychology was essential in supporting their patients.

Measuring Impact

All clinicians cited feeling that indirect psychological support was equally, if not more, important to them than direct patient-psychologist contact. Staff noted that factors such as patient reluctance for direct psychological support, due to stigma around psychology or feeling overwhelmed by the number of professionals already involved in their care, and psychologist's lack of availability to see patients directly, as key influences on the perceived importance of indirect psychological support through other clinicians.

"There's a lot of people involved, some people find it overwhelming the number of people who are involved, so when we say, "shall we add in this extra person" they go "oh god no, there is already enough of you" (P1)

"Staff support, in my opinion is more important than actually seeing patients because there are only so many times a psychologist can see someone, whereas the nurses and physios and things are seeing them all the time, dealing with the frontline, so actually that role-modelling, leadership, supporting, reflecting, giving ideas and strategies for patients, absorbing some of the distress of the difficult patients for staff who can't do that themselves…I'd say that's probably the most useful thing a psychologist does for us" (P3)

Many interviewees talked about a 'drip-down' impact of psychology, whereby the psychologist supports MDT members directly, who in turn can then support the patient and the systems surrounding them.

"She modelled it really well, she did the same in MDT's and gave permission for the MDTs to model it well, it was like a flow-down of boundaries and support, it's important to have a role-model that knows what they're doing, and it filters through" (P4)

Similarly, staff reported that the informal contact such as ‘corridor conversations’ with the psychologist was equally valued as more formal contact such as supervision or MDT psychology presence.

“One thing that’s been really useful, almost like the corridor conversations are as useful and educational as formal psychology, but formal psychology is helpful for difficult patients…it’s reassuring to know they’re getting that support” (P3)

“The input they give in MDT meetings…if she hadn’t seen individuals, she would join in conversations, pitch in and give advice. It raises awareness of this part of people’s care, and rubs off in an implicit, softer way” (P2)

Many clinicians talked about finding the service-user value of MDT psychology input difficult to prove, in part due to the indirect nature of much of the psychological work within their MDT’s.

“The difficulty is it’s hard to measure the role because that’s not a traditional, you know they haven’t seen ten patients that morning, but they have impacted on the care of ten patients” (P3)

Many clinicians perceived the absence of psychology as demonstrating its usefulness; either through experiencing withdrawal of psychology or having worked in the team prior to receiving it.

“When they’re available they play a really important role, when they aren’t there, I don’t think we always know explicitly that it’s causing a problem, but I know it absolutely does. It’s one of those things that’s hard to prove because practice still goes on, people still come in and they’re of a certain emotional mindset…it’s hard to say in the moment that them not being there is a huge problem, but we know it absolutely is because of the value that we see from when they are there” (P2)

“I was there before we had it so it’s useful to see both sides, and it’s been useful. Staff have got to engage with it, you know, it needs to be a core part of the MDT” (P3)

Furthermore, clinicians hypothesised that there was an element of 'you don't know what you don't know' – the concept that until an MDT receive integrated psychology, the value of such cannot be perceived.

"I think it's something a team can carry on unknowing if they don't have a clinical psychologist, they wouldn't notice problems…for a long time I thought I was helping, supporting the families, the patient, yet when we have a clinical psychologist it adds depth and richness to the whole team for various other reasons…you suddenly find, goodness me they really need it, it's huge, people are so grateful" (P8)

Additionally, staff discussed the 'felt' sense of value, for both clinicians and patients, which they found difficult to measure and to understand at times.

"We've been doing a double-act in clinic…you have a patient coming and they leave saying 'thank you, I feel better'… that's extraordinary…we see patients together now, and they leave feeling better…how is that possible?" (P8)

Embedded Psychological Care

This subtheme illustrates the value clinicians placed on receiving MND psychology provision integrated within the core MDT. Most participants discussed perceiving this as 'doubly-specialist'; psychology as a specialism within itself, and knowledge and experience of working within MND as a further, separate specialism. Staff illustrated this by highlighting that whilst they are MND knowledgeable, they are lacking in psychological expertise: a common sense of 'I am not a psychologist'.

"We're all psychological non-experts aren't we, apart from the psychologist…we need that insight that we can't get as psychology non-specialists, you know, we can do it a little bit but nowhere near to the rigour of a psychologist" (P2)

"MND is still a rare disease so people aren't necessarily skilled in that area, so we feel at a loss, we don't have a counselling background, we tend to sit and listen, and you know just validate their feelings, you can only go so far can't you I think (P4)

Clinicians described valuing the ‘expertise’, ‘knowledge’ and ‘specialism’ of MND psychology in the MDT, feeling that it was essential to be integrated in this way to have the biggest impact.

“Working within MND is a different patient population and can be hard for people who haven’t got experience, they need support to understand MND and the psychological input on not just the patients but on them as HCPs. Psychologists should be mandatory in MND MDT meetings, they strengthen those discussions” (P2)

Additionally, participants noted that where integrated MDT MND psychology is unavailable, the offer of support is often counselling, as opposed to MND-knowledgeable psychological support, which clinicians felt could not sufficiently meet patients’ needs.

“Our psychologist has a good understanding of MND and its impact on people. I feel that’s where the added benefit is, she’s skilled in her MND knowledge as well as her clinical psychology skills…that blend is what makes her great for us and patients, it’s that specialist knowledge” (P5)

“I feel like having someone psychology-wise that is specialist in MND is valuable because they understand the implications of the disease and treatments” (P6)

Discussion

This study aimed to explore staff perspectives of the role of clinical psychology within a multi-disciplinary team in the context of MND. Findings suggest that clinicians perceive psychology to be of significant value to both staff and the MDT, as well as to service-users; however, staff perceive the value of psychology to be difficult to measure. Psychology is perceived as a limited resource, in terms of funding and staffing, and therefore does not feel prioritised. Staff experienced MDT psychology support as reassuring and containing within the chaos and complexities of working within MND services.

Limited Resource

Clinicians indicated frustration that prior or existing psychological provision within the MDT was only ever funded for 1-3 days, and for one psychologist, which was not deemed enough of a resource to see all patients requiring psychological support. The lack of availability to see patients, and of time allocated per patient, was often described as being the main barrier to accessing psychology, with staff describing a subsequent negative impact on patient care. Furthermore, staff felt a reluctance to refer to their psychologist, despite the psychologist welcoming referrals, as staff worried about ‘swamping’ or ‘overwhelming’ the resource and seemed to feel protective over the psychologist’s workload. It is well-documented that providing the resources people and services need is one of the most important tasks for teams implementing compassionate leadership (CL; Atkins & Parker, 2012; McCauley & Fick-Cooper, 2020), which can support staff wellbeing (West, 2021), increase efficiency (Trzeciak et al., 2019) and lead to better patient outcomes (Goetz et al., 2020).

Findings highlight the importance of providing integrated psychological support within MND MDTs, which is a step beyond the recommendations of existing NICE (2019) guidance, which highlights the necessity of prompt access to psychology rather than integrated psychology. The existing literature indicates that plwMND do not routinely receive support with managing their mental health (COMMEND project; MNDA) and feel unsupported by the healthcare system, which increases emotional distress (Pinto et al., 2021). Having psychology integrated in MND MDTs could help to address this.

Chaos and Control

This theme addresses the felt systemic chaos within MND services; a feeling seemingly shared by both clinicians and patients. Key elements were defined as the sudden and significant changes associated with MND which are linked to decreased emotional and psychological wellbeing (Glennie et al., 2021; Pinto et al., 2021), necessitating constant adjustment for plwMND (MNDA, 2021) and consequently the clinicians supporting them. Participants reflected that there is a desire in plwMND to regain a sense of control (Pinto et al., 2021) which seemed to be a parallel process reflected in clinicians' experiences (Hewitt et al., 2006). Clinicians reported that due to a lack of provision (staffing, funding, etc.), patients were often not seen within an adequate timeframe to account for their ever-changing symptoms and provide the necessary support, which resulted in sub-optimal patient care (De Hert, 2020) and increased pressure on staff.

Findings suggest a parallel process between the negative psychological impact of the distressing MND-associated changes upon the patient and the psychological impact on the professionals caring for them, further indicated by clinicians' discussion of the high cognitive load placed on them, alongside the significant emotional impact staff experience when working with plwMND in a 'diagnosis to death' service. This cognitive and emotional impact on staff has potential to increase the risk of physician burnout (De Hert, 2020), supporting existing literature suggesting that clinical psychology has a role in supporting staff wellbeing, which in turn could facilitate better patient outcomes for plwMND (De Hert, 2020; Cramond et al., 2020).

Furthermore, findings also support existing literature suggesting that the unique skillset of a clinical psychologist is important in supporting clinicians working with a diverse and complex range of presentations associated with terminal illness (Strachan et al., 2020; Galfin et al., 2012).

Staff Psychological Containment

This theme explores staff perspectives of feeling psychologically contained within the MDT. Key aspects of this theme included clinicians' desire for, and appreciation of training, and the value of psychology as an educational resource within the MDT. Staff shared a sense of psychology facilitating new ways of thinking and understanding, which was experienced by both staff and patient perspectives of how psychology can support them and enhance patient outcomes. Furthermore, clinicians found containment in the reflective spaces provided by the psychologist within their core MDT. This space looked different within each team, in terms of whether the space was 1:1 supervision, group reflective practice, or informal conversations with the psychologist, yet the perceived valued benefits formed a common ground: enhanced confidence in their role and what they could offer to patients, a sense of containment, reassurance that staff were providing a 'good-enough' level of care, permission to enlist professional and personal boundaries, and freedom to grieve patients they had lost to MND.

The 'safeness-threat' regulation system evolved from attachment theory (Bowlby, 1969) and group forms of caring relationships (Camilleri et al, 2023; Dunbar, 2022) illustrates a way of regulating and coping with threat whereby individuals rely not solely on their own methods for threat-management, but also seek out 'helpful others', which in turn activates the 'secure base' and 'safe haven' relationships functioning via psychophysiology and neurocircuitry regarding helping and being helped (Gilbert, 2024; Brown & Brown, 2015). This process involves detecting threat and acting via acquiring skills and resources to cope with and prevent threat, alongside seeking and receiving emotional and practical support (Gilbert, 2024). The reported psychological staff safety and upskilling enhancing wellbeing and care provision supports previous research (West & Coia, 2019).

Findings suggest that integrated psychology within an MND MDT is of significant value to the individual clinicians and the MDT more broadly, supporting existing non-MND specific literature exploring the role and importance of integrated MDT psychology (Woods, 2019; Christofides et al., 2012). Findings also suggest an alternative perspective to existing literature indicating that in general MDTs psychology is 'valued, but not a first-line treatment' (Woods, 2019); contrastingly, this study suggests that integrated psychology within an MND-specific MDT was perceived as essential and should be prioritised as much as, if not more than, other core MDT disciplines.

Value of Psychology to Service Users

This theme incorporates concepts related to the value of psychology to service-users, as perceived by the clinicians supporting them. This included examining the indirect patient impact of psychology support, the difficulty in measuring this impact, and the acknowledgement of MND psychology forming a 'double-specialism'.

Clinicians unanimously agreed that the indirect patient impact of psychology support was essential, and possibly more important than direct patient contact with psychology. Staff described barriers to patients directly accessing psychology, including reluctance due to stigma or feeling overwhelmed by the many care professionals already involved. Staff therefore seemed to perceive indirect psychology support as a buffer to somewhat overcoming this access barrier. This led to patients receiving support to manage their cognitive and emotional wellbeing via non-psychology staff coached in psychological concepts (De Hert, 2020; Cramond et al., 2020; Strachan et al., 2020; Galfin et al., 2012), thus enhancing compassionate care. Findings again support existing research highlighting the importance of MDT-integrated psychology (Woods, 2019; Christofides et al., 2012), and suggest the importance is increased within MND-specific MDTs.

The nature of much of psychology's role being indirect patient support formed a further conundrum for clinicians; when such an impact cannot necessarily be measured in direct patient outcomes within a direct caseload, how *do* we measure it? Clinicians spoke about the 'drip-down' support offered from psychologists as the 'expert', to non-psychology staff, and then to patients. Staff also discussed that whilst a psychologist may not have physically seen 10 patients that day, they may have 'impacted 10 patient lives' through provisions such as MDT discussions or supervisory guidance. Clinicians' 'felt' sense of psychology having positively influenced patient outcomes was another common perception, which was seemingly influenced by the juxtaposition that the absence of psychology through either withdrawal or lack of provision, was often perceived to indicate the value of its presence. Such concepts are by their nature intangible, and were perceived as immeasurable, which seemingly frustrated and confused participants. Considering this conundrum within the wider framework of psychology being a limited resource, findings could potentially provide some insight into the difficulties of securing funding and proving the value of psychology to commissioners and explain why psychology is deemed lower priority than other core MDT disciplines. Furthermore, there is evidence to suggest that adopting a CL approach and supporting staff wellbeing leads to high-quality care and better patient outcomes (West, 2021;

Dawson & West; 2018), and that the absence of such leads to lower patient satisfaction (West & Dawson, 2012; West et al., 2011). This suggests that indirect psychological impact *can* and *should* be measured, highlighting a key role for integrated psychological support within MND teams.

Finally, staff shared a perception of MND-specific psychology being ‘doubly-specialist’; a certain skillset and knowledge was deemed important for clinicians working within MND generally, and the value of psychology as an ‘expert’ specialism within itself was prominently highlighted. In teams where integrated psychology was unavailable, the only offer was counselling, which whilst helpful, was perceived by participants as insufficient in meeting the needs of plwMND, due to an absence of necessary specialist knowledge of MND and the skillset of clinical psychology expertise and interventions. Clinicians described ‘a real gap’ in support and an ’unmet need’ when patients are only able to access non-MND specific support. Findings support existing literature highlighting the necessity of integrating clinical psychologists into MDTs to improve delivery of psychological support (Christophides et al., 2012; Woods, 2019) and offer a new suggestion that this is of even greater importance within MND services.

Strengths, Limitations and Future Research

The findings of this study support that of existing research and addresses previous recommendations for further research into clarifying what an MDT would find most useful in terms of psychological interventions for clients and staff training (Woods, 2019) and exploring barriers to accessing psychology within MND services (Giebel et al., 2019). It is a further strength that this study contributes to the limited existing pool of research examining the specific psychological needs of plwMND and how professionals can best meet these needs. Thus, the study goes some of the way towards bridging literature gaps and is of high clinical relevance to the field.

Another study strength is the use of TA, which allows for both social and psychological interpretations of data and thus is useful within healthcare research and policy-forming (Braun & Clarke, 2006). Furthermore, the researcher’s use of reflexivity denotes a further strength in reducing bias and enhancing transparency in the research perspective (Braun & Clarke, 2019; Byrne, 2021).

The recruitment of participants from across the UK forms another study strength; whilst this clearly does not constitute a fully-representative sample, the findings provide insight into varied teams and settings within different localities, facilitating an overview into the similarities and disparities across services.

Recruitment difficulties form a study limitation. The targeted sample size was 12 participants, however despite a long and persistent recruitment period and increased methods[5], only eight participants volunteered to interview. Despite this, information power was achieved in that data provided sufficient richness and quality to enable appropriate analysis (Braun & Clarke, 2021; Malterud et al., 2016). Furthermore, the voluntary nature of recruitment forms another limitation; participants involved may have an increased interest in psychology or research, or a polarised experience of psychology provision and therefore may not represent the full range of experiences. Further research may seek to recruit a wider, more varied participant pool. Recruitment limitations further demonstrate the lack of clinicians across the UK who have experienced integrated MDT psychology within the last 24 months. The nature of the inclusion criteria eliminated a huge portion of clinicians within MND services, purely because so few have received integrated psychology input, further illustrating funding difficulties.

It was beyond the scope of the current study to explore the role of psychology within alternative systems surrounding plwMND, for example relatives and caregivers, though much of the data discussed themes related to this. Future research would benefit from further exploring this and utilising emergent data outside of this study's research aims.

Clinical Implications

This study highlights the importance and value of integrating psychology into MDTs across MND services. Clinicians have noticed and acknowledged the benefits of integrated MND psychology towards themselves, service-users, and the MDT, across various levels including

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[5] For example the researcher made themselves available for informal conversations about the study, offered to attend MDT meetings to introduce the study, and amended ethical approval to include the use of social media advertisement.

enhanced wellbeing, skillset, delivery of care, and patient outcomes. The broader role of psychology within the MDT, including indirect support via supervision, training and MDT input was valued and deemed necessary for clinicians supporting plwMND.

On an organisational scale, this study highlights the phenomenal lack of funding provided within MND services, particularly regarding psychological support for plwMND and the clinicians supporting them. This forms an organisational barrier to psychology access for both patients and staff. Furthermore, the perceived difficulty in proving the value of psychology in tangible, measurable ways has also been highlighted, alongside evidence supporting the measurement of indirect psychological influence via supporting staff. Considering psychological theory alongside findings suggests that utilising CL or Compassion-Focussed Therapy (CFT) may be useful to promote a sense of psychological safety within MND teams via psychoeducation and upskilling, to manage the threat, worry, and the chaos and cognitive load associated with MND services. Implementing these models could provide reflective spaces to listen, understand, empathise with and validate staff (Kline, 2002; Gallo, 2017; West & Chowla, 2017) and reach their full potential, resulting in high-quality care (West, 2021). Services could benefit from implementing CL to prevent clinical burnout (Trzeciak et al., 2019), enhancing staff wellbeing, organisational aspects, and patient outcomes.

The current study has given voice to frontline workers within MND services sharing their frustration with psychology being less prioritised than other core MDT disciplines, despite the consensus of feeling it is undoubtedly high-priority. This suggests a dissonance between frontline clinicians and decision-makers in commissioning, in terms of what would enhance the quality of MND service provision. Commissioning bodies should consider the study findings and assess how they can support increasing access to psychology within MND services, for both staff and patients. Furthermore, training around CL should also be considered.

At policy level, NICE guidance currently indicates that psychological support should be provided to plwMND and their families/caregivers. Yet, no recommendations are given for a qualified clinical psychologist to be integrated within MND MDTs to undertake or support the suggested duties. Findings suggest that this support is imperative in ensuring the wellbeing of plwMND and the clinicians supporting them. Amending NICE guidelines to reflect and support the necessity of integrated psychology within MDTs across MND services could assist in highlighting the prioritisation of psychological provision and increase pressure on budget-holders to allocate funding.

