Interpreting the Meaning of Existence for the Person with Motor Neurone

Disease, and their Family Carer(s)

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Interpreting the Meaning of Existence for the Person with Motor Neurone

Disease, and their Family Carer(s)



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*This Thesis is Dedicated to my Mother, Audrey…*

# CONTENTS

## ACKNOWLEDGEMENTS

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To my husband Danny – I would like to say how grateful I am for your unfailing support, guidance and never-ending encouragement throughout my postgraduate research studies. Your continued patience and tolerance throughout this arduous postgraduate journey have kept me going, and I could not have achieved any of this without you.

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# PREFACE

Nine months before her diagnosis, my mother was already experiencing the degenerative effects of MND in her speech and movement. Looking back, she also had other symptoms. As an occupational therapist, I could relate my mother's experiences to Wilcox's (1999) theory of 'doing, being, becoming and belonging'. I considered that she was unable to undertake daily activities and unable to be an independent woman. She could not be, could not become and could not belong. This reduced sense of identity, purpose and meaning affected her mental well-being before she was diagnosed with MND.

Receiving a diagnosis of PBP MND was devastating; we were told that her MND was progressing rapidly, and palliative care was recommended. The palliative care team were my professional colleagues and were used to caring for people with MND. Two months later, my mother was unable to swallow and was admitted to hospital for intravenous hydration and nutrition. Four months later, she was 'locked in' her body, unable to speak or move, and able to communicate only through blinking her eyes and moving her head slightly. Her mind was unaffected, and her big blue eyes would follow the nurses and carers as they went about their daily routine of making their 'patient' with MND as comfortable as possible, whilst she lay in her body waiting in silence for her release.

# ABSTRACT

The genesis of this thesis lies in experiences of caring professionally for people living and dying with motor neurone disease (MND) and in personal experiences of caring for my mother with the same condition. These experiences led me to an understanding that MND threatens the sense of existence for both the person with the condition, and their family. MND is a devastating neurodegenerative terminal condition that results in loss of the motor neurones that enable a person to move, speak, and at the end of life, to breathe. At the outset of this project, previous research had focused on the narratives of people living with MND at a single point of time; thus knowledge of the meaning of existence with MND through time is limited.

This is a multiphase study that uses two distinct methodologies: hermeneutic (interpretive) phenomenology and autoethnography to explore the lived experiences of self and others. The three key areas of study are: (i) the phenomenon of existence when someone is given a diagnosis of MND and in the context of receiving healthcare; (ii) the meaning of living with uncertainty for people diagnosed with MND; and (iii) the meaning of supporting a loved one with MND as they die. The outcomes of this research have significantly contributed to knowledge through the publication of six peer-reviewed papers. The findings of the research are collated and integrated to develop a person-centred model of care that emphasises the need for MND professionals to acknowledge the temporal aspects of caring for a person with MND, and for their family carers.

The thesis concludes that MND care is complex, but that this complexity can be reduced if the range of professionals who provide MND care interpret the care needs of the people at end of life with MND to provide not only multi-professional, but inter-professional person centred care.

# CHAPTER 1 INTRODUCTION TO MOTOR NEURONE DISEASE

This chapter will introduce the reader to what is already known about motor neurone disease (MND) from a clinical perspective. It moves on to review the existing literature on the different methodologies used over a ten-year period to understand the experiences of people with MND and their family carers. A review of existing literature on how MND care is delivered follows, along with recommendations for future study made by other researchers. The chapter concludes with a brief overview of the chapters in the thesis and how this project contributes to the knowledge available.

I am a postgraduate researcher with professional experience as an NHS community occupational therapist providing person-centred care for people with neurological conditions, including MND. I came to this project through my personal experience of being a professional family carer, supporting my mother through her illness trajectory with progressive bulbar palsy MND. The focus of my project has been how MND threatens the sense of existence for both the person with the condition and their family.

## 1.1 WHAT IS KNOWN ABOUT MND?

MND is seen as the most devastating adult-onset neurodegenerative disorder and results in the degeneration of the motor neurones in the brain and spinal cord (Bäumer et al., 2014). The risk of developing MND is cumulative, with men at higher risk than women. On average, one in three hundred people suffer from the condition. The risk factors include exposure to environmental chemicals and toxins, viral infections, immune damage, premature ageing of motor neurones, loss of growth that would maintain the survival of motor neurones and genetic susceptibility (Al-Chalabi, 2019). The median time from onset to diagnosis of MND is between 9 and 15 months (Donaghy et al., 2008).

It is crucial to understand the epidemiology/demographics of MND and how these change over time and by country in order to plan health care. Logroscino et al. (2018) carried out a systematic review of cause-of-death registers (2009-2016) across 14,165 global, regional and

national locations. The findings suggested that 330,918 individuals had motor neurone diseases during that period, and that these conditions had caused 926,090 disability-adjusted life years (DALYs) and 34,325 deaths in 2016. The researchers reported a worldwide all-age prevalence of 4·5 MND sufferers per 100 000 population. They concluded that the burden of MND was greater in the high-income regions and was increasing because of ageing populations. A review of the extensive list of countries that were considered in the review suggests that the UK, USA and Australia have the highest numbers of people with MND worldwide (see Table 1 below).