Conclusion

There was a shared recognition of psychology being of value to both clinicians and patients, directly and indirectly, on many levels, though this value was perceived as difficult to measure tangibly. The chaos, complexities, and desire for control within MND services was experienced as a parallel process between patients and clinicians. The nature of a ‘diagnosis to death’ service created high cognitive load and emotive working experiences for clinicians. Psychology support was viewed as essential and necessary to provide good-quality patient care, yet clinicians felt frustrated at the sheer lack of both funding and staffing for psychology as a discipline, and for MND services generally. Clinicians shared a sense of psychology not being prioritised as equally as other core MDT disciplines, despite feeling as of equal, or enhanced, important. Barriers to accessing psychology were highlighted, alongside the benefits and value of MND-specific psychology. The value of CL within MND MDTs was also highlighted. Future research would benefit from further exploring the value of MND-specific MDT psychology in relation to families and caregivers.

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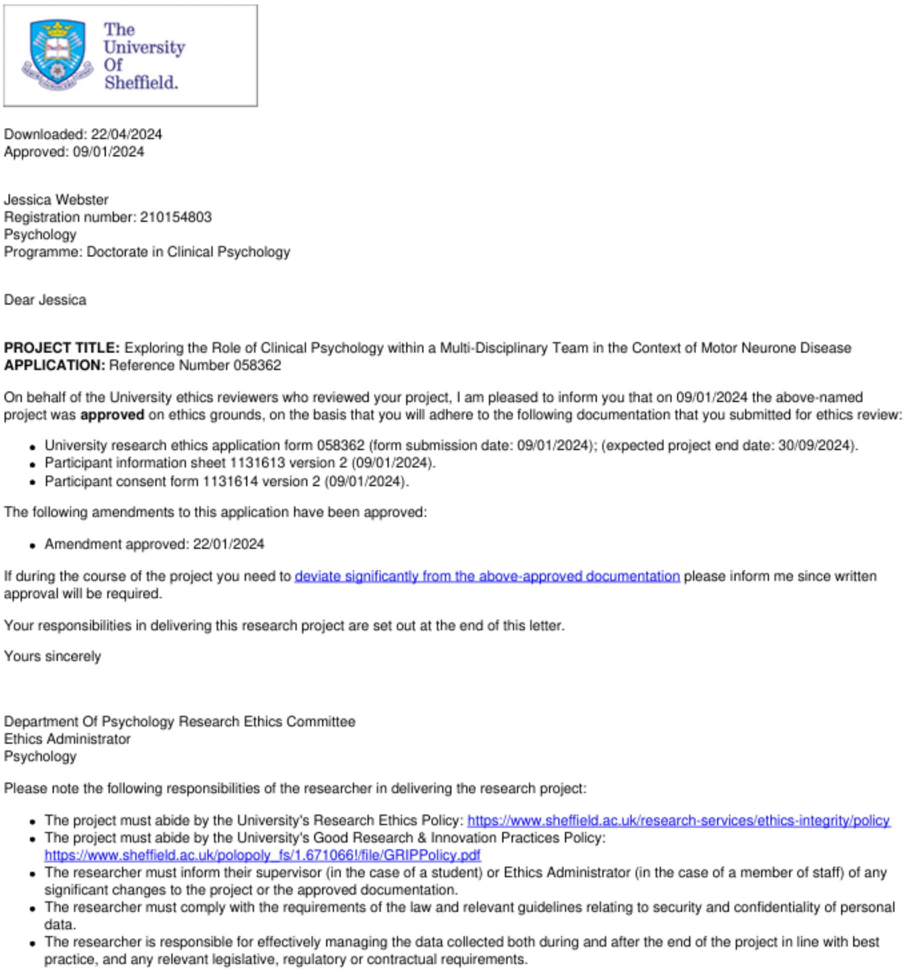
Appendices

Appendix A

University of Sheffield Ethics Approval Letter



The University Of Sheffield.

Downloaded: 22/04/2024
Approved: 09/01/2024

Jessica Webster
Registration number: 210154803
Psychology
Programme: Doctorate in Clinical Psychology

Dear Jessica

PROJECT TITLE: Exploring the Role of Clinical Psychology within a Multi-Disciplinary Team in the Context of Motor Neurone Disease
APPLICATION: Reference Number 058362

On behalf of the University ethics reviewers who reviewed your project, I am pleased to inform you that on 09/01/2024 the above-named project was **approved** on ethics grounds, on the basis that you will adhere to the following documentation that you submitted for ethics review:

- University research ethics application form 058362 (form submission date: 09/01/2024); (expected project end date: 30/09/2024).
- Participant information sheet 1131613 version 2 (09/01/2024).
- Participant consent form 1131614 version 2 (09/01/2024).

The following amendments to this application have been approved:

- Amendment approved: 22/01/2024

If during the course of the project you need to deviate significantly from the above-approved documentation please inform me since written approval will be required.

Your responsibilities in delivering this research project are set out at the end of this letter.

Yours sincerely

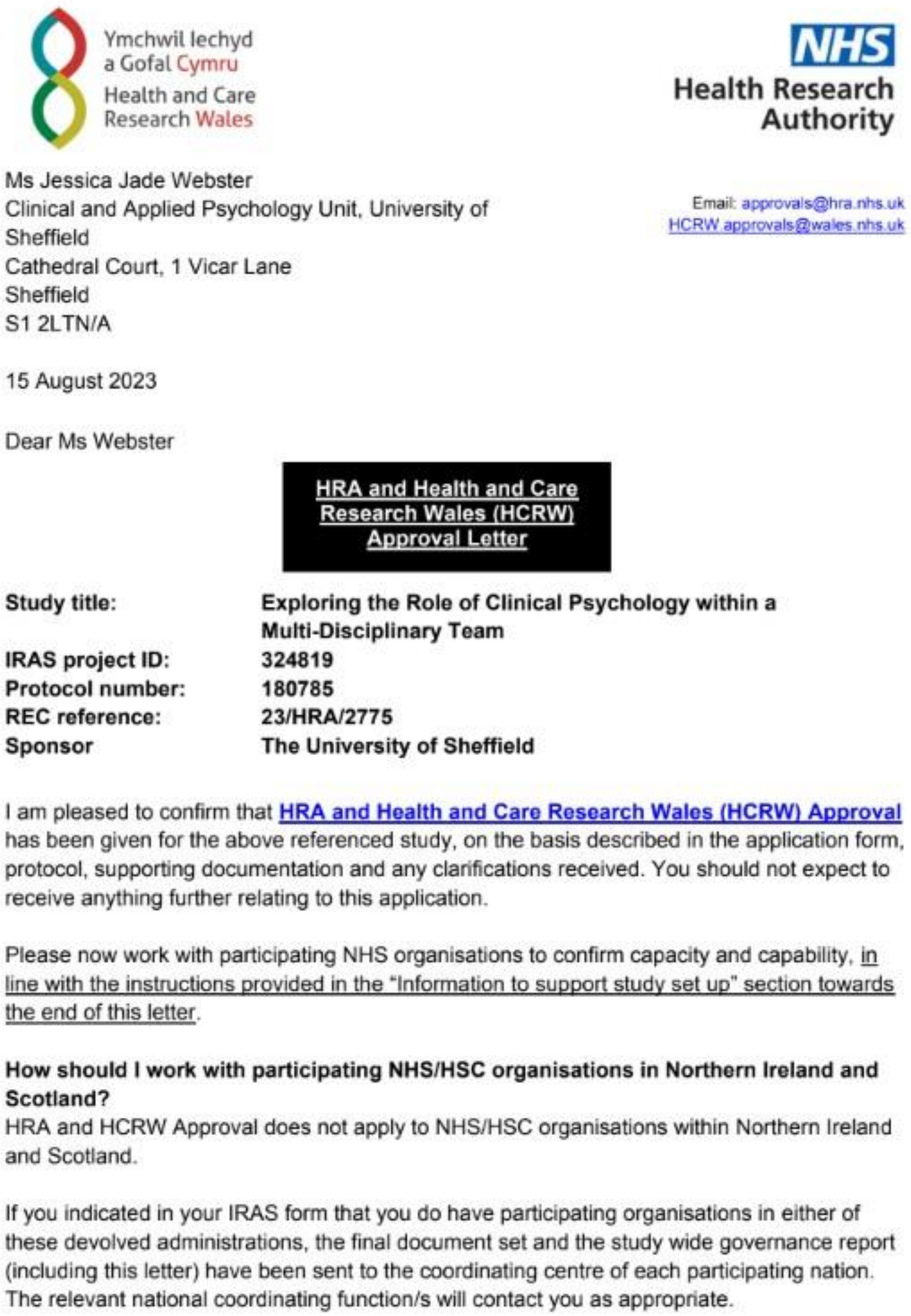
Department Of Psychology Research Ethics Committee
Ethics Administrator
Psychology

Please note the following responsibilities of the researcher in delivering the research project:

- The project must abide by the University's Research Ethics Policy: https://www.sheffield.ac.uk/research-services/ethics-integrity/policy
- The project must abide by the University's Good Research & Innovation Practices Policy: https://www.sheffield.ac.uk/polopoly_fs/1.671066!/file/GRIPPolicy.pdf
- The researcher must inform their supervisor (in the case of a student) or Ethics Administrator (in the case of a member of staff) of any significant changes to the project or the approved documentation.
- The researcher must comply with the requirements of the law and relevant guidelines relating to security and confidentiality of personal data.
- The researcher is responsible for effectively managing the data collected both during and after the end of the project in line with best practice, and any relevant legislative, regulatory or contractual requirements.

Appendix B

HRA Approval Letter



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Ms Jessica Jade Webster
Clinical and Applied Psychology Unit, University of Sheffield
Cathedral Court, 1 Vicar Lane
Sheffield
S1 2LTN/A

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

15 August 2023

Dear Ms Webster

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

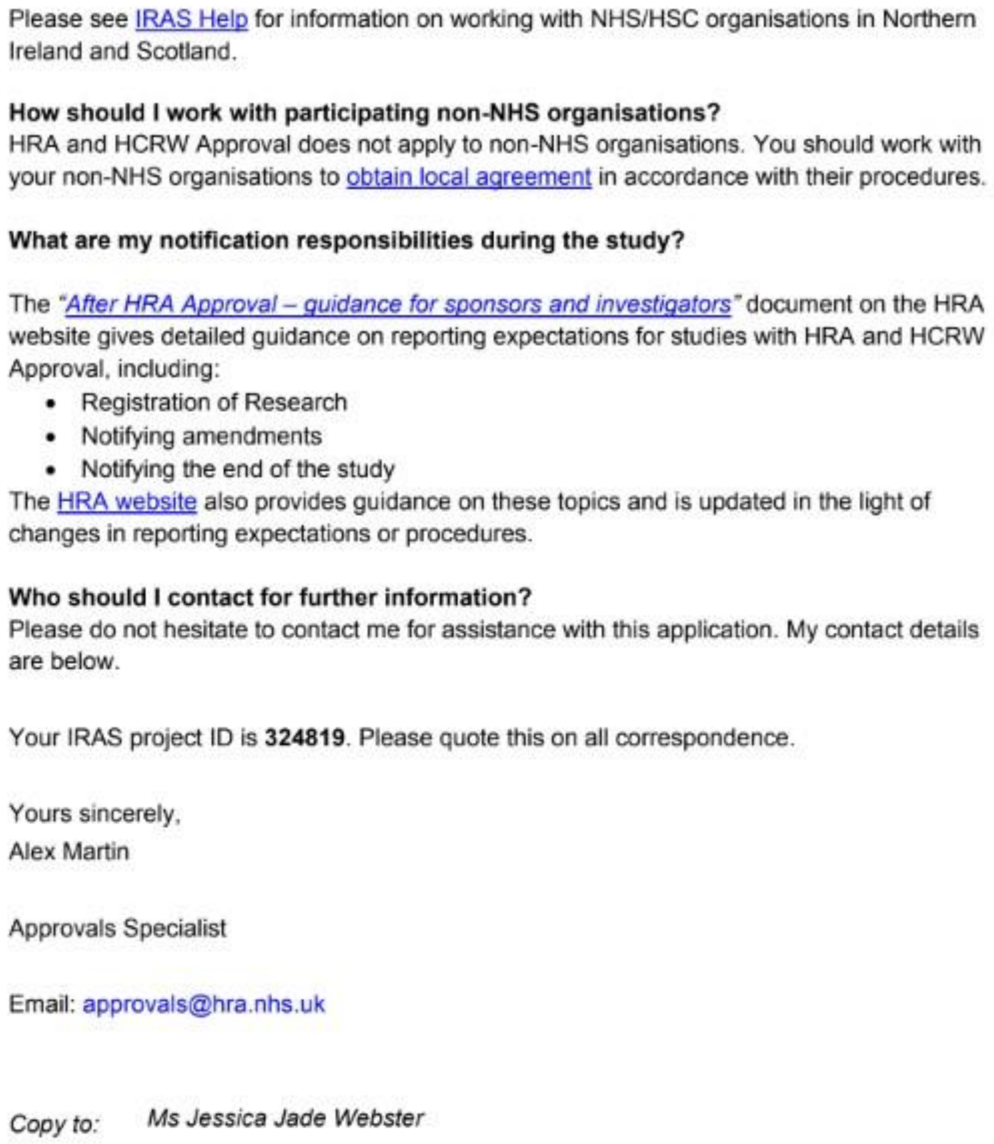
Study title:	**Exploring the Role of Clinical Psychology within a Multi-Disciplinary Team**
IRAS project ID:	**324819**
Protocol number:	**180785**
REC reference:	**23/HRA/2775**
Sponsor	**The University of Sheffield**

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 *"After HRA Approval – guidance for sponsors and investigators"* document on the HRA website gives detailed guidance on reporting expectations for studies with HRA and HCRW Approval, 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 **324819**. Please quote this on all correspondence.

Yours sincerely,
Alex Martin

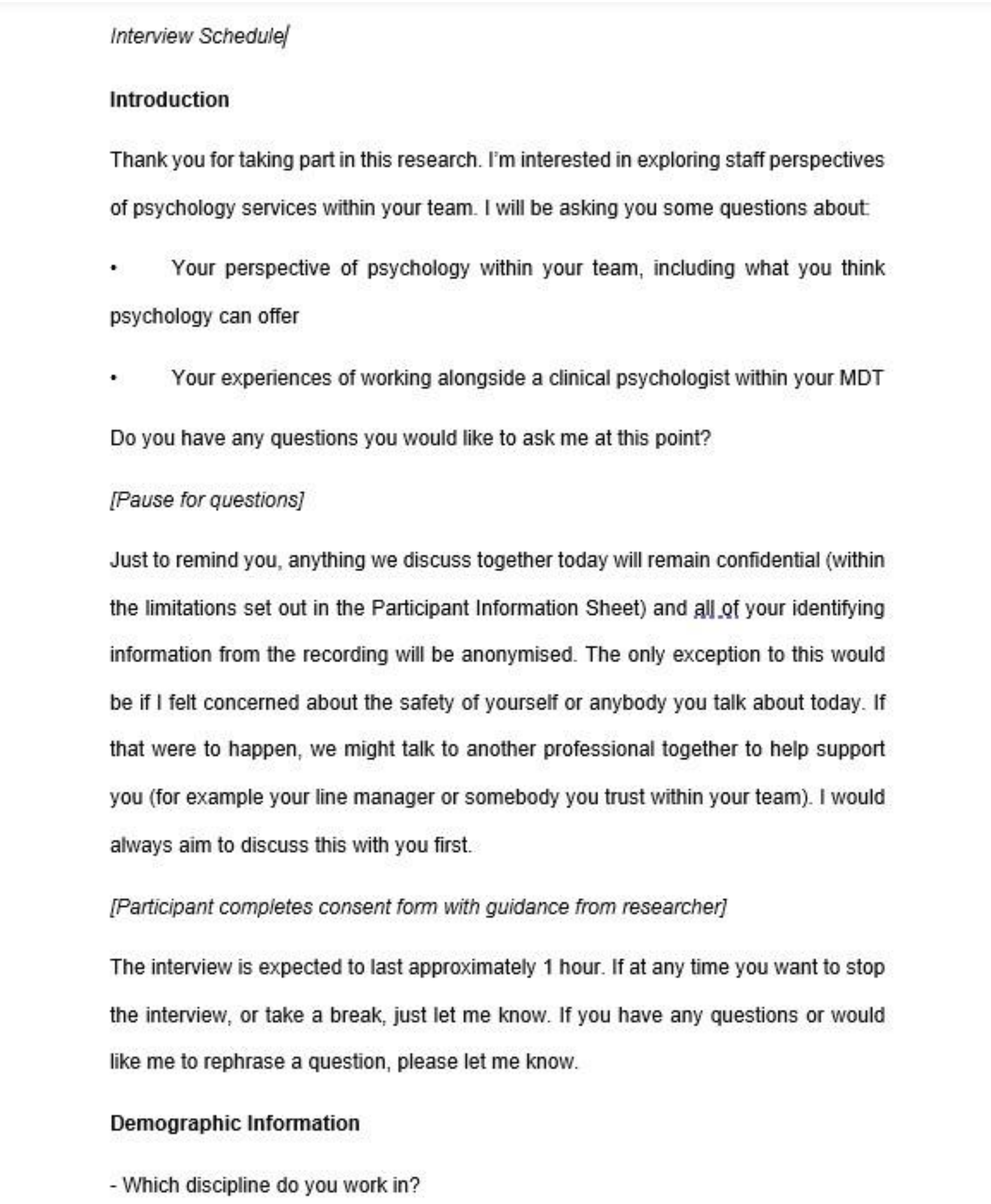
Approvals Specialist

Email: approvals@hra.nhs.uk

Copy to: *Ms Jessica Jade Webster*

Appendix C

Interview Schedule



Interview Schedule

Introduction

Thank you for taking part in this research. I'm interested in exploring staff perspectives of psychology services within your team. I will be asking you some questions about:

- Your perspective of psychology within your team, including what you think psychology can offer
- Your experiences of working alongside a clinical psychologist within your MDT

Do you have any questions you would like to ask me at this point?

[Pause for questions]

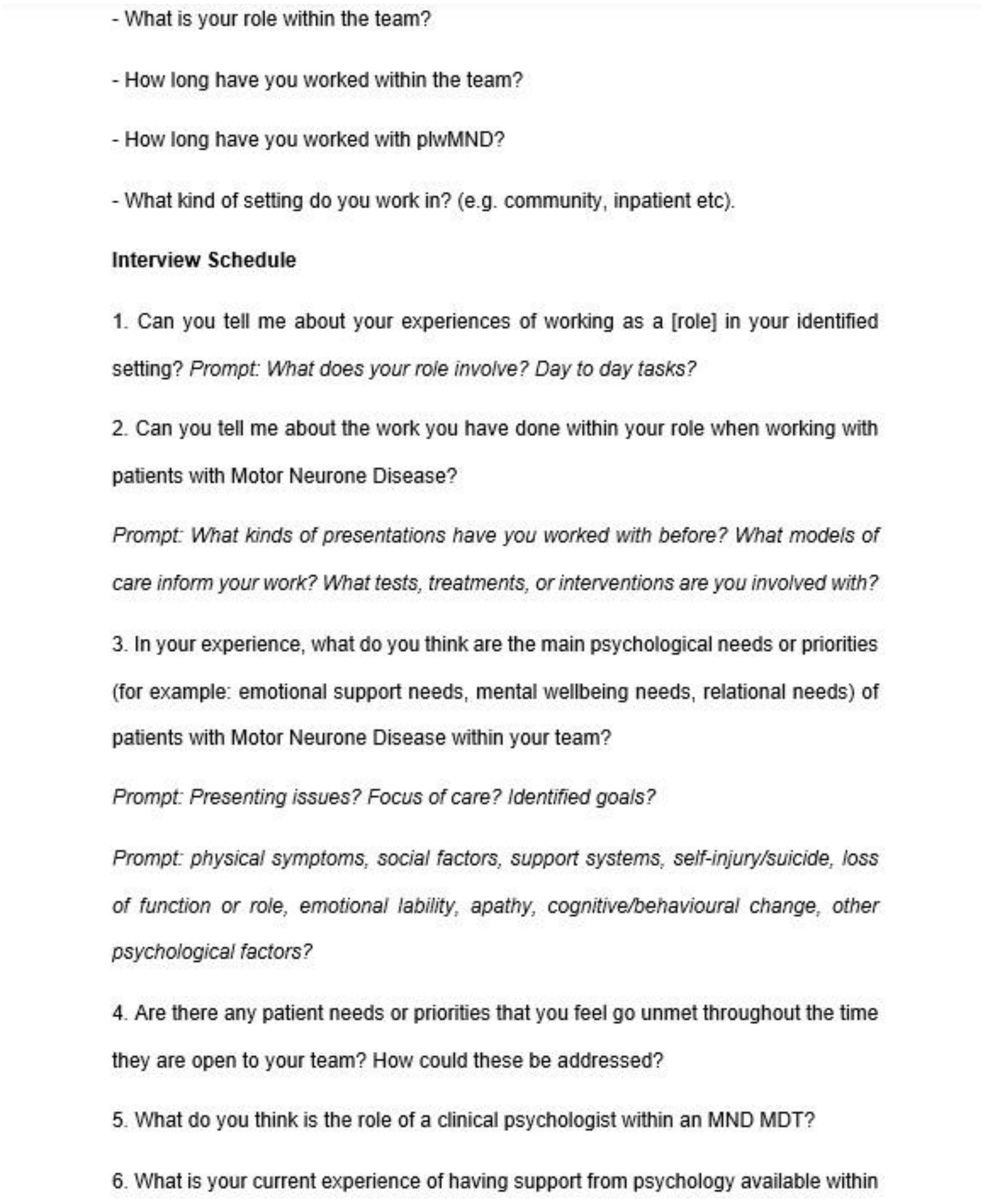
Just to remind you, anything we discuss together today will remain confidential (within the limitations set out in the Participant Information Sheet) and all of your identifying information from the recording will be anonymised. The only exception to this would be if I felt concerned about the safety of yourself or anybody you talk about today. If that were to happen, we might talk to another professional together to help support you (for example your line manager or somebody you trust within your team). I would always aim to discuss this with you first.

[Participant completes consent form with guidance from researcher]

The interview is expected to last approximately 1 hour. If at any time you want to stop the interview, or take a break, just let me know. If you have any questions or would like me to rephrase a question, please let me know.

Demographic Information

- Which discipline do you work in?



- What is your role within the team?

- How long have you worked within the team?

- How long have you worked with plwMND?

- What kind of setting do you work in? (e.g. community, inpatient etc).

Interview Schedule

1. Can you tell me about your experiences of working as a [role] in your identified setting? *Prompt: What does your role involve? Day to day tasks?*

2. Can you tell me about the work you have done within your role when working with patients with Motor Neurone Disease?

Prompt: What kinds of presentations have you worked with before? What models of care inform your work? What tests, treatments, or interventions are you involved with?

3. In your experience, what do you think are the main psychological needs or priorities (for example: emotional support needs, mental wellbeing needs, relational needs) of patients with Motor Neurone Disease within your team?

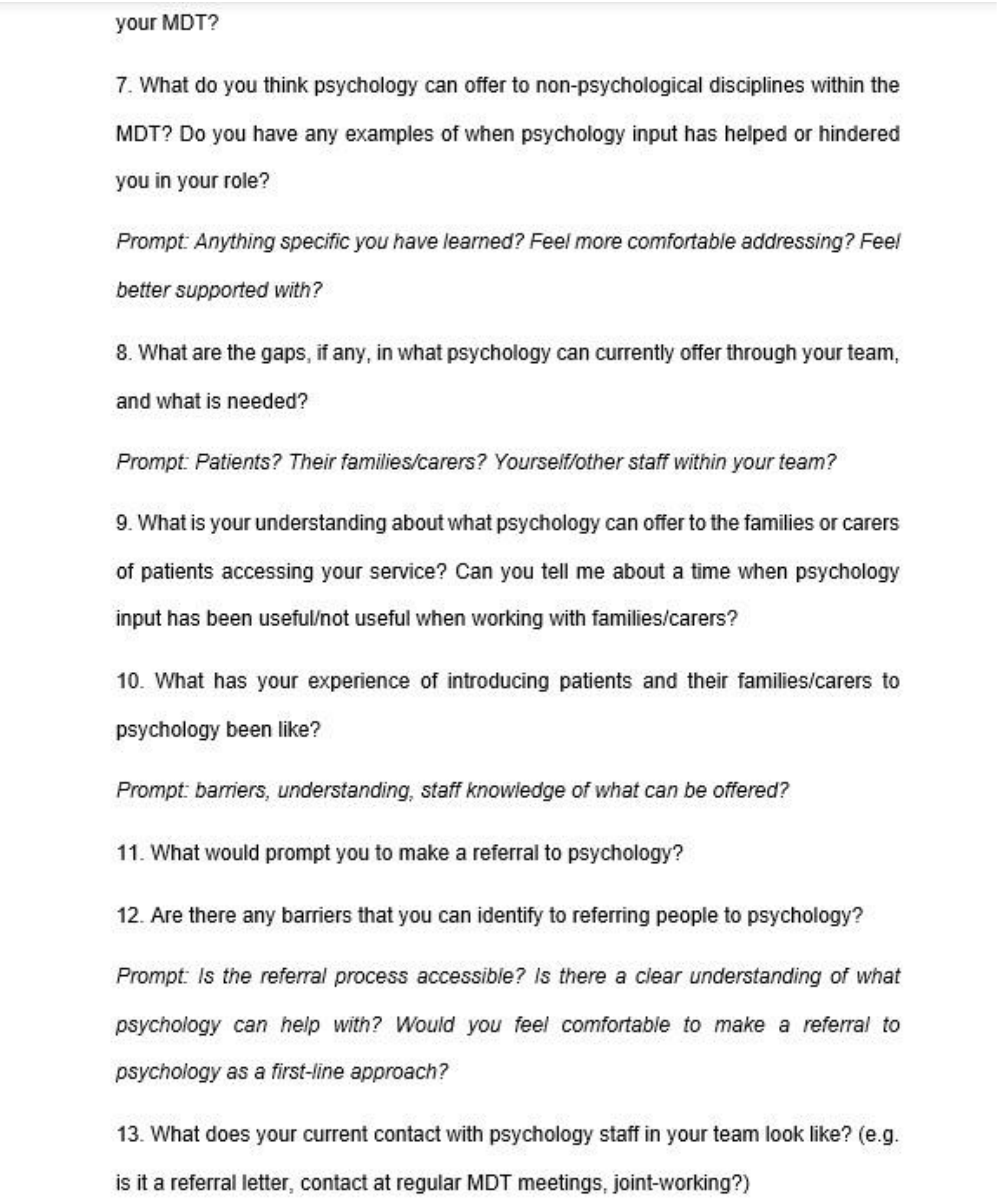
Prompt: Presenting issues? Focus of care? Identified goals?

Prompt: physical symptoms, social factors, support systems, self-injury/suicide, loss of function or role, emotional lability, apathy, cognitive/behavioural change, other psychological factors?

4. Are there any patient needs or priorities that you feel go unmet throughout the time they are open to your team? How could these be addressed?

5. What do you think is the role of a clinical psychologist within an MND MDT?

6. What is your current experience of having support from psychology available within



your MDT?

7. What do you think psychology can offer to non-psychological disciplines within the MDT? Do you have any examples of when psychology input has helped or hindered you in your role?

Prompt: Anything specific you have learned? Feel more comfortable addressing? Feel better supported with?

8. What are the gaps, if any, in what psychology can currently offer through your team, and what is needed?

Prompt: Patients? Their families/carers? Yourself/other staff within your team?

9. What is your understanding about what psychology can offer to the families or carers of patients accessing your service? Can you tell me about a time when psychology input has been useful/not useful when working with families/carers?

10. What has your experience of introducing patients and their families/carers to psychology been like?

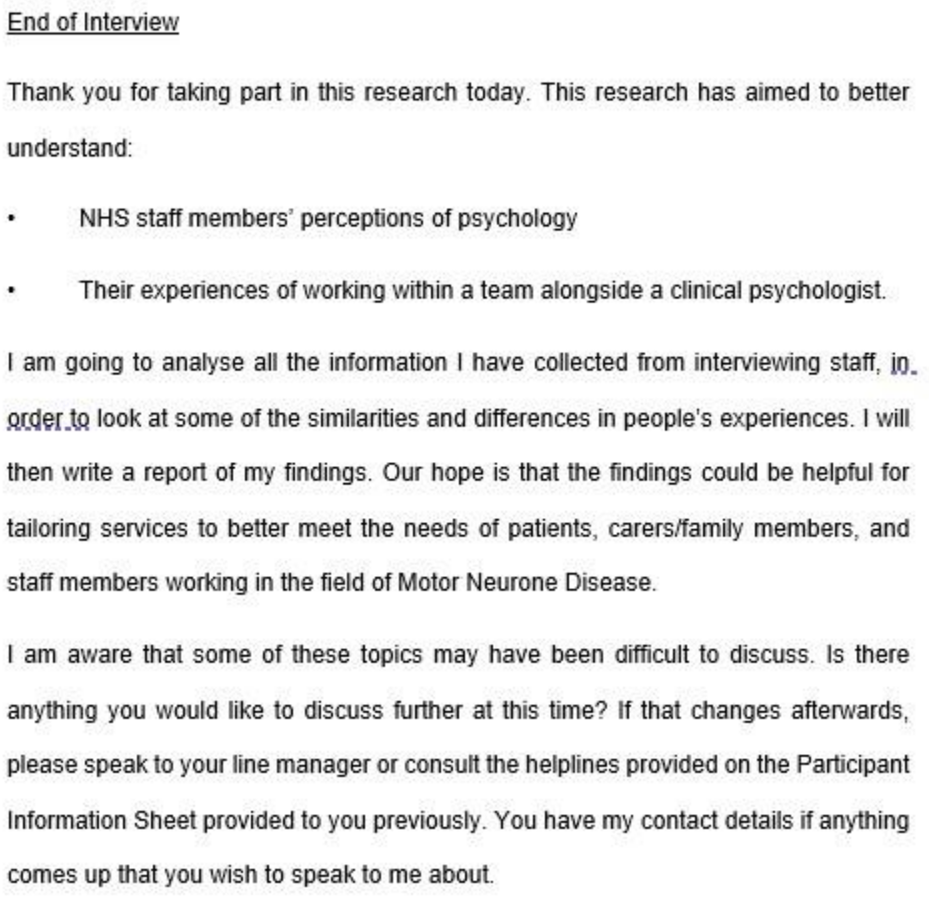
Prompt: barriers, understanding, staff knowledge of what can be offered?

11. What would prompt you to make a referral to psychology?

12. Are there any barriers that you can identify to referring people to psychology?

Prompt: Is the referral process accessible? Is there a clear understanding of what psychology can help with? Would you feel comfortable to make a referral to psychology as a first-line approach?

13. What does your current contact with psychology staff in your team look like? (e.g. is it a referral letter, contact at regular MDT meetings, joint-working?)



End of Interview

Thank you for taking part in this research today. This research has aimed to better understand:

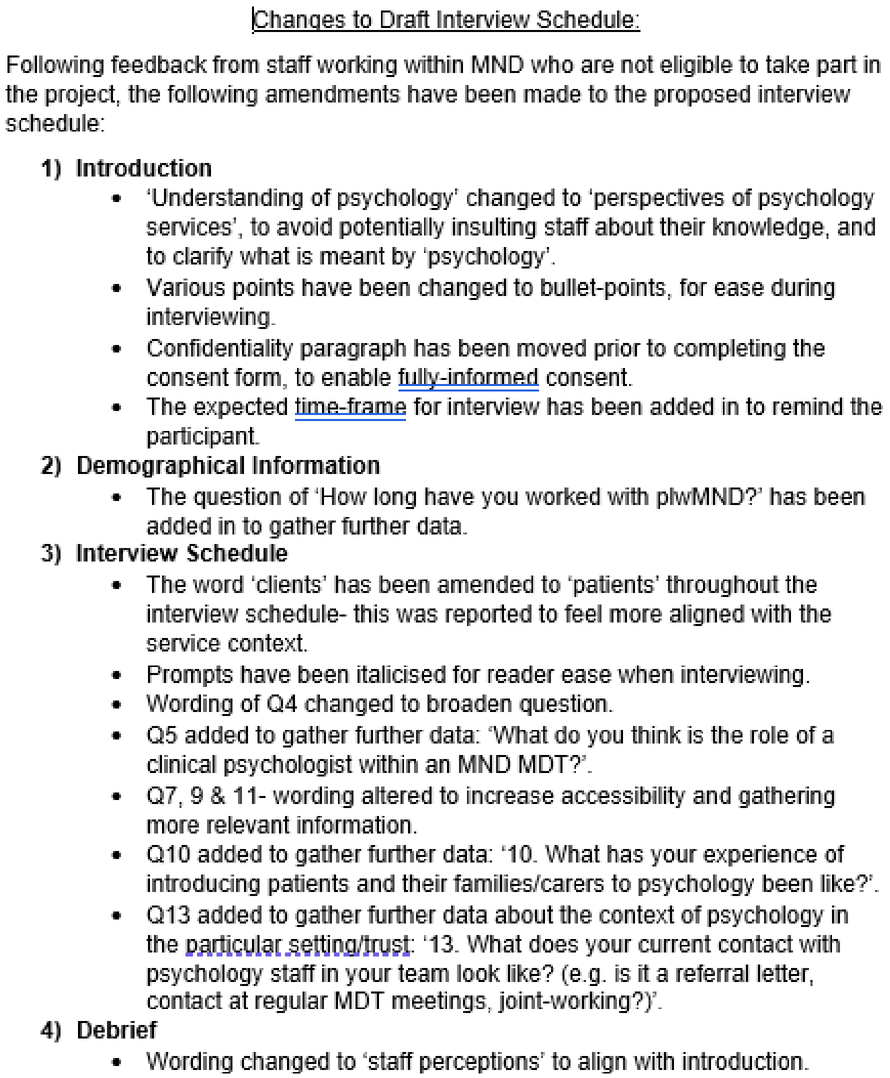
- NHS staff members' perceptions of psychology
- Their experiences of working within a team alongside a clinical psychologist.

I am going to analyse all the information I have collected from interviewing staff, in order to look at some of the similarities and differences in people's experiences. I will then write a report of my findings. Our hope is that the findings could be helpful for tailoring services to better meet the needs of patients, carers/family members, and staff members working in the field of Motor Neurone Disease.

I am aware that some of these topics may have been difficult to discuss. Is there anything you would like to discuss further at this time? If that changes afterwards, please speak to your line manager or consult the helplines provided on the Participant Information Sheet provided to you previously. You have my contact details if anything comes up that you wish to speak to me about.

Appendix D

Audit of Interview Changes



Changes to Draft Interview Schedule:

Following feedback from staff working within MND who are not eligible to take part in the project, the following amendments have been made to the proposed interview schedule:

1) **Introduction**
    - 'Understanding of psychology' changed to 'perspectives of psychology services', to avoid potentially insulting staff about their knowledge, and to clarify what is meant by 'psychology'.
    - Various points have been changed to bullet-points, for ease during interviewing.
    - Confidentiality paragraph has been moved prior to completing the consent form, to enable fully-informed consent.
    - The expected time-frame for interview has been added in to remind the participant.
2) **Demographical Information**
    - The question of 'How long have you worked with plwMND?' has been added in to gather further data.
3) **Interview Schedule**
    - The word 'clients' has been amended to 'patients' throughout the interview schedule- this was reported to feel more aligned with the service context.
    - Prompts have been italicised for reader ease when interviewing.
    - Wording of Q4 changed to broaden question.
    - Q5 added to gather further data: 'What do you think is the role of a clinical psychologist within an MND MDT?'.
    - Q7, 9 & 11- wording altered to increase accessibility and gathering more relevant information.
    - Q10 added to gather further data: '10. What has your experience of introducing patients and their families/carers to psychology been like?'.
    - Q13 added to gather further data about the context of psychology in the particular setting/trust: '13. What does your current contact with psychology staff in your team look like? (e.g. is it a referral letter, contact at regular MDT meetings, joint-working?)'.
4) **Debrief**
    - Wording changed to 'staff perceptions' to align with introduction.