Table 1. Cases of MND in high-income countries (taken from Logroscino et al. (2018))

| Country | Population, 2016 | Number of MND cases, 2016 | Number of DALYs, 2016 | Number of deaths, 2016 |
|---|---|---|---|---|
| UK | 65,380,000 | 13,249 (0.02026%) | 45,310 (0.06930%) | 2,199 (0.0033%) |
| USA | 323,100,000 | 62,531 (0.01935%) | 182,359 (0.0564%) | 7,632 (0.0023%) |
| Australia | 24,190,000 | 4,247 (0.01755%) | 15,625 (0.0645%) | 711 (0.0029%) |
| France | 66,720,000 | 11,712 (0.01755%) | 34, 427 (0.0515%) | 1,557 (0.0023%) |
| Italy | 60,670,000 | 9,553 (0.01574%) | 30,525 (0.0503%) | 1,418 (0.0023%) |
| Germany | 82,180,000 | 12,502 (0.01521%) | 42,111 (0.0512%) | 1,911 (0.0023%) |

A person diagnosed with MND will learn that there is no known cure and that they have one of four types of the disease, each with variable prognostic indicators (Hardiman et al., 2011). Amyotrophic Lateral Sclerosis (ALS) MND is the most common type of MND and accounts for 66% of all cases, affecting upper motor neurones (UMN) and lower motor neurones (LMN) without sensory disturbance; the average survival is 2–5 years. Progressive bulbar palsy (PBP) MND accounts for 20% of cases, affecting bulbar LMN and corticobulbar UMN palsy onset, with a poorer prognosis. Progressive muscular atrophy (PMA) MND accounts for 10% of cases; affecting LMN initially, it can develop to UMN and has a slower disease progression. Primary muscular sclerosis (PMS) MND accounts for 0.5% of cases, affecting UMN signs at the onset, and can develop to ALS; those with this form can retain an average life expectancy (Hobson et al., 2016; Oliver, 2016). A person may also present with frontal temporal dementia, with the cognitive changes evident before any physical changes. Dementia occurs in 15% of all people diagnosed with MND (Oliver, 2016).

The person with MND will face physical problems, such as difficulties with speech and language, swallowing, breathing, weight loss, mobility and immobility. In addition, they may have to manage a number of psycho-social issues, such as attitudes to MND, anxiety, bereavement, sense of loss,[1] control, coping, decision-making, projecting into the future, and family issues (Talbot and Marsden, 2008). The family of a person with MND will face the challenges of obtaining a diagnosis, providing 24-hour care, anxiety, coping, decision-making, observing the impact of MND and making best interests decisions (Talbot and Marsden, 2008).

Therapy treatments include the drug Riluzole, the effects of which are known to be modest, prolonging mean survival by 12–15 months (Bäumer et al., 2014). A multidisciplinary team (MDT) approach within specialist clinics is known to have a greater impact on preserving the quality of life of those with the condition, and is led by MND-focussed neurologists with a specialist nurse and other multidisciplinary care professionals, as well as links to gastroenterology and respiratory teams (Hardiman et al., 2011). Reviews are recommended after diagnosis and in the later stages of the disease, with less frequent reviews if the condition is progressing slowly (Andersen et al., 2012). People with MND, however, face barriers to attending the MND clinics for reviews (James et al., 2019).

## 1.2 LIVED EXPERIENCES OF MND

Researchers have used different methodologies to research the experiences of those living with MND and have focussed on different aspects. Brott et al. (2007) were interested in the occupational disruption of living with MND in their study guided by phenomenology. They identified four themes, which they described as 'wobbly body', 'doing and being', 'changed world' and 'changed future'. Brown (2003) examined the experiences of users, carers and professionals related to MND and, found that people with MND had holistic needs but care

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[1] The decline in their physical function results in a loss of control of their body, and possibly their speech, and affects their ability to interact with their family and friends. For the person, family and friends there is a profound sense of loss, and bereavement, long before death: loss of the life lived and loss of the life still to be lived. Indeed, death might ultimately be a welcome relief (Nicol, 2017: 45).

was focussed on function. She emphasised the need to maintain the focus on the person rather than the disease, which appears simple, yet is challenging (p.215).

Brown and Addington-Hall (2008) explored patients' experiences and how they talked about living and coping with MND, using narrative case studies to understand how people live and cope with the loss of movement and speech. The findings uncovered four narrative types: sustaining, enduring, preserving and fracturing. The authors stated that the fracturing narratives were difficult to listen to, due to the expressions of loss and fears for the future. Even so, understanding and being able to recognise these narrative types may be useful to carers and professionals. Locock et al. (2009) examined whether the concept of 'biographical disruption and repair' can be applied to people living with MND and found that being diagnosed with MND is a 'biographical abruption' of life. Allen-Collinson and Pavey (2013: 803) explored the in-depth accounts of lived-body experiences of touch for people with MND. They found two dimensions emerged: i) the loss of certain forms of touch as part of the MND process, and (ii) unwelcome touch, in which participants recounted experiencing distress and discomfort at patronising physical contact from medical and health practitioners.

Existential concerns have been the main focus in research on people living with MND and receiving palliative care in Sweden (Bolmsjö, 2001), and the focus of the secondary analysis in studies carried out in the U.K. (Brown, 2003) and Australia (Ray and Street, 2007). Suffering has also been observed by those caring for people living with MND towards the end of their lives (O'Toole, 2011). These studies have, however, focussed on single points in time; thus, knowledge of the meaning of existence with MND through time is limited.

Since this project began, there has been limited research on the lived experiences of MND; research has, rather, focussed on family carers' experiences of MND. The reason for this may be the degenerative nature of MND, and the vulnerability of those with the condition (ESRC, 2020). Researchers have used various methodologies to explore the experiences of family carers. Aoun et al. (2012) carried out a literature review of family care-giving for MND and found that family carers experienced a substantial burden, which created distress at different points in the illness trajectory. The authors called for family carers to receive practical and psycho-social support throughout the illness and bereavement. In later research, Aoun et al.