Appendix E

Advertisement for Study

ARE YOU AN NHS STAFF MEMBER WORKING WITH THOSE WITH MOTOR NEURONE DISEASE?

DO YOU WORK ALONGSIDE A CLINICAL PSYCHOLOGIST WITHIN A MULTI-DISCIPLINARY TEAM?

COME AND SHARE YOUR VIEWS!

I am looking for participants for a research study aimed at understanding the role of clinical psychology within a multi-disciplinary team, in the context of Motor Neurone Disease.

This will involve taking part in an hour-long virtual interview about your experience of:

Working alongside a clinical psychologist • Understanding of the role of psychology in your team • How you think clinical psychology could best support those with motor neurone disease (MND)

We hope that the research will be helpful for tailoring psychological input to clients with MND, and to help us to support staff to understand what clinical psychology can offer within their team. I am a Trainee Clinical Psychologist, and this project will form part of my thesis. You will be eligible to take part if you:

01 Work clinically within an NHS multi-disciplinary team focused on caring for people living with MND, and you have a clinical psychologist working in your team

02 Have worked within a multi-disciplinary team alongside a clinical psychologist, in the context of Motor Neurone Disease within the last 24 months

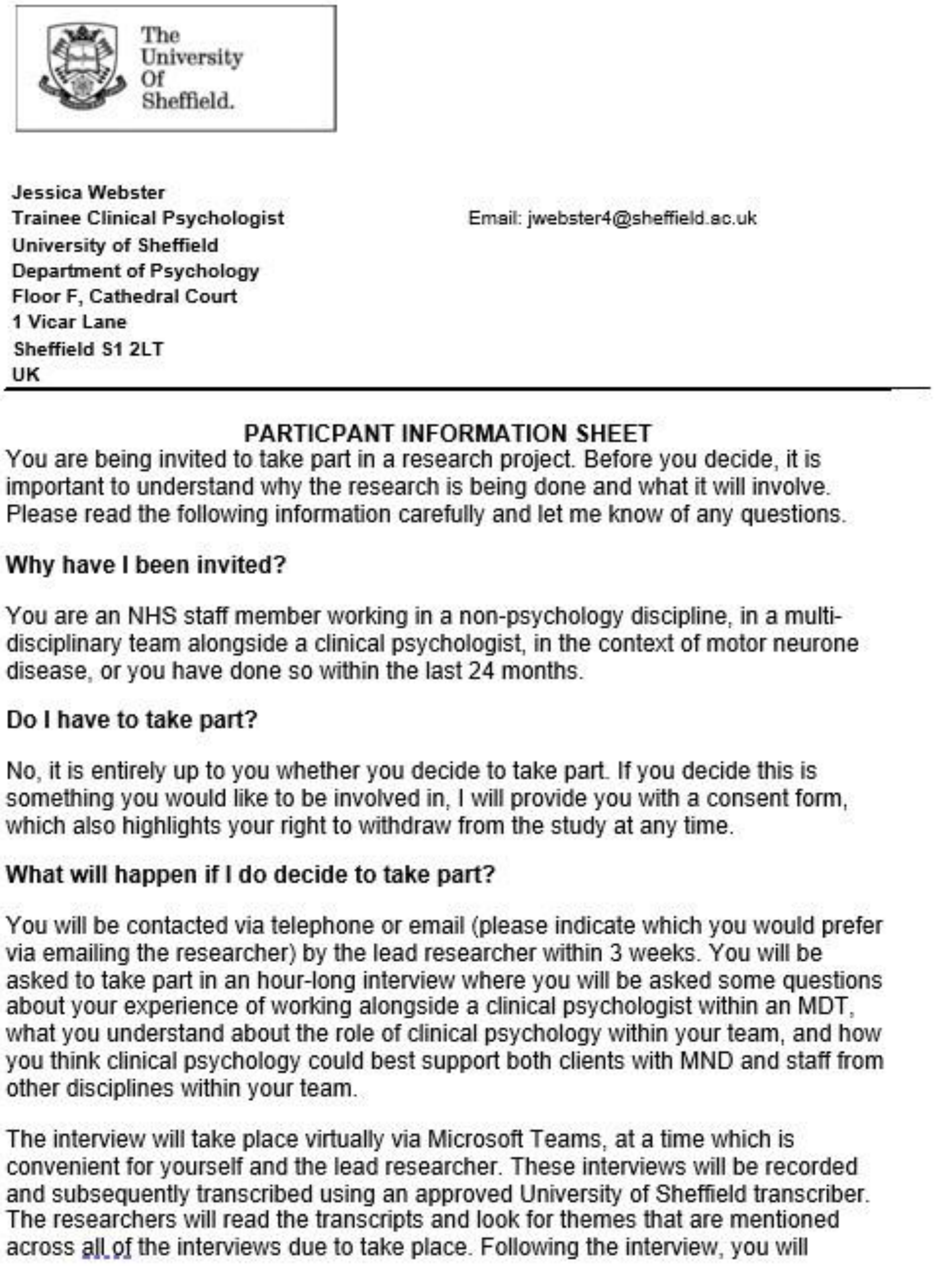
03 Are NOT working within the discipline of Psychology

GET IN TOUCH NOW:

jwebster4@sheffield.ac.uk

Appendix F

Participant Information Sheet



The University Of Sheffield.

Jessica Webster
Trainee Clinical Psychologist
University of Sheffield
Department of Psychology
Floor F, Cathedral Court
1 Vicar Lane
Sheffield S1 2LT
UK

Email: jwebster4@sheffield.ac.uk

PARTICPANT INFORMATION SHEET

You are being invited to take part in a research project. Before you decide, it is important to understand why the research is being done and what it will involve. Please read the following information carefully and let me know of any questions.

Why have I been invited?

You are an NHS staff member working in a non-psychology discipline, in a multi-disciplinary team alongside a clinical psychologist, in the context of motor neurone disease, or you have done so within the last 24 months.

Do I have to take part?

No, it is entirely up to you whether you decide to take part. If you decide this is something you would like to be involved in, I will provide you with a consent form, which also highlights your right to withdraw from the study at any time.

What will happen if I do decide to take part?

You will be contacted via telephone or email (please indicate which you would prefer via emailing the researcher) by the lead researcher within 3 weeks. You will be asked to take part in an hour-long interview where you will be asked some questions about your experience of working alongside a clinical psychologist within an MDT, what you understand about the role of clinical psychology within your team, and how you think clinical psychology could best support both clients with MND and staff from other disciplines within your team.

The interview will take place virtually via Microsoft Teams, at a time which is convenient for yourself and the lead researcher. These interviews will be recorded and subsequently transcribed using an approved University of Sheffield transcriber. The researchers will read the transcripts and look for themes that are mentioned across all of the interviews due to take place. Following the interview, you will receive a debrief from the researcher to reiterate study information and points of contact. A debrief sheet containing this information will also be provided to you.

Why would I want to take part?

You have the opportunity to share your valuable experience of understanding clinical psychology input within your team, and to potentially help to influence the future of psychological service provision for clients with MND and staff supporting them. A written report of the findings will be published with the aim to help tailor psychological support to be most helpful for this client group.

What if I take part but then decide I don't want to?

If you decide to take part and then change your mind, you can let the researcher know and they will support you to withdraw from the study. Please note that withdrawal is only possible within the two weeks following the interview- after this point, data analysis will begin.

What if I take part and something comes up that I find difficult/upsetting to talk about?

You do not have to answer anything you feel uncomfortable discussing. You can let the researcher know if there is something you do not wish to talk about. If you find you want to continue but are upset following the interview, there are points of contact provided at the bottom of this Participant Information Sheet to support your wellbeing and safety. If you decide you no longer wish to continue, you may withdraw from the study.

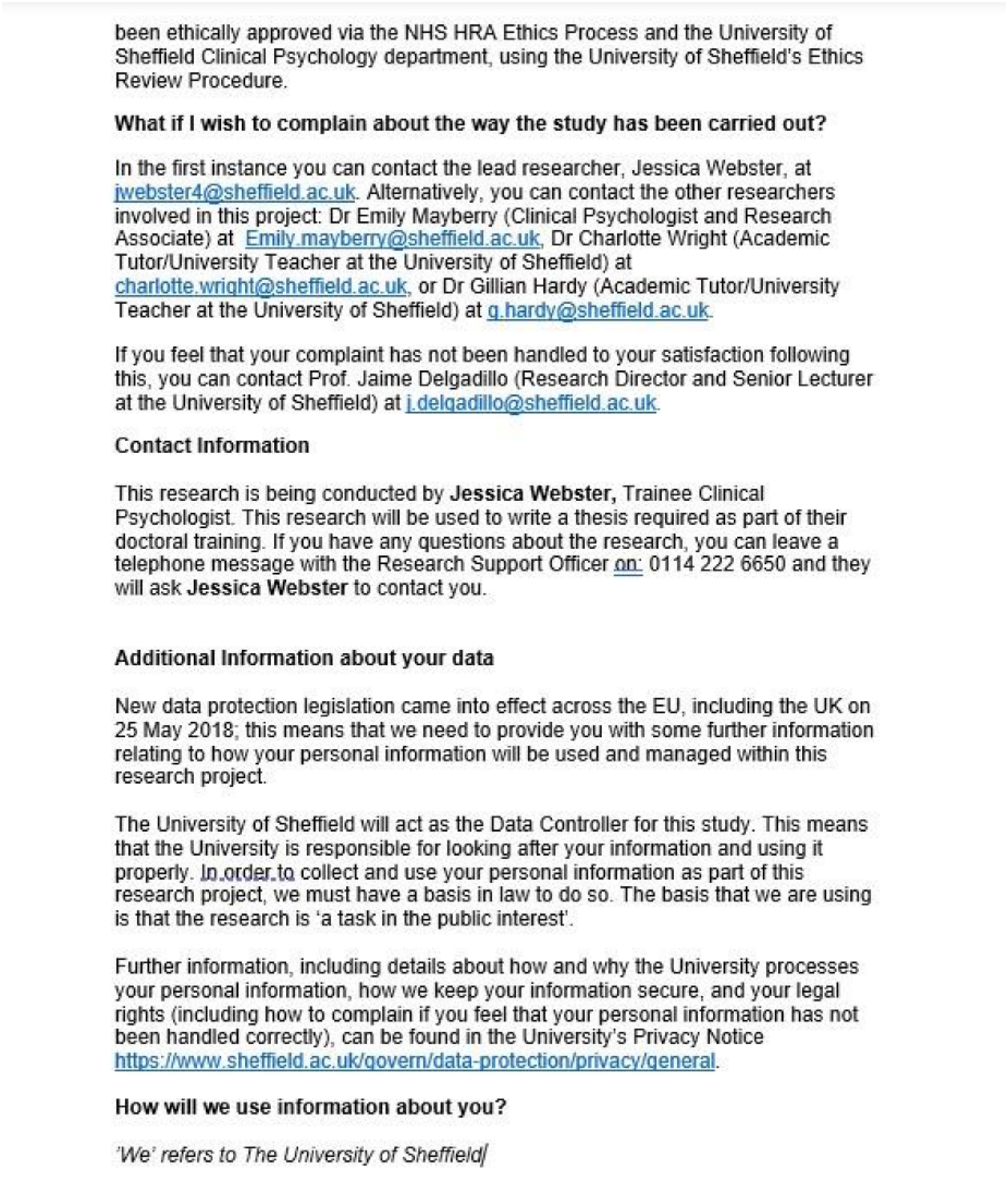
Will all the information be kept confidential?

All the information we collect about you and your experiences will be kept strictly confidential. Direct quotes may be published; however any identifying information will be entirely anonymised so that you will not be identifiable in any reports or publications. Other staff members within your team will only know that you are participating in this study if you choose to tell them yourself.

The only exception to this would be if the researcher became concerned about a potential risk of harm to yourself (e.g. suicidal risk), or somebody else (e.g. hurting a client or staff member). If this situation occurred, the researcher might need to breach confidentiality to support and ensure the safety of yourself and those around you (for example, it may involve letting relevant services know about the situation to help to support those involved). Wherever possible, the researcher would speak with you about this before contacting others.

What will happen to the results of the study?

The results will be submitted as part of the researcher's doctoral thesis (planned submission in May 2024), then prepared for publication. If you would like a copy of the results, please feel free to let the researcher know, and they can facilitate this in due course.



been ethically approved via the NHS HRA Ethics Process and the University of Sheffield Clinical Psychology department, using the University of Sheffield's Ethics Review Procedure.

What if I wish to complain about the way the study has been carried out?

In the first instance you can contact the lead researcher, Jessica Webster, at jwebster4@sheffield.ac.uk. Alternatively, you can contact the other researchers involved in this project: Dr Emily Mayberry (Clinical Psychologist and Research Associate) at Emily.mayberry@sheffield.ac.uk, Dr Charlotte Wright (Academic Tutor/University Teacher at the University of Sheffield) at charlotte.wright@sheffield.ac.uk, or Dr Gillian Hardy (Academic Tutor/University Teacher at the University of Sheffield) at g.hardy@sheffield.ac.uk.

If you feel that your complaint has not been handled to your satisfaction following this, you can contact Prof. Jaime Delgadillo (Research Director and Senior Lecturer at the University of Sheffield) at j.delgadillo@sheffield.ac.uk.

Contact Information

This research is being conducted by **Jessica Webster,** Trainee Clinical Psychologist. This research will be used to write a thesis required as part of their doctoral training. If you have any questions about the research, you can leave a telephone message with the Research Support Officer on: 0114 222 6650 and they will ask **Jessica Webster** to contact you.

Additional Information about your data

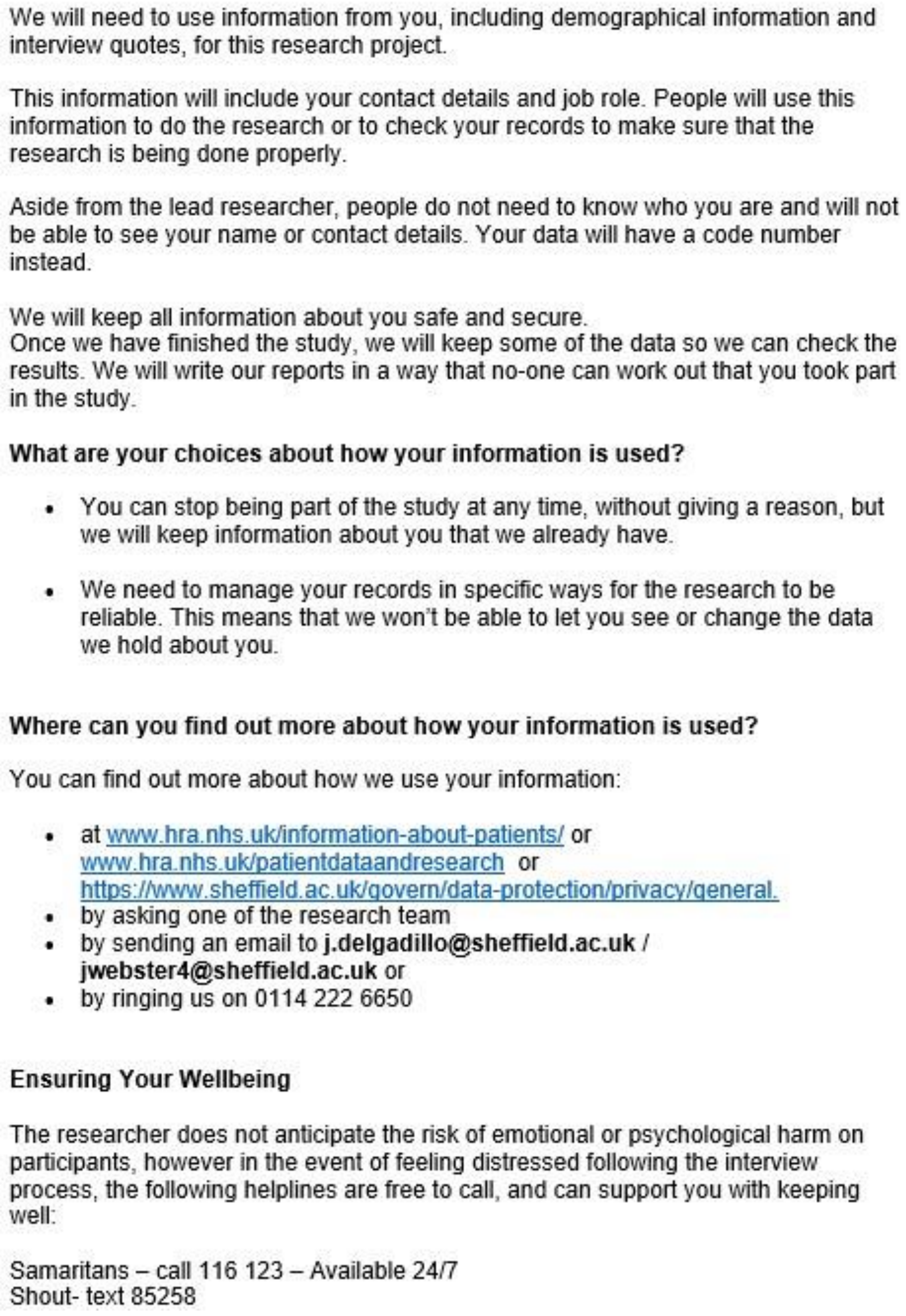
New data protection legislation came into effect across the EU, including the UK on 25 May 2018; this means that we need to provide you with some further information relating to how your personal information will be used and managed within this research project.

The University of Sheffield will act as the Data Controller for this study. This means that the University is responsible for looking after your information and using it properly. In order to collect and use your personal information as part of this research project, we must have a basis in law to do so. The basis that we are using is that the research is 'a task in the public interest'.

Further information, including details about how and why the University processes your personal information, how we keep your information secure, and your legal rights (including how to complain if you feel that your personal information has not been handled correctly), can be found in the University's Privacy Notice https://www.sheffield.ac.uk/govern/data-protection/privacy/general.

How will we use information about you?

'We' refers to The University of Sheffield



We will need to use information from you, including demographical information and interview quotes, for this research project.

This information will include your contact details and job role. People will use this information to do the research or to check your records to make sure that the research is being done properly.

Aside from the lead researcher, people do not need to know who you are and will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.
Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Where can you find out more about how your information is used?

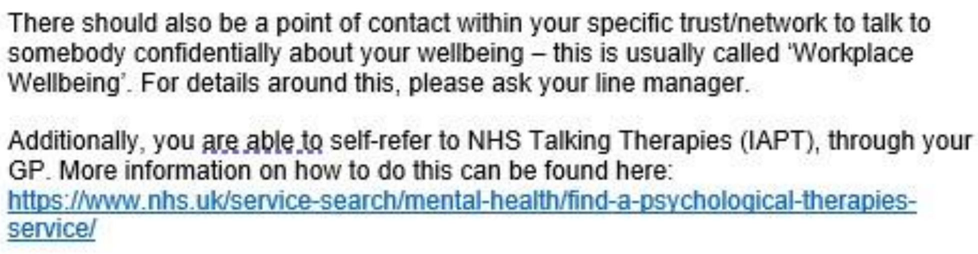
You can find out more about how we use your information:

- at www.hra.nhs.uk/information-about-patients/ or www.hra.nhs.uk/patientdataandresearch or https://www.sheffield.ac.uk/govern/data-protection/privacy/general.
- by asking one of the research team
- by sending an email to **j.delgadillo@sheffield.ac.uk / jwebster4@sheffield.ac.uk** or
- by ringing us on 0114 222 6650

Ensuring Your Wellbeing

The researcher does not anticipate the risk of emotional or psychological harm on participants, however in the event of feeling distressed following the interview process, the following helplines are free to call, and can support you with keeping well:

Samaritans – call 116 123 – Available 24/7
Shout- text 85258

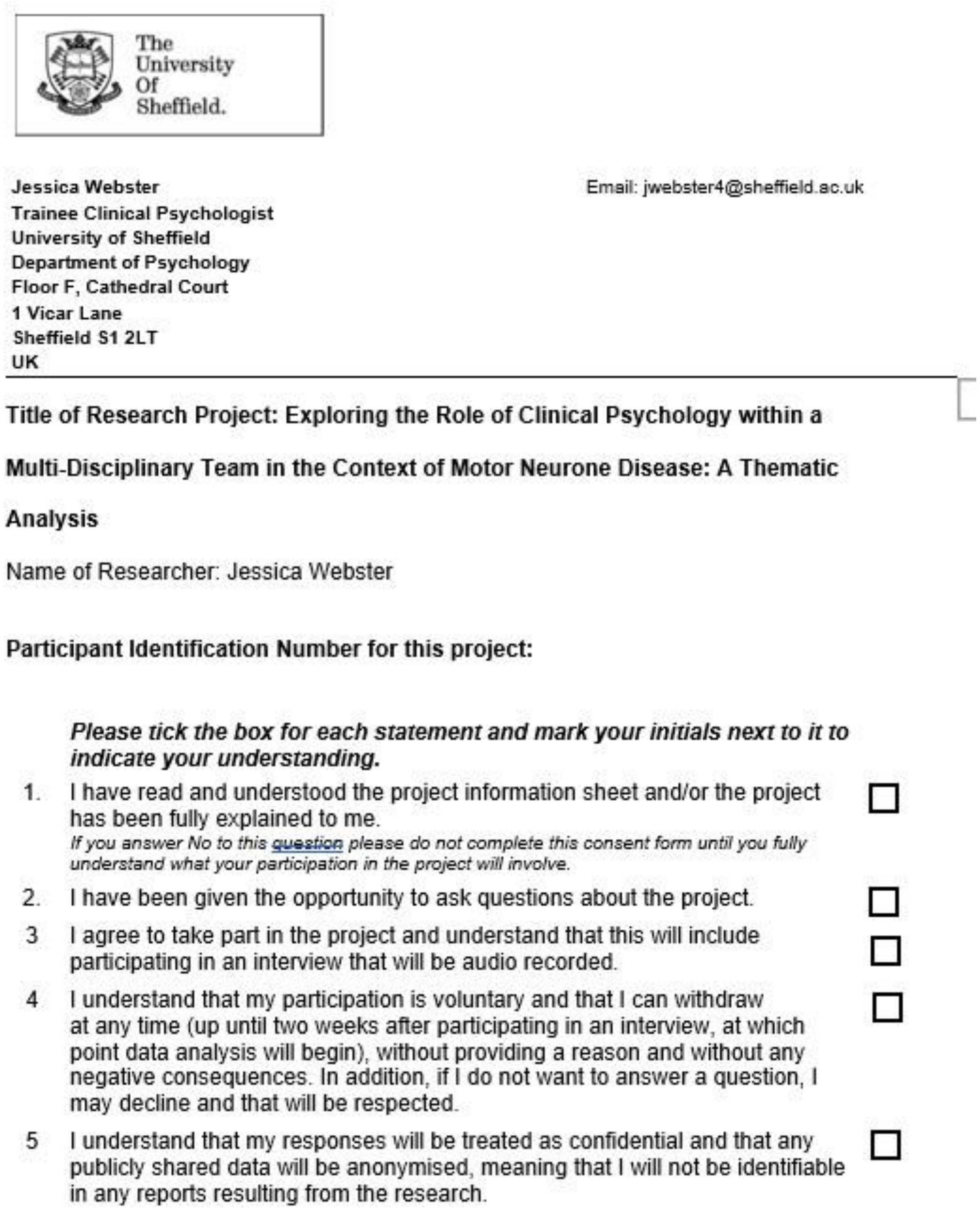


There should also be a point of contact within your specific trust/network to talk to somebody confidentially about your wellbeing – this is usually called 'Workplace Wellbeing'. For details around this, please ask your line manager.

Additionally, you are able to self-refer to NHS Talking Therapies (IAPT), through your GP. More information on how to do this can be found here: https://www.nhs.uk/service-search/mental-health/find-a-psychological-therapies-service/

Appendix G

Consent Form



The University Of Sheffield.

Jessica Webster
Trainee Clinical Psychologist
University of Sheffield
Department of Psychology
Floor F, Cathedral Court
1 Vicar Lane
Sheffield S1 2LT
UK

Email: jwebster4@sheffield.ac.uk

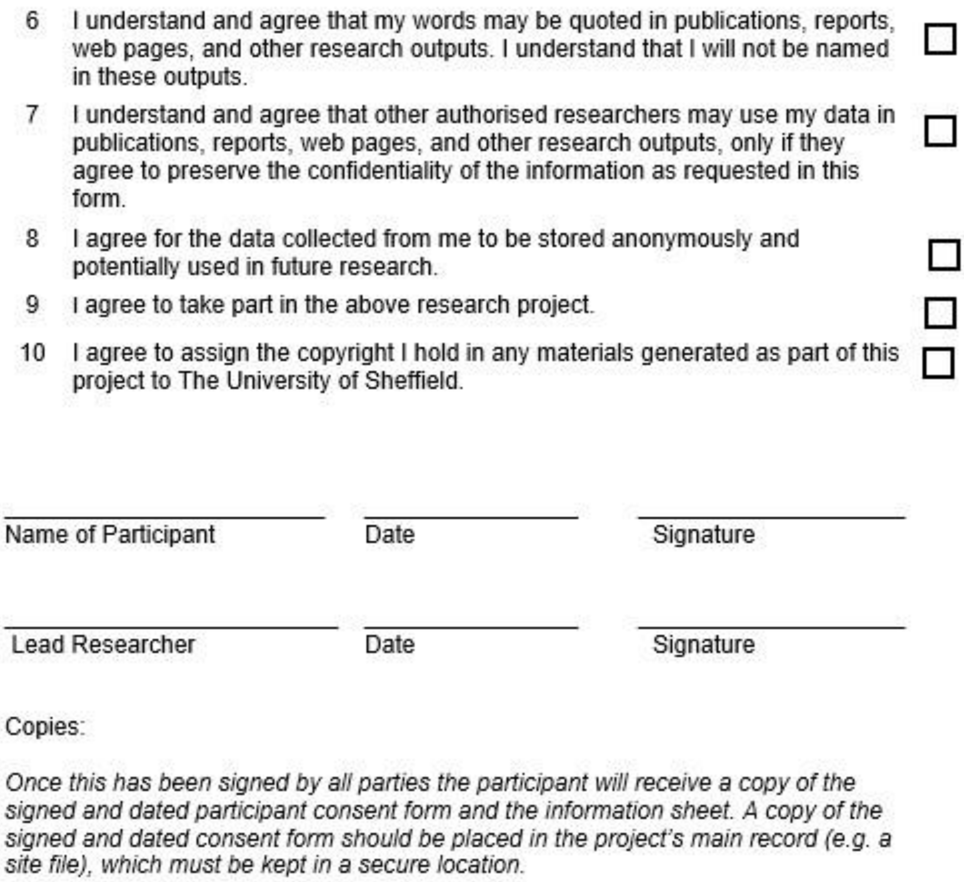
Title of Research Project: Exploring the Role of Clinical Psychology within a Multi-Disciplinary Team in the Context of Motor Neurone Disease: A Thematic Analysis

Name of Researcher: Jessica Webster

Participant Identification Number for this project:

Please tick the box for each statement and mark your initials next to it to indicate your understanding.

1. I have read and understood the project information sheet and/or the project has been fully explained to me. ☐
   If you answer No to this question please do not complete this consent form until you fully understand what your participation in the project will involve.
2. I have been given the opportunity to ask questions about the project. ☐
3. I agree to take part in the project and understand that this will include participating in an interview that will be audio recorded. ☐
4. I understand that my participation is voluntary and that I can withdraw at any time (up until two weeks after participating in an interview, at which point data analysis will begin), without providing a reason and without any negative consequences. In addition, if I do not want to answer a question, I may decline and that will be respected. ☐
5. I understand that my responses will be treated as confidential and that any publicly shared data will be anonymised, meaning that I will not be identifiable in any reports resulting from the research. ☐



6 I understand and agree that my words may be quoted in publications, reports, web pages, and other research outputs. I understand that I will not be named in these outputs. ☐

7 I understand and agree that other authorised researchers may use my data in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form. ☐

8 I agree for the data collected from me to be stored anonymously and potentially used in future research. ☐

9 I agree to take part in the above research project. ☐

10 I agree to assign the copyright I hold in any materials generated as part of this project to The University of Sheffield. ☐

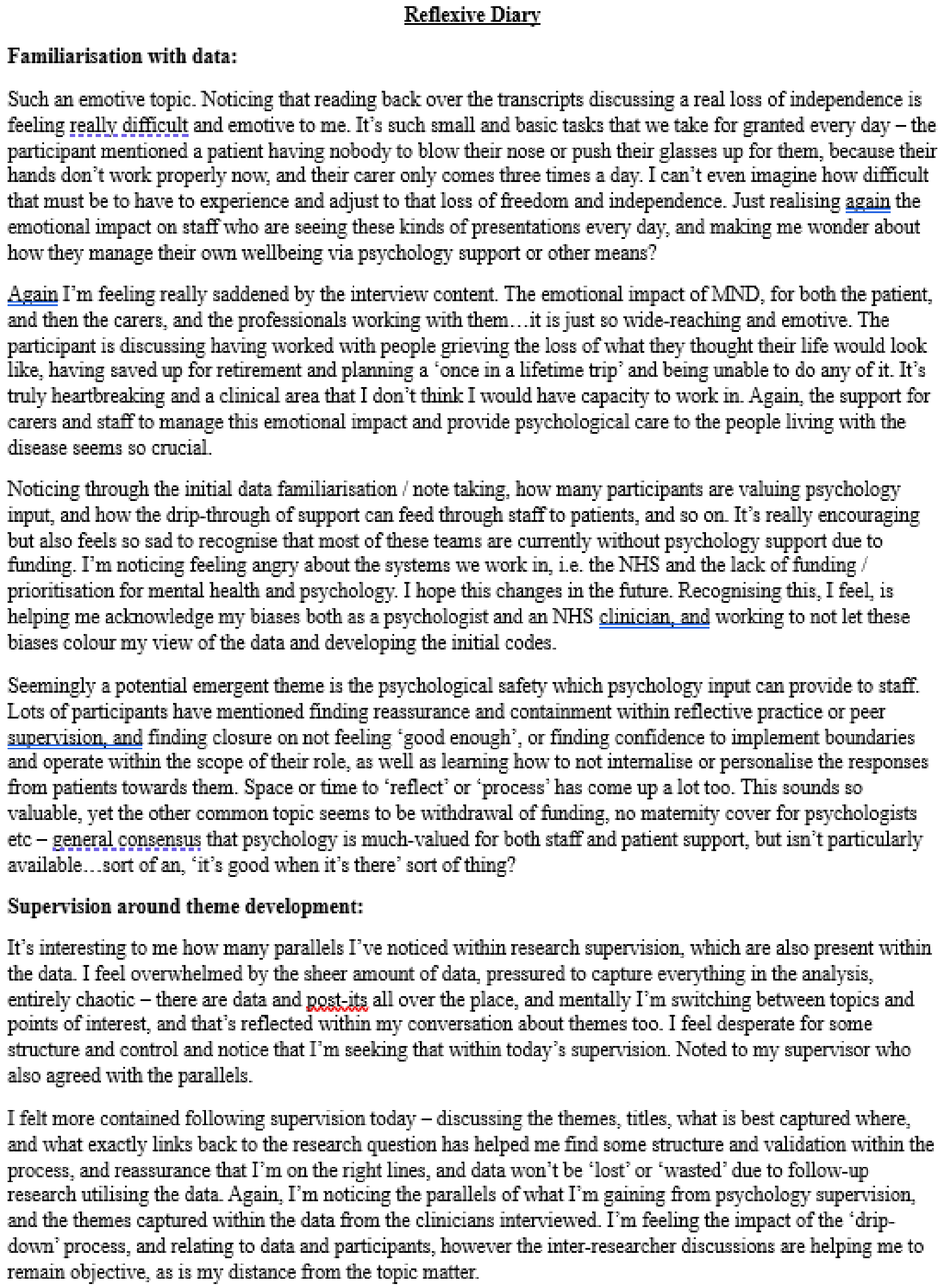
Name of Participant	Date	Signature
Lead Researcher	Date	Signature

Copies:

Once this has been signed by all parties the participant will receive a copy of the signed and dated participant consent form and the information sheet. A copy of the signed and dated consent form should be placed in the project's main record (e.g. a site file), which must be kept in a secure location.

Appendix H

Reflexivity Log Excerpt



Reflexive Diary

Familiarisation with data:

Such an emotive topic. Noticing that reading back over the transcripts discussing a real loss of independence is feeling really difficult and emotive to me. It's such small and basic tasks that we take for granted every day – the participant mentioned a patient having nobody to blow their nose or push their glasses up for them, because their hands don't work properly now, and their carer only comes three times a day. I can't even imagine how difficult that must be to have to experience and adjust to that loss of freedom and independence. Just realising again the emotional impact on staff who are seeing these kinds of presentations every day, and making me wonder about how they manage their own wellbeing via psychology support or other means?

Again I'm feeling really saddened by the interview content. The emotional impact of MND, for both the patient, and then the carers, and the professionals working with them…it is just so wide-reaching and emotive. The participant is discussing having worked with people grieving the loss of what they thought their life would look like, having saved up for retirement and planning a 'once in a lifetime trip' and being unable to do any of it. It's truly heartbreaking and a clinical area that I don't think I would have capacity to work in. Again, the support for carers and staff to manage this emotional impact and provide psychological care to the people living with the disease seems so crucial.

Noticing through the initial data familiarisation / note taking, how many participants are valuing psychology input, and how the drip-through of support can feed through staff to patients, and so on. It's really encouraging but also feels so sad to recognise that most of these teams are currently without psychology support due to funding. I'm noticing feeling angry about the systems we work in, i.e. the NHS and the lack of funding / prioritisation for mental health and psychology. I hope this changes in the future. Recognising this, I feel, is helping me acknowledge my biases both as a psychologist and an NHS clinician, and working to not let these biases colour my view of the data and developing the initial codes.

Seemingly a potential emergent theme is the psychological safety which psychology input can provide to staff. Lots of participants have mentioned finding reassurance and containment within reflective practice or peer supervision, and finding closure on not feeling 'good enough', or finding confidence to implement boundaries and operate within the scope of their role, as well as learning how to not internalise or personalise the responses from patients towards them. Space or time to 'reflect' or 'process' has come up a lot too. This sounds so valuable, yet the other common topic seems to be withdrawal of funding, no maternity cover for psychologists etc – general consensus that psychology is much-valued for both staff and patient support, but isn't particularly available…sort of an, 'it's good when it's there' sort of thing?

Supervision around theme development:

It's interesting to me how many parallels I've noticed within research supervision, which are also present within the data. I feel overwhelmed by the sheer amount of data, pressured to capture everything in the analysis, entirely chaotic – there are data and post-its all over the place, and mentally I'm switching between topics and points of interest, and that's reflected within my conversation about themes too. I feel desperate for some structure and control and notice that I'm seeking that within today's supervision. Noted to my supervisor who also agreed with the parallels.

I felt more contained following supervision today – discussing the themes, titles, what is best captured where, and what exactly links back to the research question has helped me find some structure and validation within the process, and reassurance that I'm on the right lines, and data won't be 'lost' or 'wasted' due to follow-up research utilising the data. Again, I'm noticing the parallels of what I'm gaining from psychology supervision, and the themes captured within the data from the clinicians interviewed. I'm feeling the impact of the 'drip-down' process, and relating to data and participants, however the inter-researcher discussions are helping me to remain objective, as is my distance from the topic matter.