(2018) carried out a postal survey which found that the way a diagnosis is delivered can have a significant impact on the emotional well-being of people with MND and their family carers. Ozanne et al. (2015) focussed on spouses' experiences of caring for people with MND and found that they experienced loneliness, imprisoned lives and loss of their future. Holkham and Soundy (2018) carried out a thematic synthesis of the experiences of informal caregivers and reported experiences of loss of control, inability to choose and isolation. The authors called for family carers to have better communication with professionals, through a single point of contact. To conclude, family carers witness the devastating nature of the disease and experience their own existential concerns.

## 1.3 MND CARE

MND care is a challenge for all those involved in this illness's trajectory – neurology, neurorehabilitation, general medicine and palliative care (Oliver et al., 2016). Several researchers have noted that MND lies beyond being a chronic or terminal illness (Brown, 2003; Locock et al., 2009). Lerum et al. (2015) suggest that the distinction between the two is, in any case, ambiguous and that MND should be considered an 'unstable terminality', which creates challenges for primary care. Lerum et al.'s (2017: 1) findings suggest that the challenges include: i) building relationships with those giving and receiving care in the home; (ii) preventing caregiver burnout and breakdown; (iii) providing tailored care; (iv) ensuring good working conditions in patients' homes; and (v) recruiting and retaining qualified nursing assistants. Pagnini (2013: 194) acknowledged that the psychological impact of MND on the person and their family is 'huge', yet clinical guidelines and reviews have focussed on the physical symptoms of MND (Janssens et al., 2016). There are both physical and psychological symptoms to manage in MND (Mathis et al., 2016). In a scoping review and synthesis, Harris et al. (2018a) suggested that disease management is not focussed on the psychosocial well-being of the wider social network, including carers, family, others and healthcare professionals. Glebel et al.'s (2019) staff service evaluation, meanwhile, identified the need for further training of a range of professionals in communicating psychosocial well-being in MND. Hogden et al.'s (2017: 212) review of the current evidence has shaped current practice and explains how multidisciplinary MND care is delivered. The focus on rehabilitation assists people with MND in adapting to the physical and psychological challenges of living with the

disease. The focus of palliation, meanwhile, seeks to alleviate physical, psychological and existential distress. The multidisciplinary approaches to symptom management focus on identifying the issue, recommending treatment options, and referring to healthcare and support professionals who can meet the patient's needs (see Table 2 below). The authors conclude that stronger links between specialised MND services, general neurology and primary care services could improve the quality of care for patients in their community.

**TABLE 1 MULTIDISCIPLINARY APPROACHES TO SYMPTOM MANAGEMENT**

| Issue | Treatment options | Health care and support professionals involved |
|---|---|---|
| Disease progression | Riluzole | Neurologist/rehabilitation physician |
| Breathing difficulty | Assisted ventilation | Respiratory physician, respiratory therapist, nursing |
| Eating and drinking difficulties | Gastrostomy | Gastroenterologist, dietitian, speech pathologist, nursing |
| Saliva management | Medication Botox | Neurologist/general practitioner/palliative care team neurologist |
| Mobility | Mobility equipment | Physiotherapist, occupational therapist, MND association |
| Cognitive, behaviour and mood issues | Counselling and support for patient and family | Neuropsychologist, psychologist |
| Self-care | Assistive equipment | Occupational therapists, nursing, MND association |
| Grief and loss | Counselling and support for patient and family | Social worker, psychologist, MND Association, palliative care team |
| Carer support | Counselling and support for patient and family | Social worker, MND Association, palliative care team |

Taken from Hogden et al. (2017: 205–215).

There is an acknowledgement that psychologists are under-utilised in MND care (Harris et al., 2018a) and in end of life care in general (Ftanou et al., 2017). In the absence of psychologists, the need for palliative care throughout the illness trajectory is even more essential (Oliver and Aoun, 2013). In a consensus review of palliative care in neurology, the European Academy of Neurology/European Association for Palliative Care (EAN/EAPC) suggested that 'the care of patients with progressive neurological disease and their families continues to improve and develop. There is a pressing need for increased collaboration between neurology and palliative care' (Oliver et al., 2016: 30). However, the majority of people with progressive

neurological diseases are not receiving palliative care (Veronese, 2018) or only receive it in the last weeks of their life (Fleming et al., 2020), with the result that holistic care needs remain unmet (McVeigh et al., 2019). McVeigh et al. (2019) recommended further research to explore an optimal model of palliative holistic care for people with MND. To conclude, in the absence of neuropsychology, psychology and palliative care for people with MND and their families, there is a concern that people will experience life in crisis or existential suffering at the end of their life.

My previous experiences as both a formal and informal carer have influenced how I have approached the research reported in this thesis and I must, therefore, acknowledge that I have brought presuppositions into this research. These cannot be 'bracketed' as if they do not exist. Instead, they have inspired this research project and the choice of methodologies. Hermeneutic phenomenology and autoethnography are two distinct methodologies but both acknowledge that the researcher's presuppositions are essential for interpreting the meaning of self and others, as will be explained further in this thesis. The six published papers are presented in four chapters, as outlined below.

## 1.4 CHAPTERS OF THE THESIS

This thesis has been structured into four chapters, which include a narrative linking the six published papers. The papers are numbered chronologically, i.e. in order of publication, but are linked thematically within chapters.

### Chapter 2: Interpreting philosophy, developing a research methodology

Embedded in this chapter, **Paper 1** sets out to provide a reflective account of interpreting the existential phenomenology and philosophical hermeneutics, which underpins the work presented in the thesis (Heidegger, 1927/1962; Gadamer, 1975) (Harris, 2017).

### Chapter 3: Research approaches enabling reflection

Papers 2 and 4 are both embedded in this chapter. **Paper 2** is a descriptive personal reflection, written as part of the research process and drawing on the philosophy of hermeneutic

(interpretive) phenomenology (Harris, 2017a). **Paper 4** explores the meaning of supporting a loved one with MND to die (Harris et al., 2019). Using an autoethnographic approach, it concludes that:

> dying with MND is a complex phenomenon, especially if the "body is experienced in silence", so a person can no longer take part in decision-making about end of life care. People are dependent on others to act in their best interests, and this challenges the relationships between all those involved in end of life care. Palliative care perspectives are essential in supporting a person as they die, regardless of the care setting, as lived space and time take on new meanings. (Harris et al., 2019: 290)

**Chapter 4: Phenomenological research**

Papers 3 and 5 are both embedded in this chapter. **Paper 3** answers the research question 'What does it mean to be a person living through the illness trajectory of MND?' and researches the phenomenon of existence after receiving a diagnosis of MND, in the context of receiving healthcare (Harris, 2015: 1579). It concludes that 'the four participants provided eloquent stories of their unique existence from the time they first noticed something untoward was happening to them until the present day' (Harris, 2015: 1591) and that 'the findings from this study help us to make sense of what it means to be a person living through the illness trajectory of MND' (Harris, 2015: 1593). From the data, it emerged that people with MND live with uncertainty throughout the trajectory of their illness, and it was determined that this required further examination. The aim of **Paper 5** was to explore 'the meaning of living with uncertainty for people diagnosed with motor neurone disease (MND)' (Harris et al., 2018: 2062). It concludes that:

> people with MND are living with uncertainty and other concerns throughout their illness trajectories. The effects of this can result in people experiencing life in crisis at different stages of their illness, resulting in the desire to hasten death because of various losses. People are having to turn to palliative care professionals who are more able to meet their concerns than those caring for other aspects of their condition. (Harris et al., 2018: 2069)

**Chapter 5: Proposing a person-centred model of care**

**Paper 6** is embedded in this chapter, and aims to 'provide practical insight into the way that professionals caring for a person with MND can recognise, respect and respond to that person's temporality; i.e. the person that they have been, that they are now, and that they will be in the future' (Harris et al., 2020). It concluded that:

> *MND has a significant impact on a person's lifeworld. The proposed person-centred care model focuses on understanding (interpreting) a person in a wider temporal frame, and beyond the context of their illness. The expected collaborative outcomes are that a person is acknowledged as more than a "patient with MND" and that a professional is providing person-centred care based on the individuality of the person, through a temporal lens. (Harris et al., 2020)*

## 1.5 CONTRIBUTIONS MADE BY THIS PROJECT TO KNOWLEDGE IN THE FIELD

- This research provides a nuanced account of interpreting two philosophical positions on existential phenomenology (Heidegger, 1927/1962) and philosophical hermeneutics (Gadamer, 1975), and applying these as a methodology.

- It provides a descriptive personal reflection of supporting my mother through three phases of the illness trajectory, including my observations of MND care: 'walking the walk' of diagnostic reasoning (investigation and diagnosis); life as before, but not as before (continuity and decision-making); observing existential suffering (end of life). The hidden thread linking these experiences together is my loss.

- In returning to previously published reflections to explore the meaning of supporting a loved one with MND as they die, the research identifies four themes relating to the end of life trajectory of MND: loss of person (lived body experienced in silence); loss of relationships (lived relations are challenged); loss of home and loss of time (lived space and lived time take on new meaning); loss of future (dying – facing it alone).

- The method of data collection and analysis enabled a sensitive methodology for researching the phenomenon of existence with MND through time. The findings uncovered the concept of 'existential loss', of past ways of being-in-the-world, embodiment, spatiality, and the once projected future.

- In returning to the individual philosophical framework analysis to explore the meaning of uncertainty for people diagnosed with MND, the findings uncovered three phases of the MND illness trajectory: 'body failing prematurely and searching for answers'; 'body deterioration and responses to care'; and 'body nearing its end and needing to talk.'

- The findings of the research are collated and integrated to develop a person-centred model of care which emphasises the need to acknowledge the temporal aspects of caring for a person with MND and their family/significant others.

# CHAPTER 2 INTERPRETING PHILOSOPHY, DEVELOPING A METHODOLOGY FOR RESEARCH

## 2.1 LINKING NARRATIVE FOR PAPER 1

Embedded in this chapter, **Paper 1** sets out to provide a reflective account of interpreting existential phenomenology and philosophical hermeneutics, which underpins the work presented in the thesis (Heidegger, 1927/1962; Gadamer, 1975). I initially found the complexity of the language overwhelming and, therefore, turned to the work of others to help my understanding (Bullington, 2006; Cohn, 1997; Koch, 1995; Polt, 1999; Finlay, 2011; Fleming et al., 2003) before returning to the original texts. This narrative will explore my research journey and the rationale for the choices I made along the way.