Appendix I

Reflexive Statement

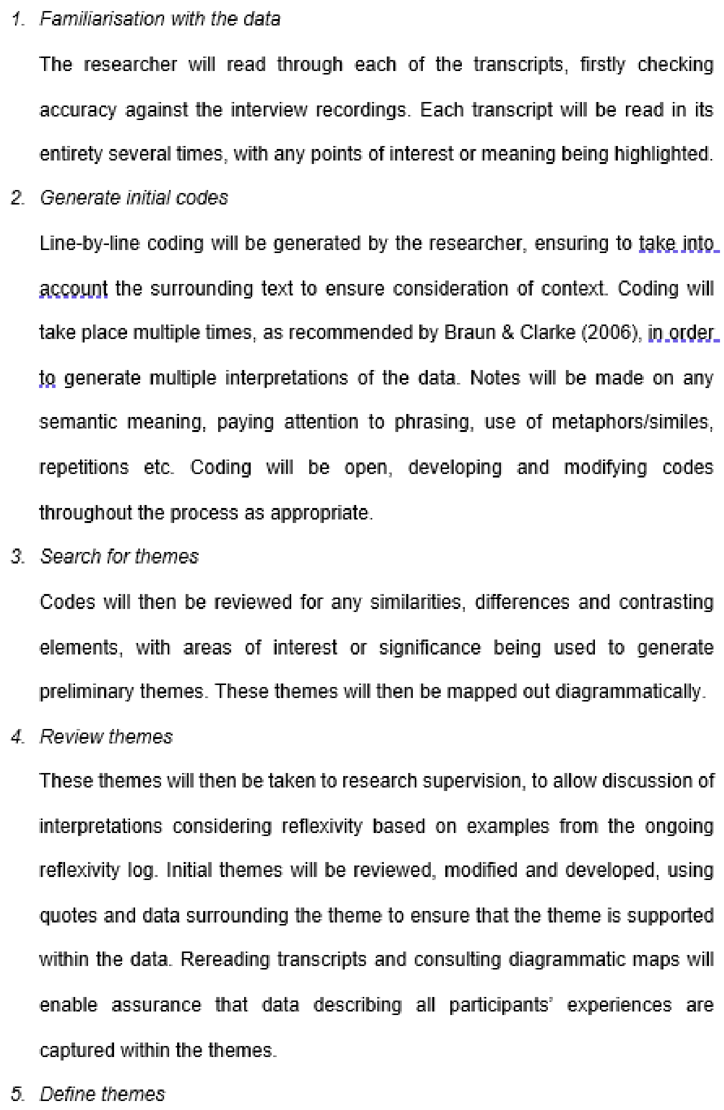
I, the researcher, am a white, a woman, and a trainee clinical psychologist. I have no professional background working within the field of MND, or any personal or professional experience in interacting with plwMND.

Within my clinical practice, I work with many different modalities, however, I align particularly with narrative and systemic elements. I selected a qualitative project, and in particular reflexive TA, as this felt well-aligned with my belief that analysis and subsequent themes should be data-driven, alongside TA lending itself to forming both social and psychological interpretations of data, making it particularly useful within the field of healthcare.

Furthermore, I have some prior experience of conducting interviews and utilising TA within my previous research as part of a requirement for a Bachelor of Science undergraduate degree.

Appendix J

Braun & Clarke's (2006) Six Steps of Thematic Analysis



1. *Familiarisation with the data*

   The researcher will read through each of the transcripts, firstly checking accuracy against the interview recordings. Each transcript will be read in its entirety several times, with any points of interest or meaning being highlighted.

2. *Generate initial codes*

   Line-by-line coding will be generated by the researcher, ensuring to take into account the surrounding text to ensure consideration of context. Coding will take place multiple times, as recommended by Braun & Clarke (2006), in order to generate multiple interpretations of the data. Notes will be made on any semantic meaning, paying attention to phrasing, use of metaphors/similes, repetitions etc. Coding will be open, developing and modifying codes throughout the process as appropriate.

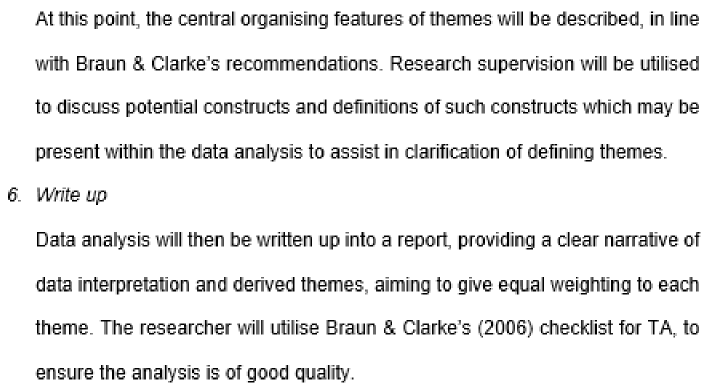
3. *Search for themes*

   Codes will then be reviewed for any similarities, differences and contrasting elements, with areas of interest or significance being used to generate preliminary themes. These themes will then be mapped out diagrammatically.

4. *Review themes*

   These themes will then be taken to research supervision, to allow discussion of interpretations considering reflexivity based on examples from the ongoing reflexivity log. Initial themes will be reviewed, modified and developed, using quotes and data surrounding the theme to ensure that the theme is supported within the data. Rereading transcripts and consulting diagrammatic maps will enable assurance that data describing all participants' experiences are captured within the themes.

5. *Define themes*



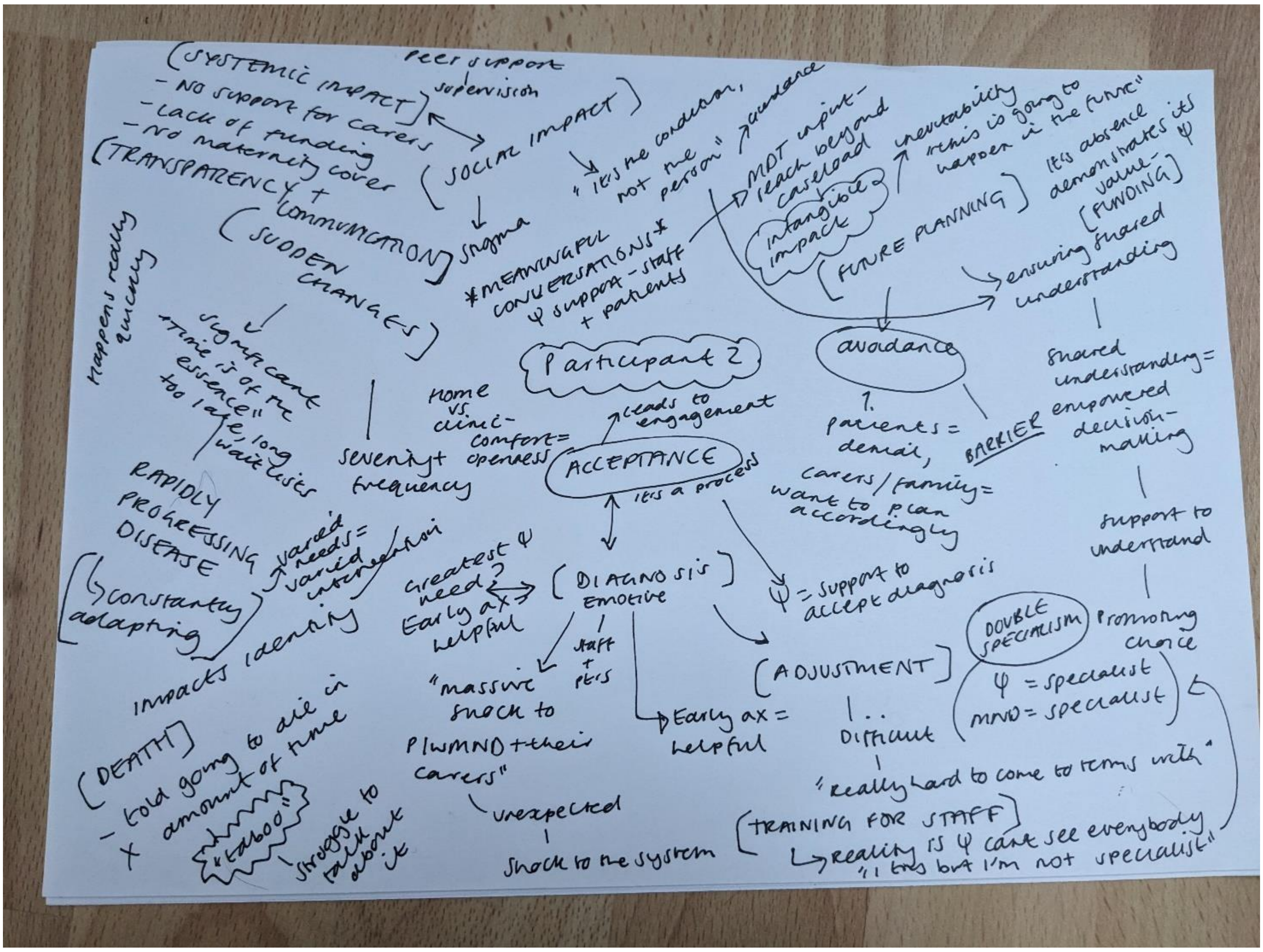
   At this point, the central organising features of themes will be described, in line with Braun & Clarke's recommendations. Research supervision will be utilised to discuss potential constructs and definitions of such constructs which may be present within the data analysis to assist in clarification of defining themes.

6. *Write up*

   Data analysis will then be written up into a report, providing a clear narrative of data interpretation and derived themes, aiming to give equal weighting to each theme. The researcher will utilise Braun & Clarke's (2006) checklist for TA, to ensure the analysis is of good quality.

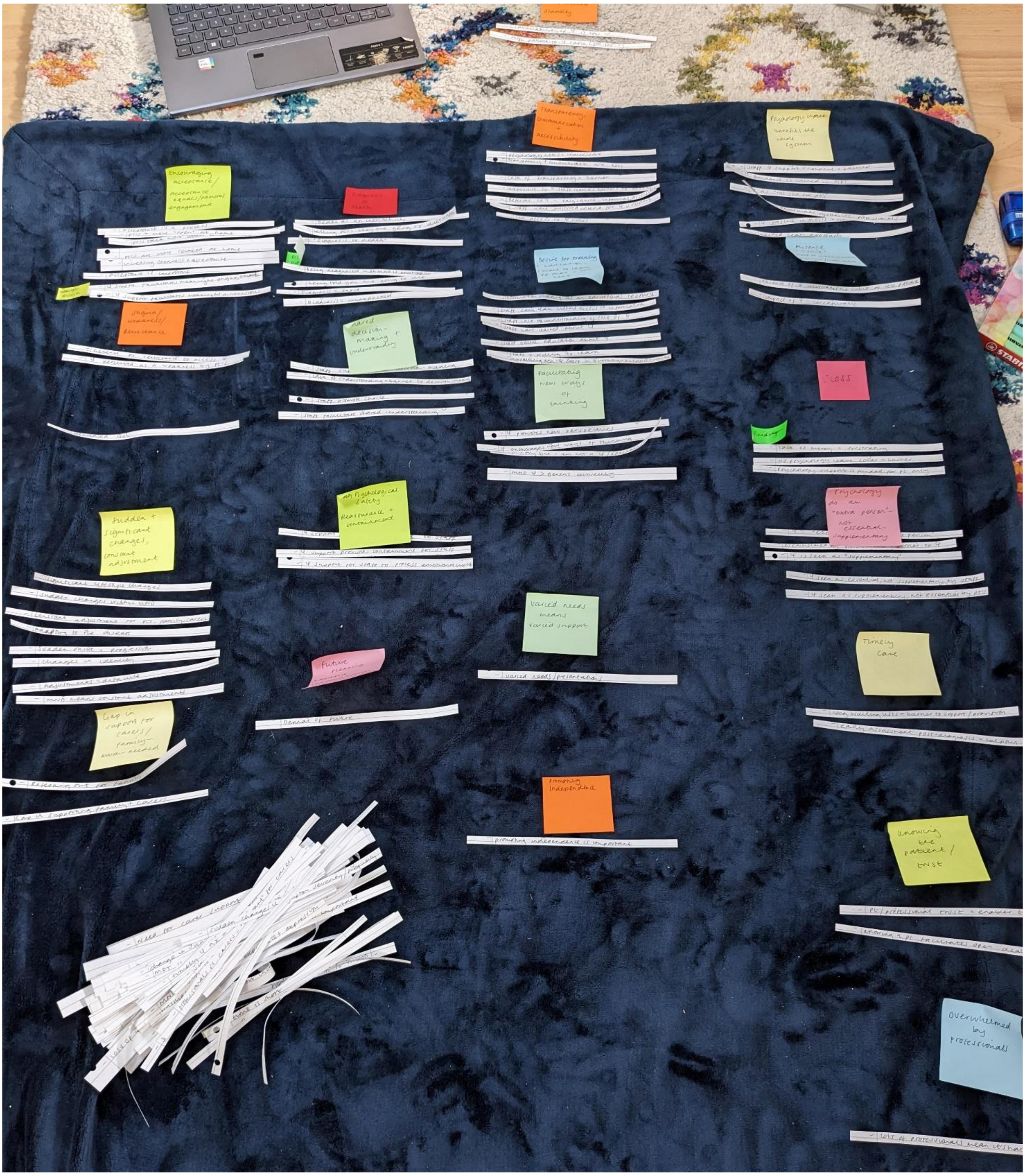
Appendix K

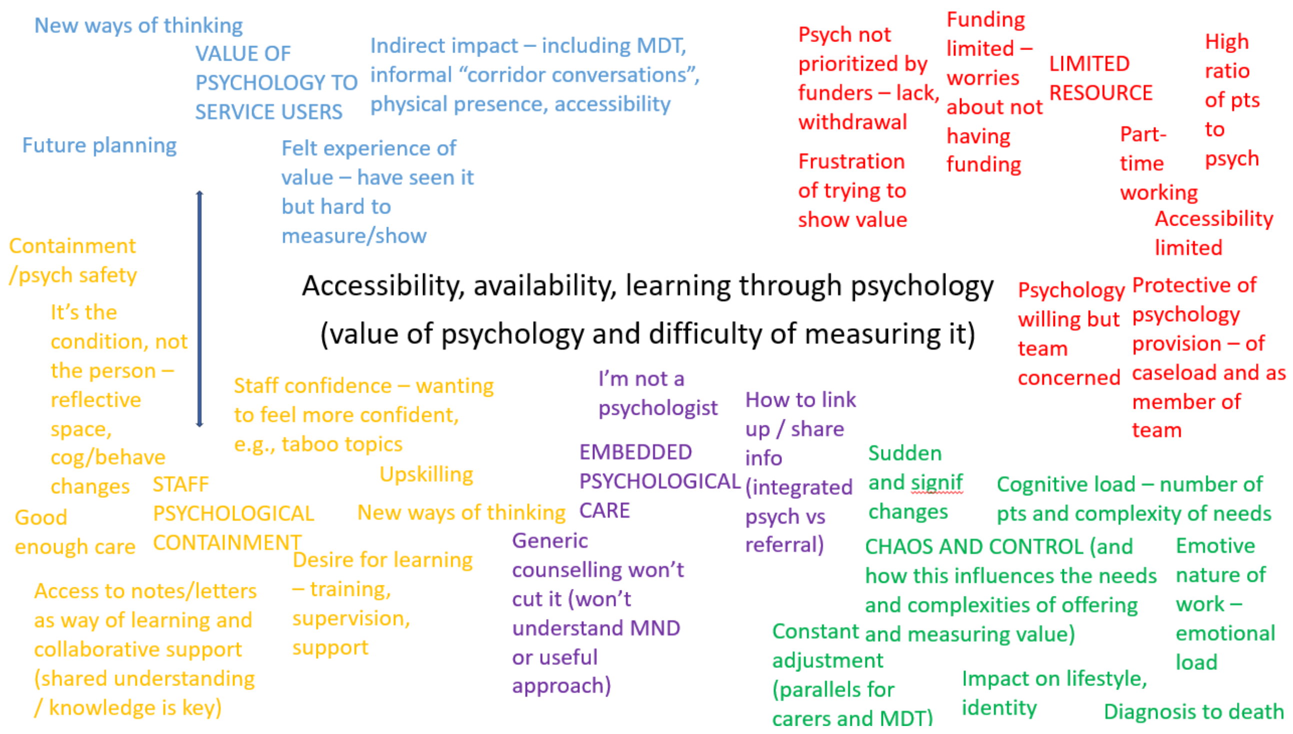
Example of Familiarisation Notes

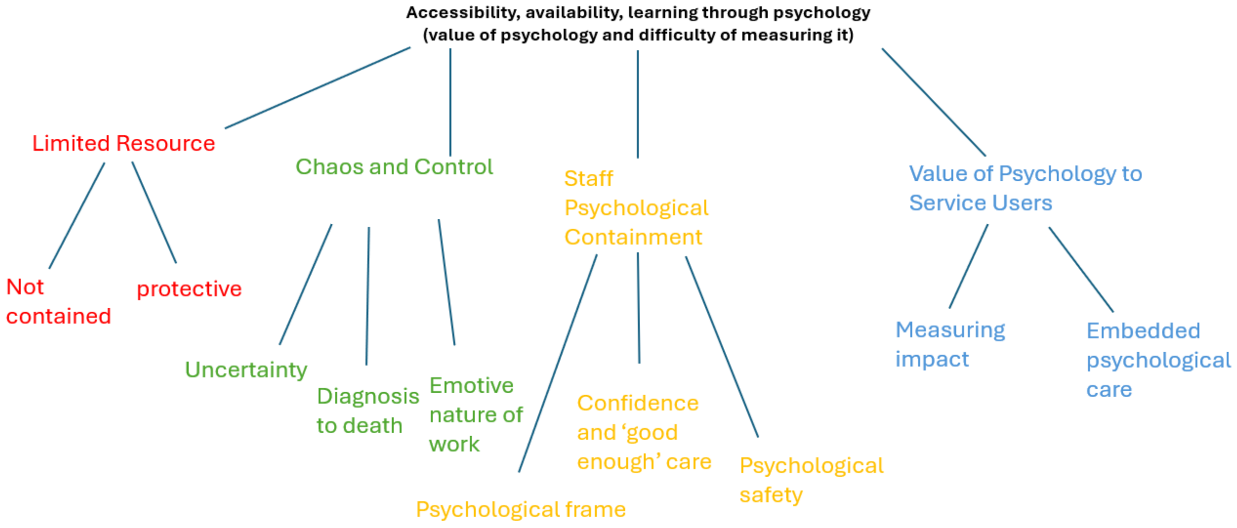


Appendix L

Example of Theme Development

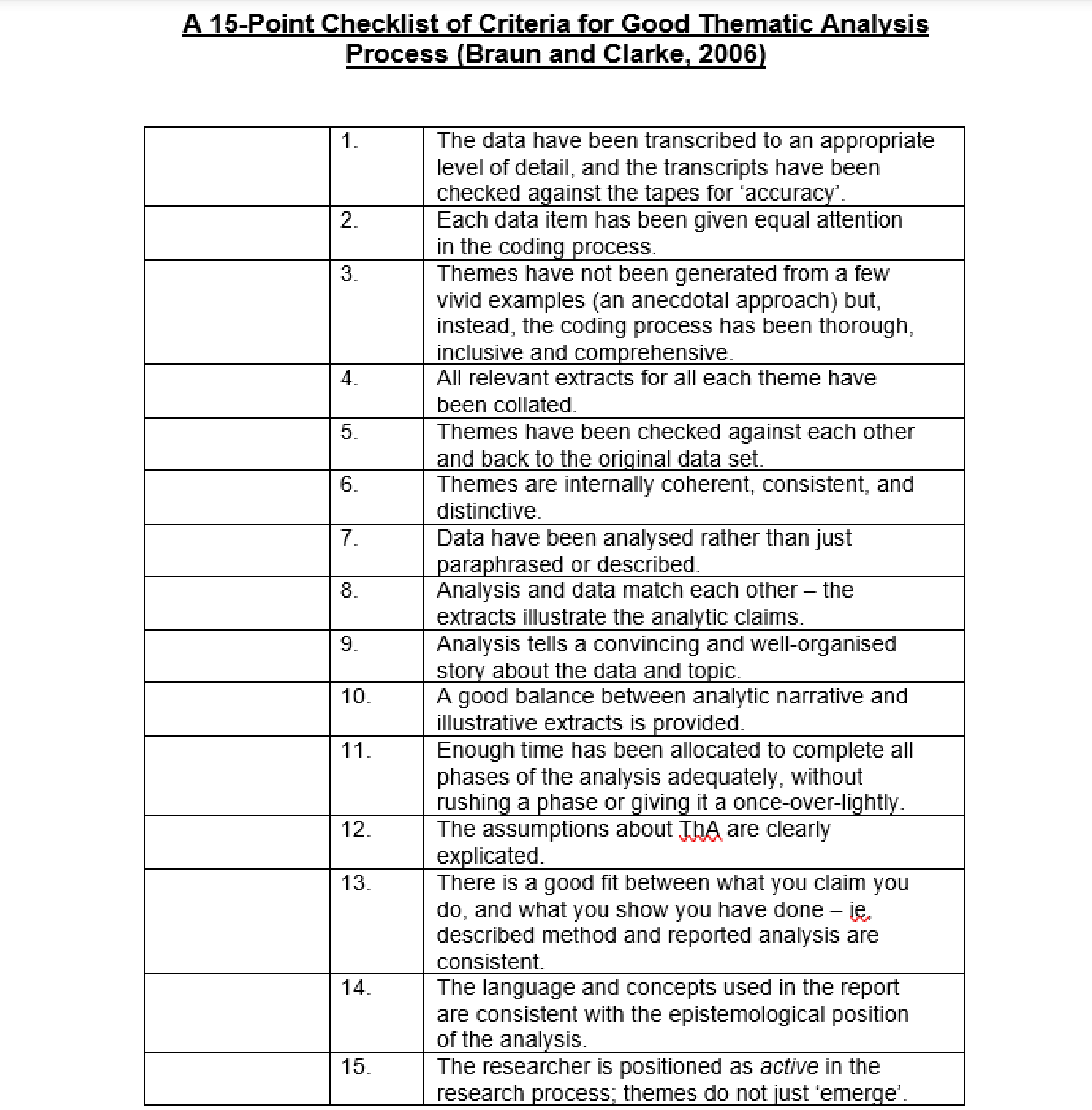



Accessibility, availability, learning through psychology
(value of psychology and difficulty of measuring it)
New ways of thinking
VALUE OF PSYCHOLOGY TO SERVICE USERS
Indirect impact – including MDT, informal "corridor conversations", physical presence, accessibility
Future planning
Felt experience of value – have seen it but hard to measure/show
Psych not prioritized by funders – lack, withdrawal
Funding limited – worries about not having funding
LIMITED RESOURCE
High ratio of pts to psych
Part-time working
Frustration of trying to show value
Accessibility limited
Psychology willing but team concerned
Protective of psychology provision – of caseload and as member of team
Containment /psych safety
It's the condition, not the person – reflective space, cog/behave changes
STAFF PSYCHOLOGICAL CONTAINMENT
Good enough care
Staff confidence – wanting to feel more confident, e.g., taboo topics
Upskilling
New ways of thinking
Desire for learning – training, supervision, support
Access to notes/letters as way of learning and collaborative support (shared understanding / knowledge is key)
I'm not a psychologist
EMBEDDED PSYCHOLOGICAL CARE
How to link up / share info (integrated psych vs referral)
Generic counselling won't cut it (won't understand MND or useful approach)
Sudden and signif changes
Cognitive load – number of pts and complexity of needs
CHAOS AND CONTROL (and how this influences the needs and complexities of offering and measuring value)
Emotive nature of work – emotional load
Constant adjustment (parallels for carers and MDT)
Impact on lifestyle, identity
Diagnosis to death


Accessibility, availability, learning through psychology
(value of psychology and difficulty of measuring it)
Limited Resource
Not contained
protective
Chaos and Control
Uncertainty
Diagnosis to death
Emotive nature of work
Staff Psychological Containment
Psychological frame
Confidence and 'good enough' care
Psychological safety
Value of Psychology to Service Users
Measuring impact
Embedded psychological care

Appendix M

Braun and Clarke's (2006) Checklist for Good Thematic Analysis



A 15-Point Checklist of Criteria for Good Thematic Analysis Process (Braun and Clarke, 2006)

	1.	The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for 'accuracy'.
	2.	Each data item has been given equal attention in the coding process.
	3.	Themes have not been generated from a few vivid examples (an anecdotal approach) but, instead, the coding process has been thorough, inclusive and comprehensive.
	4.	All relevant extracts for all each theme have been collated.
	5.	Themes have been checked against each other and back to the original data set.
	6.	Themes are internally coherent, consistent, and distinctive.
	7.	Data have been analysed rather than just paraphrased or described.
	8.	Analysis and data match each other – the extracts illustrate the analytic claims.
	9.	Analysis tells a convincing and well-organised story about the data and topic.
	10.	A good balance between analytic narrative and illustrative extracts is provided.
	11.	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly.
	12.	The assumptions about ThA are clearly explicated.
	13.	There is a good fit between what you claim you do, and what you show you have done – ie, described method and reported analysis are consistent.
	14.	The language and concepts used in the report are consistent with the epistemological position of the analysis.
	15.	The researcher is positioned as *active* in the research process; themes do not just 'emerge'.

Appendix N

Additional Participant Quotations

Theme	Subtheme	Supporting Quotes
Limited Resource	Not contained	“I think that is you know a symptom of how poorly funded and staffed the NHS is…a lot of it is to do with funding, it’s just having the money to increase the hours” (P1) “I know lots of MND patients don’t get any [psychology input], erm I think in [location] they get something like two hours a week, which covers the whole of [district] or something ridiculous” (P1) “If money wasn’t an issue, availability of psychologists wasn’t an issue, the best gold standard would be having a psychologist see someone whenever we felt that was needed…I accept this is the real world and it won’t happen anytime in the near future because the money’s not there, and the psychologists aren’t there either” (P2) “We’ve done joint appointments that have been really, really useful where we were having challenges and you can discuss them at the same time, I found that really, really valuable, again we don’t do that enough and they don’t have the resources to either” (P2) “The main barrier is the lack of psychologists. Absolutely we need more psychologists, it’s quite a basic equation you know, we just need more of them. The main barrier is…they’re just not there.” (P2) “They might see someone for fifteen minutes per patient, half an hour for diagnosis…they are quite pushed to provide the psychological care that people need” (P3)

	“it’s really good when we’ve had it, so we’ve had it taken away you know, through reasons that aren’t anyone’s fault’ (P3) “If we can’t have a psychologist at every centre, we could at least have some way that patients from other centres could access the sort of support we can…leadership, role-modelling et cetera…there may be difficult patients needing very high level psychology support for which isn’t necessarily provided locally. It's difficult because of commissioning and funding, you know, getting very specialist services is really challenging” (P3) “There are quite a lot of gaps, we used to have a clinical psychologist who unfortunately left because the health boards no longer funded it. Psychology in [country] isn’t great, there’s massive waiting lists…support in general is an issue…when the psychologist left, we just couldn’t match the support we’d been getting and giving” (P4) “As a network, we’ve lost psychology. We do what we can but the resources are very, very limited, it’s a massive area we feel we’ve lost and we should be doing more, but we aren’t able to” (P4) “I think the fact that people have to come into hospital when it’s a bit geographical area…they might have a two hour drive to get in, it’s a massive barrier for a lot of people” (P6)
	“we need the contract to be permanent, we could genuinely fill another two days…but we haven’t the money, and that’s very frustrating” (P8) “our psychologist is on maternity leave and there’s no cover for her” (P1)

	“if you don’t think MND is gonna have a psychological impact on somebody and they need specialist support for that I just don’t get it, I really don’t get it. You know I would say psychology should come above, you know, you shouldn’t have a pecking order but it should come above a lot of the core MDT that we already get, that you get in every single MND centre, but you don’t get psychologists and I just don’t, I don’t get that.” (P2) “it depends on who the patient sees in the hospital MDT – it really depends where people are, others just don’t get psychology because of their locations, what’s available to them” (P3) “we have tried to budget in our network but at the moment we are struggling to get the funding to continue, we are struggling to fund the network without the clinical psychologist, let alone with one, we just can’t get any continuation of funding for a clinical psychologist” (P4) “It was a massive loss, it speaks for itself that patients were outraged when she left, there was no one to follow them up so they sort of felt left I suppose” (P4) “we need to be more proactively trying to put business cases in and fight, keep fighting for the…benefits of psychology. However much they see the need, they don’t prioritise, they are literally not able to spend the money” (P8)

	Protective	“our psychologists work one day a week ‘cause that’s all they’re funded for…they will come and see you but it might not be this week, it might be next week or the week after, you know so people are getting the care but there’s a delay” (P1) “one day a week isn’t a lot for the amount of patients we’ve got” (P1) “if I could read the psychology letters I might have learnt about that maybe six months earlier. It comes down to confidentiality but obviously it is a barrier” (P1) “the more they’re around the more the team learn about what they can do…they say, ‘that’s where I can step in and help’” (P1) “she was just one person, she could only do so much and on the days when she was working so the gaps are availability. You should be able to follow up on assessments you’re doing, and I don’t know that’s the case…it feels pointless to have a single appointment knowing that most interventions need follow up for them to be effective and you think, well if that’s not happening, what’s the point in doing it in the first place?” (P2) “staff making every conversation count and not just relying on the psychologist” (P2)

	“everyone’s aware they are a limited resource, even though we’d love to send everybody I guess we sometimes rely on there being a problem, if you dig deeper I imagine you’d find chinks in people’s armoury…we talked about all the other areas psychology can have a benefit on, but you’d need an army of psychologists to be able to do that” P2 “It’s difficult to know who to refer because you can’t refer everyone every week, you’ll have an allotted amount of time you know that a psychologist has, and if we bombarded them with every single person at every point then they would be overwhelmed, so there has to be an element of prioritisation” (P3) ““Timely referrals, waiting lists…you know, we were starting to write down patients that we felt would require psychological input and it was a lot, it was a vast number for various different reasons, but it’s not there” (P4) “We have around 300 patients, we do our best to support them but I don’t think we’re fully able to meet the needs of them. We have our psychologist for three days which is great, yet it’s still part time” (P5) “Our psychologist is incredibly open to referrals, there are no barriers there…I suppose I’m conscious of not wanting to completely overwhelm and swamp her” (P5) “I mean, the service provision prevents the psychologist being able to support people for a prolonged period of time, which is what they need…it’s difficult to refer to psychology to be able to explain what support they might be able to get when actually that might be more limited than probably what it should be” (P6) “the MND nurses have been looking at doing some joint-working with the psychologist but it hasn’t been possible due to the staffing at the moment” (P6)

		“There’s just not enough capacity, it’s really tricky because like funding…it’s not like we have a full-time psychologist…the majority of conversations I have are surrounding the psychologist not having capacity” (P7) “there’s not really time devoted to maybe fully explain what [psychology] might involve and what the benefits might be for them” (P7) “she [psychologist] promotes a very open dialogue…would prefer to discuss somebody potentially inappropriate for referral to avoid missing anyone” (P7) “We have a psychologist for three days, really we need one for five. It’s a massive unmet need, I mean cavernous, the more we offer the more people would clearly want and accept…” (P8) “the obvious gap mis she’s three days a week. There’s two things we need - we need it to be a permanent contract and we could genuinely fill another two days” (P8)
Chaos and Control	Uncertainty	“fast progressing disease, their condition either changes quickly or is likely to change quickly in the future, we need to get that timing right, it informs how proactive we are in discussions” (P2) ‘how someone’s adapting psychologically to the disease…is relevant to all of us and our conversations” (P2) “there’s a lot of patients presenting quite late and needing a lot done very rapidly, there’s uncertainty, people don’t know how long they’re going to live for” (P3) “Often it can be chaotic, we don’t have a structured referral. I’ve also referred patients before with distressing symptoms, but often by the time they get seen it’s a often a bit late for that” (P3)

	“people struggle with MND diagnosis because you can’t say…with MND, nobody really knows timelines, how quick or slow that progression will be…we can’t promise anything, it all feels very fragile, very chaotic because you can’t pin anything down, and so people feel like they’re out of control with this condition, and that’s one of the main psychological things. You don’t feel in control, then you might feel in control for a bit and then the goal posts change, and chaos ensues” (P4) “Appointments are kind of every three months and three months is a long time for things to happen and change” (P5) “The uncertainty I think is so huge” (P5) “Things are changing quite rapidly and you’re only seeing them every, well I’m seeing them every two months, if things are changing in that time it’s quite important…” (P6) “Lack of control, anxiety…the surrounded by uncertainty” (P7) “their emotions don’t always match what they’re feeling, so they can be sad but laugh, they can be happy but cry” (P1) “you know in the future he might behave sort of X, Y, Z…that’s helped me prepare mentally for how he might be the next six, twelve months…” (P1) “it does affect you mentally, so I find speaking to [the psychologist], there’s a lot of value in that for me” (P1) “I review the literature around presenting choice, making sure people are aware, presenting information, weighing up pros and cons, following processes…” (P2)

		“you’re dealing with crisis management, thinking about advanced care planning, guidelines, there’s a lot…and there’s a lot going on in your head, in and outside of the consultation room that patients might not necessarily appreciate” (P3) “There’s a lot of thinking around when people are first diagnosed and adjustment of how that changes their whole life, their outlook, plans, the future they thought they had, trying to get their head around that, I mean gosh there is so much adjustment for somebody and we support with all of that” (P5) “having somebody there with you in clinic…I used to go home and want to lie in a darkened room, but now having somebody there with you…I don’t feel quite so head-spinning as I leave. You’ve shared, you’ve worked together and it’s a different feeling, it feels good” (P8)
	Diagnosis to death	“there’s lots of psychological support around diagnosis…work around acceptance, fears for the future, anxiety” (P1) “depending on their symptoms at diagnosis they may not have much time at all, it’s unexpected, it’s a massive shock to people. Being told you’ve got this life-limiting, fatal diagnosis, it’s hard for people to come to terms with. They’re told they’re gonna die, within two, three years, and that impacts you” (P2) “…after diagnosis, that’s obviously a really key part of when people need [psychology] support…the greatest need is often around diagnosis” (P2) “We provide a diagnosis to death service, we get to know people really well” (P3)

	“self-care in MND is actually not that high a priority for patients…it’s not like asthma or diabetes where you can expect the patient to take some control, manage it, live with it…they become increasingly dependent so you know certainly they need support to manage psychologically” (P3) “We get into discussions around assisted suicide…acceptance of the diagnosis is massive. It’s a scary, scary condition, and I think that’s why a lot of this assisted suicide comes up, because they want to feel in control” (P4) “I think it’s a normal adjustment to being diagnosed with MND to feeling overwhelmed and like they’re not coping and everything ids chaotic in their brain and they’re thinking of all the different ways they’re going to die, and that general chaotic feeling of they can’t do anything to control what’s happening to them” (P4) “We see people from diagnosis right up until kind of end-of-life care, so the full range of what that brings within MND” (P5) “There’s a risk of taking their own life after diagnosis and the psychologist gives insight into the level of risk and whether there is a support system in place” (P5) “Diagnosis appointments can be pretty heavy for the clinician…I suppose the psychologist just being present when that information’s being given and that sudden kind of emotional reaction from individuals which can be varied, it’s been a real help from a professional’s point of view” (P5) “Obviously the diagnosis is a difficult thing to accept, trying to deal with that is really difficult, especially when they might have been fighting, like they might already be quite advanced in their disease…accepting their diagnosis is

		really important…if you can have someone help support them accepting their diagnosis, I think that can go a long way” (P6) “death, I think that could be a conversation that feels less taboo within the MDT and that clearly trickles down to patients if that feels challenging as a team, we should be a team where that’s flowing off the tongue…the sticky taboo topic of when and how you’re gonna die” (P7) “It’s giving people that control back, a sense of control…helping them make decisions…alongside supporting them with their diagnosis and getting their heads around it which is obviously really difficult” (P6) “Having a diagnosis is really quite overwhelming for them” (P8)
	Emotive nature of work	“it’s quite an emotive topic [MND] that we provide a lot of support with” (P1) “it’s a really emotive job, all the patients we see you know, unfortunately die, some within quite a short time frame, two years…that’s, you know, it’s hard when you meet a patient and you know they’re gonna die” (P1) “I think psychologists have a huge role in supporting healthcare professionals working in a pretty difficult clinical area to be honest” (P2) “they’re frightened about how they’re gonna manage, which is a real, it’s a real fear that we empathise with” (P1) “A lot of people working with MND patients find it so upsetting” (P3)