Bengtsson (2013) suggested that it is essential to be explicit in a research project about why one has chosen a particular direction of phenomenology. Descriptive phenomenology (Husserl 1913/1962) and hermeneutic phenomenology (Heidegger 1927/1962) are two different philosophical perspectives. While both focus on the human experience of the 'lifeworld' (Brooks, 2015; Finlay, 2011), there are key differences. Husserl's approach to phenomenology is epistemological: he asks, 'How do we know what we know?' For him, what is shared is the essence of the conscious mind, and its meaning is unaffected by the interpreter's view of the world (Koch, 1995). Husserl believed in the notion of reduction as a rigorous method of examining human experience, bracketing or putting aside all presuppositions, theories and ideas about the phenomenon in question, in order to be completely open to it as it appears (Bullington, 2006). Heidegger's approach to hermeneutic phenomenology, in contrast, is ontological. He asks, 'What is the meaning of being?' and believed bracketing presuppositions to be impossible. Gadamer (1975) took philosophical hermeneutics further, asking how people come to understand. For Gadamer, understanding

occurs through historical awareness,[2] presuppositions,[3] openness to the meaning of others [4]and a fusion of horizons [5](Koch, 1995).

Heidegger introduced the term *Dasein* to emphasise 'being-there' or existence. His thoughts on existence suggest that a person is born into a pre-existing history, culture and practice and then experiences their own existence along a temporal line, where the past is carried along by a present that is already anticipating the future (Cohn, 1997; Polt, 1999). A person achieves an authentic existence through having the freedom to choose how to conduct their life, projecting themselves forward and forming the essence of their existence. In contrast, inauthentic existence is occupied with everyday life, distracted from oneself and involved with the 'they'[6] (Wartenberg, 2008). In this, we can choose to deny death, or we can choose to accept death as an intrinsic aspect of living (Cohn, 1997). In making such choices, for example, a person born into a family may choose to adopt their forebears' cultural ways of being, or they may decide to distance themselves and become, for example, a lecturer; in doing so, they assume different ways of existence. Indeed, this was the pathway chosen by Heidegger, as he moved away from his place of birth to learn philosophy; ultimately this became the essence of his existence, although he returned to his cultural ways of being towards the end of his life. A person diagnosed with MND may have to give up a former role, such as being a lecturer. They may choose to accept death with MND as an intrinsic aspect of living or deny life and death with MND; either way, they can reflect on the essence of their existence. I felt that Heidegger's philosophical ideas would help me to answer the research question, 'What does it mean to be a person living through the illness trajectory of MND?'

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[2] Historical awareness is learning to understand ourselves better and recognise that, in all understanding, whether we are expressly aware of it or not, the efficacy of history is at work (Gadamer, 1975: 300).

[3] Presuppositions include preunderstandings, prejudices and beliefs (Heidegger 1927/1962: Gadamer, 1975).

[4] Openness to the meaning of others does not mean that when we listen to someone or read a book we must forget all our presuppositions concerning the content and all our own ideas (Gadamer, 1975: 271).

[5] Fusion of horizons is to learn to look beyond what is close at hand, not in order to look away from it but to see it better, within a larger whole and in truer proportion (Gadamer, 1975: 304)

[6] 'They' personifies the 'social expectations and interpretations that mark me as belonging to a culture' (Polt, p.63).

**Paper 1** is a reflective paper partly written to help other researchers to adopt hermeneutic phenomenology. They may be experiencing the same difficulties I had when interpreting the philosophical ideas to develop a research methodology.

## 2.2 PAPER 1

Harris, D.A. (2017). 'Doing research drawing on the philosophy of existential hermeneutic phenomenology.' *Palliative and Supportive Care,* 15 (2): 267–269.

**Link to paper** - https://doi.org/10.1017/S1478951516000377

**On journal website:**

HTML views          22

PDF views           208

Abstract view       884

**On ResearchGate:**    163

**This paper is cited by:**

- Nyblom, S., Arnby, M., Molander, U., & Benkel, I. (2020). End of life Experiences (ELEs) of Spiritual Nature Are Reported Directly by Patients Receiving Palliative Care in a Highly Secular Country: A Qualitative Study. *American Journal of Hospice and Palliative Medicine*.

- Khoshnood, Z., Iranmanesh, S., Rayyani, M. and Dehghan, M. (2018). 'Getting Out or Remaining in the Cage of Inauthentic Self: The Meaning of Existential Challenges in Patients' with Cancer.' Indian Journal of Palliative Care 24 (2): 131–138.

- Moquin, F.K. (2019). 'How do teachers experience lesson study.' Proquest Dissertations Publishing 1–24.

- Sowden, R. (2018). 'An investigation into the perceptions of "outsider" contributions to sustainable services for people with communication disabilities, in majority world countries .' Doctoral thesis (PhD) Manchester Metropolitan University 1–451.

Two of the citations above are from university PhD dissertations in which this paper helped researchers to unpack their methodology.

Manchester
Metropolitan
University

# PhD BY PUBLISHED WORK (ROUTE 1/2): CONTRIBUTION TO PUBLICATIONS

*This form is to accompany an application for registration for PhD where the PhD is by Published Work. A separate form should be completed for each publication that is submitted with the proposal and should accompany the RD1 form.*

## 1. The Candidate

| | | | |
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| Personal e-mail address: | denise.harris13@outlook.com | Student ID Number: | 15502486 |

## 2. Title of PhD Proposal

A Lifeworld Approach to palliative and supportive care

## 3. Title of Research Output

Doing research drawing on the philosophy of existential hermeneutic phenomenology

## 4. Candidate's contribution to the research output
### (State nature and approximate percentage contribution of each author)

Denise Harris 100% contribution

## 5. Co author(s):

I confirm that the contribution indicated above is an accurate assessment of the contribution by the candidate to the research output named in section 3.

| Name | Signature | Current e-mail address |
|---|---|---|
| | | |
| | | |

## 6. Statement by Director of Studies/Advisor

I confirm that I have read the above publication and am satisfied that the extent and nature of the candidate's contribution is as indicated in section 4 above.

Signature: **Kirsten Jack**  Digitally signed by Kirsten Jack Date: 2017.02.27 10:47:14 Z   Date:

(Director of Studies/Advisor)

## 7. Signature of Faculty Research Degrees Administrator

Signature: **Chris Wills**  Digitally signed by Chris Wills DN: cn=Chris Wills, o=Manchester Metropolitan University, ou=Faculty HPSC, email=hcwills@mmu.ac.uk, c=GB Date: 2017.02.27 14:57:01 Z   Date:

(Faculty Research Degrees Administrator)

## ESSAYS/PERSONAL REFLECTIONS

# Doing research drawing on the philosophy of existential hermeneutic phenomenology

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Phenomenologists seek to depict the "lifeworld"[1] experiences of people. Researchers applying Heidegger's (1962) existential phenomenology and Gadamer's (1975) philosophical hermeneutics seek to examine and be aware of their own past experiences with "openness and sensitivity" in order to be open to the meaning of others. Heidegger's existential phenomenology focused on the meaning of human existence (lifeworld). He asked questions about experiencing and understanding: what does it mean to be a person? As a researcher interpreting Heidegger's existential phenomenology, I understand the person to be a self-interpreting being. As a researcher, I can only make explicit what is already understood. But I can interpret their story using Heidegger's aspects of existence to gain a deeper level of meaning. The present paper brings forward a reflective account of how I interpreted Heidegger's existential phenomenology and Gadamer's hermeneutics and applied them as methodology to understand the meaning of existence for others living through the illness trajectory of motor neurone disease (MND).

## BRINGING PRESUPPOSITIONS TO CONSCIOUSNESS BEFORE RECRUITING AND MEETING THE PARTICIPANTS, AND DURING INTERPRETATION

As a researcher, I have the background experience of supporting my mother living with MND. Heidegger understood that presuppositions—defined as preunderstandings, prejudices, and beliefs—cannot be "bracketed" as though they do not exist. Instead, Heidegger (1962) and Gadamer (1975) recommend

engaging with one's own presuppositions in order to understand oneself and others. Finlay (2011) terms engaging with one's presuppositions "hermeneutic reflexivity." Hermeneutic reflexivity was completed in the first year of my study, before completing the research proposal and before recruiting and meeting with participants. Documenting the experiences gave me a greater understanding of those past experiences—it gave me closure on many events that were not worthy of further study, to bring forward what experiences remained important, and it enabled me to focus on the questions that remained important to me as a person and as a healthcare professional. This reflective account is reported elsewhere (Harris, 2016). The participants understood that I had both a professional and personal understanding of how MND affects people in different ways. Atkinson (1998) acknowledges that shared understanding of the topic can naturally lead the participant to reveal more than he or she otherwise might.

## CHOICE OF DATA COLLECTION METHOD

Heidegger holds that human beings exist in the world through time—not time determined by a 24-hour clock, but temporal time determined by our past, present, and future. First, human beings are born into a particular history, culture, and practice. They may choose to adopt their forebears' ways of being or project themselves forward into other possibilities (Inwood, 1997; Moran, 2000). Projecting themselves forward into the future of other possibilities may include being a self-employed businessman, a sales manager, and other ways of being. A hermeneutic position holds that stories are interpretations of life. A story helps us to communicate the unity of our lives and therefore to create an identity (Widdershoven, 1993, cited in Atkinson, 1998). With this premise, a life story interview was chosen

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[1] Lifeworld = existence (Heidegger, 1962).

as a method of data collection, inviting participants to tell their story from when they first became aware that something untoward was happening to them. This provided them with an opportunity to bring forward the meaning of their existence with motor neurone disease and how this impacted on their past, present, and future. As a researcher, I listened to their stories and brought them back to the themes they had raised, and invited them to elaborate on the meaning of these experiences in their lifeworld.

## WHOLE STORIES TRANSCRIBED, SO THAT OTHERS CAN UNDERSTAND (INTERPRET) THEM

The first interview was complete. Whole stories were transcribed, so that others could understand (interpret) them. I listened to participant stories several times and made a decision to have them transcribed professionally, to put the important intonations into the text. I then took their story along to the second interview and asked, "Is this the story you have told so far? Is there anything you would like to add or remove?" Gadamer (1975) would refer to this as a "fusion of horizons." All the participants chose not to change the story and to continue on to the second interview. I then asked the participants three questions related to the study. This method of data collection meant that I had four detailed accounts of the meaning of existence with MND. I had to consider how to analyze these data without losing their meaning, and to search for deeper meaning. During the five stages of interpretation, the focus has been to remain as present as possible with the existential phenomenon (via the participant story). A more detailed account of methods and findings are published elsewhere (Harris, 2015).

## USE OF A PHILOSOPHICAL FRAMEWORK TO ANALYZE THE TEXT THAT FOCUSES ON THE PARTICIPANT'S MEANING OF EXISTENCE (LIFEWORLD), AND NOT THE RESEARCHER'S

Heidegger understood the three ecstasies of time as a lived-through past, experienced present, and anticipated future. This existential phenomenon is evident through the telling of stories. All the participants started their story about the activities they were doing when they first noticed something untoward was happening to them. They all talked openly about their past ways of being-in-the-world—being a professional sportsman, being an international business man, being a retired salesman, and being a retired care assistant. In the present, they each talked about how MND was impacting on other aspects of their existence. Those aspects of existence most apparent in their stories included: thrownness, spatiality, temporality, embodiment, mood, and mortality (Cohn, 1997). Aspects of existence bring forward their being, identity, and difference—their individual uniqueness.