“We services really struggle with frontal temporal dementia because they can be quite inappropriate in their behaviour and so we find that really, really challenging” (P4)

“We often have a number of phone calls with a number of people crying down the phone, screaming down the phone in aner that things aren’t being done quick enough, and expectations are really high of us” (P4)

“to be able to share that kind of intensity, because you see kind of four people, one after the other after that huge emotional reaction, that huge kind of life-changing news so you’re trying to support them in that moment but you know it’s like okay, 45 minutes of that and then let’s do it again, and again, and again, and then again…” (P5)

“they are actually a really difficult group of patients to look after but also emotionally they deteriorate really quickly, knowing you’ve got that outlet to say ‘actually, this is really hard…having that discussion around the patient and whether they are still alive or whether it’s that they’ve passed away and it was someone you knew really well…having that support in the team is really valuable” (P6)

“I think as clinicians we forget about our own psychological needs when working with individuals whom we might form close rapport with and then pass away, and the impact on us of working with people with life-limiting conditions” (P7)

Staff Psychological Containment	Psychological frame	“I feel that’s the one thing missing in our education, is a bit about psychology and in a job like this I think it’s really important” (P1) “I’ve learnt more over the years about what psychology could offer, and I guess my lack of understanding of the role…the more time I’ve spent with the psychologist, they go ‘oh I’m going to do ECAS or you know, graded exposure, and that’s certainly educated me” (P1) “I should be getting training, there should be formal training for me, and I’ve never been made aware or offered it. I’m not sure about the rest of the MDT and how much formal training they would have in meeting people’s emotional and psychological needs or whether they just think because we have experience in working in MND it means we’re gonna be good at this” (P2) “Having a psychologist give training to the MDT so they know how they can integrate this into whatever there sphere is, from a clinical point of view, I personally would value being able to do that in a considered way, so education at the MDT would be crucial” (P2) “the other thing from a professional point of view would be training, MND teams in my experience don’t change much over the years, lots of people stay around…it should be expected that they complete some form of training around the psychological management of people with MND and how they can contribute outside of what the psychologist does” (P2) “the psychologist may only see that patient once, whereas if I’ve got the tools and skills to deliver psychological care at a basic level then that’s very helpful” (P3)

	"I don't know whether the psychologist does this, but we have our core hospital MDT and the nurse goes to different area ones, the physio does, so they'll talk about their patients and they would be quite helpful in disseminating knowledge, skills, concepts, thinking processors…supporting people outside of our core MDT is probably gonna be really useful and dispersing to people who have less skills and opportunities to talk to a psychologist" (P3) "Staff often don't want to say the wrong thing…the other night, one of the nurses said, 'the patient asked me in the night if they are going to die, and I didn't know what to say'. The nurses all admitted they have never really been trained in how to talk to people about difficult issues, which is bizarre, it's quite distressing for them. So another way psychology could support…" (P3) "we attended a presentation held by psychologists…supported with clinic letters and formulation and that kind of conceptualisation, discussion of complex cases, supervision" (P7) "I've seen [psychology] help with changing people's views on things and how they are psychologically changes" (P2) "the psychologist guiding some of the MDT discussions is really valuable because we can get very procedural driven and sometimes forget the psychological impact of interventions or thinking about the future…another opportunity for them to educate the MDT about the psychological impact of MND" (P2) "I think the value is in where it helps bring that level of detail, things we won't have thought about" (P2) "with clinical psychology they're given a reframe, like a new way of seeing the world, I guess a sort of structure, a way of thinking that they can use to show up" (P4)

	“It’s a skill that people, and you know if they’re taught about it and they learn it they can use that in every day, and it’s so powerful and it retrains the brain to think another way and act another way” (P4)
	“…can speak to them and have some different thoughts around how it might be best to approach them [patient]” (P6)
	“she’ll say, ‘have you thought about this, or maybe that’ and we say ‘oh yes, okay’ and it’s kind of giving them the knowledge…we can enhance patients’ experience, it’s phenomenal” (P8)
	“I’ve spent quite a bit of time talking to our Clinical Psychologist about one of my patients who’s been quite challenging and she’s explained to me why he behaves the way he does and I’ve just found that so helpful to understand him” (P1)
	“we don’t have access to the psychology notes so I can see what other disciplines have written but I can’t see any psychology notes, we don’t have access to them…because I can’t read the letters I can’t learn from them” (P1)
	“as I say, it can be a bit frustrating when you know the patient has spoken to someone and, you can’t see the letters, you think oh it would be useful to know what they talked about yesterday, I don’t know what the psychologist said…you’ve just got a bit of a blank” (P1)
	“they have a responsibility to share information wit the MDT, make sure we’re all aware of the assessments that happened, what advice not only that they’re giving to the patient but what advice have they got for the MDT about how to incorporate it? The communication to the MDT effectively is really important” (P2)
	“I think we were educated certainly by the letters, the amount of detail, I found it really valuable as an education to understand and using in my feedback in discussions, so it had an educational effect on me and others as well” (P2)

		“I’m not aware of any formal pathways, e.g. when we should be referring to psychology, that would probably help prompt people if we knew some criteria or screening we could do as a formal MDT process” (P2) “We find that we’re saying – it’s the condition, it’s not them” (P4) “It’s the condition not the person, and education around understanding that is helpful” (P5) “Having the psychologist support was helpful to understand that actually it was probably more like a panic attack…having the communication with the psychologist was really helpful to be able to work together and all be on the same page for the patient, and they are all getting the same message” (P6) “having the psychologist be involved…and understanding, enabling us to deal with situations and see how we can best support, to better understand somebody and their behaviour, situation, and explain it to the family” (P8)
	Confidence and ‘good-enough’ care	“I felt like I wasn’t meeting his expectations all the time and she said that’s who he is and no matter what you’ll do you’ll never actually meet them…that really helped because I was getting quite stressed about, you know, erm feeling like I wasn’t good enough and I wasn’t looking after him well enough as it were…I found having that professional support really helpful (P1) “managing my sense of self-worth, you know you sort of doubt it when someone’s sending you texts saying you’re rubbish and not supporting them…you know, she helped me understand that and see ‘okay, it’s not actually me, it’s, he’s angry because he’s been diagnosed with MND and it’s not aimed at you” (P1)

	“Sometimes it’s the reassurance that you’ve done everything you can do, I think that’s really important and sometimes takes someone a little bit outside of the MDT or that person’s care to say, you know, you’ve offered everything you can offer and they don’t want it, we can’t do any more, or just that the disease is rubbish and you know, there’s no more that can be done, we’ve done everything right” (P3) “A lot of new people working with MND patients find it so upsetting, and actually my belief is that they think they don’t have the skills or the ability to do the job, but often I think they are the ones most suited to do it, they just haven’t had the training or confidence in how to understand or approach the situation, but actually when they had that knowledge and a bit of support they are much more able to do it, less likely to leave, and that again trickles down to patient care” (P3) “You want to help people don’t you, the expectation on us is so high nowadays, we want to be giving more and more, and she helped us create boundaries, she almost gave us permission to have those boundaries in place” (P4) “the clinical psychologist provided us with some training because none of us felt particularly confident to explore that area and the risk of that [suicide]…I felt slightly more confident, obviously it was still difficult but I felt I was able to explore that with her…I had slightly more skills and confidence” (P6) “we have newer members of the team and I know the clinical psychologist has *really* given them support in confidence and…jut understanding the impact” (P8)

	Psychological safety	“psychological wellbeing sessions with us with a focus on how we can process how we’re feeling and support ourselves…I personally really enjoy those sessions, I think they’re really important…I think it’s safe to say a lot of the team certainly benefit as well, it’s not that she’s just supporting the patients, it’s the pastoral support, peer support [the psychologist] gives us as well” (P1) “we would discuss elements if care and how it made us feel and the challenges we face from a psychological point of view, it was really valuable to support and reflect” (P2) “in a way it’s more about me than the patient just to help with my mental wellbeing and emotions” (P1) “reflecting on those sessions we used to have with the psychologist, I certainly found them really, really valuable, it informed my practice, and if that’s not happening everywhere, you know, they are a huge source of support for healthcare professionals working within MND” (P2) “the psychologist would run the group supervision, ask us how we had been doing and it was a chance to really sit down and tell each other, led by her appropriately, how we were doing. It was almost like a comfort blanket, you could go to them for support, they knew what they were talking about, they could help you problem solve from a patient point of view. We knew we had someone to go back to if we weren’t sure about things. From a staff personal point of view we have *greatly* missed her being a source of support for our roles” (P4)

"It's a role model who knows what they're doing, knows the implications of blurred boundaries, going above and beyond, burnout, compassion fatigue, not looking after yourself and all that sort of stuff. From a personal and professional point of view outside the clinical stuff, that was one thing that was massive that has gone" (P4)

"just to reflect on what's important (SIGH) yeah I think reflect, acknowledge and sit with the difficult emotions" (P5)

"Having support from psychology is massive. It's a place where you can go to have permission to grieve and to talk and to listen" (P4)

"Managing that risk of the patient as kind of psychologically and having that reassurance that it's been assessed and is being monitored accordingly" (P5)

"having the chance to reflect I guess on that person, whether they're still alive or whether it's that they've passed away and it was someone who you knew really well, having that support in the team is really valuable. To be able to go to the psychologist and have a chat about it, and that's always an option for me…to have that reflective time" (P6)

"Being able to debrief about that with the psychologist and to be able to sya, this is what happened, this is what I did, and not necessarily if it was the right thing, but like, thank you for that because it helped" (P6)

"we forget about our own psychological needs…and the impact on us…our psychologist is incredible at supporting the MDT to consider these…the psychological support creates a sense of safety" (P7)

		"something that's been incredibly helpful, we've set up kind of reflection groups, where people can focus on aspects of care and reflect on that, it's very well attended and we look at supporting each other" (P8) "support, strategies for dealing with difficult cases, enabling us to reflect on challenging times and conversations, we're able to reflect on those with the clinical psychologist" (P8)
Value of Psychology to Service Users	Measuring impact	"there's a lot of people involved, some people find it overwhelming the sheer number of people who are involved, so when we say "shall we add in this extra person" they go "oh god no because there is already enough of you" (P1) "the input they give in MDT meetings…even if she hadn't seen the individuals, she would join in conversations and absolutely pitch in and give advice. It raises awareness of this part of people's care, and it rubs off in a maybe an implicit way, in a softer way" (P2) "the staff support, in my opinion is more important than actually seeing patients because there is only so many times a psychologist can see someone, whereas the nurses and physios and things are seeing them all the time and dealing with the front line, so actually that role-modelling, leadership, supporting, reflecting, giving ideas and strategies for patients, absorbing some of the distress of the difficult patients for staff who can't do that themselves…I'd say that's probably the most useful thing a psychologist does for us" (P3) "One thing I think has been really useful and that its almost like the corridor conversations are as useful and educational as the formal psychology but formal psychology has been helpful for difficult patients, and it's reassuring to know they're getting that extra support" (P3)

	“I think the skills, set up and ways of working have improved [through psychology staff support] and it shows it’s as important as you know, I’m able to refer this patient to a psychologist…the patients who are most distressed have often got a million, yeah they are probably seeing someone every day, so another person in the mix is impossible. Yeah that sort of trickling down of support almost, from the specialist psychologist going to the staff and then to patients and so on” (P3) “she and modelled it really well, she did the same in MDT’s and gave permission for the MDT’s to model it really well, so it was er like a flow down of boundaries and support, it’s important to have a role model that knows what they’re doing and it filters through” (P4) “Supporting people’s wellbeing feels a bit of a catchall as it’s supporting the team to bring psychological aspects to their work as well, it highlights that we all have a duty of care to people’s psychological wellbeing, and so we kind of bring that into our own work as well and have the potential to support colleagues and patients too” (P5) “They’ve already got so many people involved in their care and they’re having to go over things again and again...I think if that staff member is well-supported then it’s only going to be better at supporting the person with MND and giving them the best care possible” (P6) “I think the thing I’ve possibly personally found most helpful is actually sometimes just sitting down and discussing patients and having that time to say “I’ve go this patient and they’re struggling…often the patients will have a stigma around being referred to psychology…but I think having that person within the MDT, even if the patient won’t see them, you can speak to them for advice, it[‘s really helpful” (P6)

“we can just bring patients to discuss that we might have found difficult or we might want to refer to psychology but they’ve not wanted to engage…they’re the main ways” (P6)

“I feel that could be a conversation that feels less taboo within the MDT and clearly that trickles down to patients, we should be a team where that’s flowing off the tongue and very open…” (P7)

“we’re incredibly fortunate that the psychologist is absolutely fantastic…it’s given us a depth and breadth in supporting people which we’ve never had before. We can give information, advice, support, ensure things are there…we could do that but we are missing a big chunk by not having a clinical psychologist to support us and the patients in that. I think it’s just made our care holistic, which I don’t think it’s been before really” (P8)

“it’s informal, I can just say ‘ooh can you catch up with…’ and so it’s quick, or I can write an email” (P8)

“she doesn’t see every single person necessarily, but she can have the conversations…signposting is another really valuable thing” (P8)

“when they’re [psychologists] available they play a really important role, when they aren’t there I don’t think we always know explicitly that it’s causing a problem but I know it absolutely does. It’s one of those things that’s hard to prove because practice still goes on, people still come in and they’re still of a certain emotional mindset…it’s hard to say in the moment that them not being there is a huge problem, but we know it absolutely is because of the value that we see I guess from when they are there, you know” (P2)

“(SIGH) the difficulty with that is it’s hard to measure the role because that’s not a traditional, you know they haven’t seen ten patients that morning, but they have impacted on the care of ten patients” (P3)

	“I was there before we had it so it’s kind of useful to see both sides, and it’s been really useful. Staff have got to engage with it, you know, it needs to be a core part of the MDT” (P3) “We have more patients asking for psychological support now than we ever have, and so when we told them we did have a psychologist it was almost met with relief and gratitude” (P4) “I’m amazed at how we kind of did without it for so long because I think they bring such a necessary element of dealing with a progressive life-limiting condition and helping people to cope and manage” (P5) “I think it’s something a team can carry on unknowing if they don’t have a clinical psychologist and they wouldn’t notice a problem because you know for a long time I thought I was helping, you know supporting the families, the patient, and yet when we have a clinical psychologist it adds depth and richness to the whole team for various other reasons, but I think you suddenly find, goodness me they really need it, it’s huge and people are so grateful” (P8) “we’ve been doing a sort of double act in clinic, and people leave saying, and this is weird…it always makes me think ‘oh my goodness they must have been having a terrible time’. You have a patient coming to clinic and they leave saying ‘thank you, I feel better’ and that’s extraordinary…we see patients together now, and they leave feeling better, now how is that possible?” (P8)
Embedded psychological care	“people do see a generic counsellor…and, you know, they need different support because it’s so specialist” (P1)

	“I can’t really imagine not having them because I can go out and talk to someone about how they’re feeling but I’m not trained to support them in depth with that…I can empathise with someone but I don’t know strategies and coping mechanisms that I can put into place with them” (P1) “if the role isn’t there they go to the general psychology pool…a real gap…they don’t come to our clinic” (P1) “We try to have conversations but we’re certainly not well-trained…that’s an unmet need where we haven’t got the expert…in an ideal world we would be able to refer to that specialist input. It comes with a skillset” (P2) “we’re all psychological non-experts aren’t we, apart from her the psychologist…weneed that insight that we can’t get as psychology non-specialists, you know, we can do it a little bit but nowhere near to the rigour of a psychologist” (P2) “Working within MND is a very different sort of patient population and can be really hard for people who haven’t got the experience, they need support to understand MND and then also the psychological input on not just the patients but also on them as healthcare professionals. Psychologists should be mandatory in MND MDT meetings, they absolutely strengthen those discussions” (P2) “MND is still a rare disease so people aren’t necessarily skilled in that area, erm so we feel at a loss, we don’t have a counselling background, we tend to sit and listen and you know just validate their feelings, you can only go so far can’t you I think and from a professional point of view, we are not the specialist people they should be seeing, and when we had [psychologist] involved she used specialist therapies and patients did not do well when she left, they were gaining so much from her support and we couldn’t match that, we couldn’t match what they were getting” (P4)

	“at the moment we are giving patients the counselling directory and saying the MND Association will fund you for your counselling, which doesn’t feel enough and it depends where they live as to whether they can get any services via palliative care, but you know, there are some psychologist support but it’s not MND and it’s not *clinical* psychology” (P4) “that’s not my role – it’s not one that I’m necessarily good at, you know I can listen and validate but that’s not what I was trained to do and I would never think that is my role, I’ve seen it first hand from patients that have had clinical psychology how life-changing it is” (P4) “I think colleagues have been doing elements of that, but they’re not trained you know, and to have such a particular focus of one person I think is brilliant, and with their expertise and knowledge” (P5) “we were talking earlier today about someone who’s having psychological support from another service, which is brilliant but they don’t have the understanding of MND and the nature of changes and complexities that that brings, and the challenges, whereas our psychologist has such a good understanding of MND and its impact on people that I feel that’s where the added benefit is, that she’s skilled in her knowledge of MND as well as her clinical psychology skills and that blend is what obviously makes her great for us and our patients, so I suppose its that specialist knowledge” (P5) “I feel like having someone psychology wise that is specialist in MND is really valuable because they can understand the implications of the disease and other treatments they might have, so a psychologist in another area might not know what an IV was, what the feeding tube was for them to be able to support the patient” (P6)

	“being able to refer them on to someone who is specialist that’s got those specialist skills around how an MND patient is going to present…having those specialist skills around MND makes a massive difference in being able to support the patient…if the psychologist doesn’t have that level of skill or knowledge of MND then it’s gonna be really difficult” (P6) “there’s a need for a more specialist psychological input, cos I don’t, I’m not a psychologist…some will jump at any opportunity…to seeing a more specialist psychologist” (P7)