## USE OF PARTICIPANT STORIES (EXCERPTS) TO BRING RESONANCE TO THE FINDINGS

Excerpts taken from each participant story bring resonance to the findings of "existential loss" of the past ways of being-in-the-world, loss of embodiment, loss of spatiality, and loss of future (Harris, 2015). One participant does not focus on his concern for the loss of his past or for himself in the present, despite being on noninvasive ventilation and unable to move independently. His concern is for his family and their future. He states, "I look forward to see the kids back from university, to know that we are getting on all right." In contrast, one participant story is all about his existential loss of past ways of being-in-the-world. His mood in the experienced present tells of how he has been beaten by MND, of his present situation, and how he is anticipating his future: "It's a funny old situation. You sort of— it's like being in— It's like being on death row without knowing when the executioner is going to pop in."

## STRENGTHS AND LIMITATIONS OF THE STUDY

This study brings forward a developed hermeneutic phenomenological approach to study what it means to be a person living through the illness trajectory of MND. In doing so, the concept of "existential loss" could be found in the stories told by four participants. Existential loss refers to loss of past ways of being, embodiment, spatiality, and future. Though existential loss is varied, there were comparisons that could be drawn across all the stories. This study involved a small sample size of four participants. Small sample sizes present a challenge to the generally accepted norms of transferability (Blank et al., 2016). However, the trustworthiness of the study was attended to in the methodological approach chosen, the methods of data collection and analysis, the process of reflection, transcription of whole stories, and peer-reviewed interpretations. Asking the participants to tell their stories resulted in large amounts of data to interpret. In addition, interpretation involved iterative reading of the stories, which was extremely time-consuming. The process of reflecting on one's own experiences in relation to the

experiences of the participants was emotionally draining for me as researcher (Harris, 2015).

## FINAL THOUGHTS

As a researcher using hermeneutic phenomenology as methodology, I have become versed as a phenomenologist, that is, seeking to depict the "lifeworld" experiences of people living through the illness trajectory of MND. It is because of one's background experiences that I ask the research question (Heidegger, 1962). I was asked at the research proposal stage to pull the threads of hermeneutic phenomenology through the study. What followed was total immersion in the work of Heidegger and Gadamer and those who had also interpreted and applied, albeit differently, their philosophical ideas. As Finlay (2011) claims, hermeneutic phenomenology does not offer methods of data collection and analysis. The reason for this is because each researcher comes to a study with their own history, culture, and practice impacting on their interpretation. What followed were developed methods of data collection and interpretation, resulting in deeper layers of meaning than anticipated. Other researchers with their own history, culture, and background may choose to develop their own methods to understand the meaning of the existential phenomenon.

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## 2.3 CONCLUSION

At the time of writing this reflective paper, there were limited reflections published on how to implement the philosophy of existential hermeneutic phenomenology as a methodology for research. Paper 1 provides a nuanced account of interpreting the two philosophical positions of existential phenomenology (Heidegger, 1927/1962) and philosophical hermeneutics (Gadamer, 1975), and applying these in a research methodology. As a researcher, I do not deny that my presuppositions will have affected the choices I have made. Another researcher approaching the study of the phenomenon of existence would also have their historical-cultural situatedness[7] and would interpret these philosophical ideas in their own way. This paper has received a degree of interest (see views and citations above). I am in no doubt that researchers will use different aspects of my methodology because there are particular gaps in these areas:

1. Bringing presuppositions to consciousness before recruiting and meeting the participants, and during interpretation;

2. Choice of the data collection method;

3. Whole stories transcribed so that others can understand (interpret) them;

4. Use of a philosophical framework to analyse the text that focusses on the participant's meaning of existence (lifeworld) and not the researcher's;

5. Use of participants' stories (excerpts) to bring resonance to the findings.

On a personal level, the paper enabled me to internalise the meaning of hermeneutic (interpretive) phenomenological research. I understand that this paper demonstrates a phenomenological approach to research that is consistent with the holistic therapy values of occupational therapy, and with the potential to extend research practices. Finlay (2011: 40) suggested that, 'as therapists, we bring a huge advantage with us when we do phenomenological research because we routinely engage with the body in our work.' Engaging with the person, their environment and occupation was an intrinsic part of my everyday practice as an occupational therapist; engaging with the person in their world forms

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[7] Heidegger emphasises the historicality of understanding as one's background or situatedness in the world (Laverty, 2003: 24).

part of my role as a researcher. I learnt more about people in their world as a researcher than I could do as an occupational therapist. The reason for this is simple: I had time to dwell on their lived experiences in a wider temporal frame, and beyond the context of their illness.

# CHAPTER 3 RESEARCH APPROACHES ENABLING REFLECTION

## 3.1 LINKING NARRATIVE FOR PAPER 2

Papers 2 and 4 are both embedded in this chapter. **Paper 2** is a descriptive personal reflection, written as part of the research process and drawing on the philosophy of hermeneutic (interpretive) phenomenology (Harris, 2017a). **Paper 4** explores the meaning of supporting a loved one with MND to die (Harris et al., 2019). In the second paper, I use autoethnography[8] to connect with broader meanings and gain a greater understanding of the experience of approaching death. Hughes and Penning (2007: 7) compare and contrast other qualitative approaches with autoethnography; for example, researchers using a hermeneutic approach ask, 'What are the conditions under which a human action occurred in the past, making it possible to interpret its meaning in the present?' Researchers using autoethnography ask, 'What am I learning by exploring my identities, power, privileges and penalties in one or more cultural contexts?' (Hughes and Pennington, 2017). This narrative will explore how I interpreted the differing qualitative approaches which enable reflection.

Starting out as a postgraduate student, I had both personal and professional experiences of MND. These experiences encompassed supporting my mother living through the trajectory of PBP MND, including when she was unable to move or communicate her needs, priorities and preferences at the end of her life, and my experience as an occupational therapist caring for other people with ALS MND. Thus, I had experience of person-centred care from the perspectives of both the receiver and the provider. These experiences created a number of challenges for me, and created a tension between my need to develop as a researcher and a background of personal loss.[9] This is something that still impacts on my writing about MND.

My situation is not unique; others have used their own experiences of MND to develop as researchers, and to interpret the experiences of other people living with, or affected by, MND (Clabburn, 2018; Sakellariou, 2013). Clabburn (2018: xi) was a young boy when his father was

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[8] Autoethnography is a research method that uses personal experience (auto) to describe and interpret (graphy) cultural texts, experiences, beliefs and practices (ethno) (Adams et al., 2015: 1).

[9] Loss is defined as the state of being deprived of or being without something one has had, or as a detriment or disadvantage from a failure to keep, have or get (Humphrey and Zimpfer, 2008: 3).

diagnosed with ALS MND, resulting in lasting memories of observing his father struggle to remain in control, with his mother and family caring for him at home until his admission into a hospice. He missed his father's voice and would find comfort in replaying an answerphone message recorded by his father prior to his diagnosis with MND. His past experiences have enabled in-depth research into the benefits of creating a digital legacy, both for the person with MND and for young family members. Sakellariou (2013: 12) was also a young man when his mother was diagnosed with PBP MND, and remembers observing her struggle to manage her loss of speech, swallowing, movement and breathing. He reflects on his positionality in terms of what he was exploring and, thus, also on his insider-outsider position throughout the study, using this explicitly to illuminate findings. However, there is still limited research using the lived experiences of being both a family carer and a professional in the field of MND.

Gadamer (1975) notes that every act of understanding involves reflection on one's preunderstandings. Preunderstandings become obvious through confronting different prejudices or beliefs (Fleming et al., 2003). The process of reflection began for me with reviving memories of my mother's illness and then writing a timeline of the events and experiences that challenged my preunderstanding of person-centred care. Many of the events and experiences had occurred within the care context but would not be in any written report. The timeline that I created revealed and examined my preunderstanding of the events and experiences of MND.

Reflective practice in nursing and healthcare is seen as essential for continued professional development (RCOT, 2017; NMC, 2020) and maintaining patient safety (Collins et al., 2015); for me it was a cathartic process because it enabled me to make sense of experiences (Johns, 2009), although I was not consciously aware that I was using it as such. Kim (1999: 1207) indicates that the descriptive phase of reflection invites professionals to 'open a door that has been closed behind, and to look back into the past'. This phase of reflection was about opening a closed door and looking back at my experiences of a devastating and extremely challenging journey. Potentially, 'opening a door' had enormous implications for me, as a daughter and a healthcare professional, and it might be said that it was a courageous act. As a daughter, I am letting others (the readers of my reflective paper) into our lives, an exceptionally private world once shared with only those

my mother cared for. As a healthcare professional and researcher, however, I am raising awareness of actual practice in a specific clinical situation, while also including the circumstances, actions taken, and my thoughts and feelings.

In a similar attempt to raise awareness of actual practice in a specific clinical situation, Koch (1998) returns to unpublished observational notes generated in 1990 for her PhD study, to revisit her experiences as a nurse and researcher on the geriatric wards in Australia for seven months. Her research project was inspired by Munro, an Irish man with dysphasia who was admitted to the ward for a stroke assessment. The aim of the project was to allow patients' voices to be heard, so she asked, 'What is it like to be a patient on a geriatric ward, and what is it like for those who cannot talk?' She put herself in his world. Koch (1998: 1186) stated, 'I believe that the voices of those marginalised in our culture need to be heard.' I also recognised that my mother's voice needed to be heard.

Paper 2 acknowledges that my mother was so much more than a patient with MND: she was the matriarch of our family, whose MND affected her body but not her mind. She was a courageous woman, who was determined to remain in control of her life and her death, despite adversity. Thus, I acknowledge her strength and capability, although she was locked within her body, while also affirming the inherent values of being a daughter and a healthcare professional in the MND care context.

## 3.2 PAPER 2

Harris, D.A. (2017a). 'Supporting a loved one living with motor neurone disease.' *Palliative and Supportive Care,* 15 (1): 141–142.

**Link to paper:** https://doi.org/10.1017/S1478951516000134

**On journal website:**

HTML views             4

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Abstract views       469

**On ResearchGate:**     20

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### 2. Title of PhD Proposal

A Lifeworld Approach to palliative and supportive care

### 3. Title of Research Output

Supporting a loved one living with motor neurone disease

### 4. Candidate's contribution to the research output
#### (State nature and approximate percentage contribution of each author)

Denise Harris 100% contribution

### 5. Co author(s):

I confirm that the contribution indicated above is an accurate assessment of the contribution by the candidate to the research output named in section 3.

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## ESSAYS/PERSONAL REFLECTIONS

# Supporting a loved one living with motor neurone disease

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In the present, I could only anticipate what was going to happen in the future. My mother had been my world, and I had to imagine a lifeworld without her being there for my family and I. She accepted the "givens" of being diagnosed with motor neurone disease (MND), and she was relieved to finally know what had caused her speech loss. I just want to emphasize what this loss of speech meant to her and us all at that time. That once-familiar voice was gone, communication replaced by a pen and paper in the early months and then by use of a lightwriter. We listened to Professor Stephen Hawking responding to us through the lightwriter. I missed the phone calls giving me those words of wisdom, sometimes well received, and sometimes not. She still looked the same, though she seemed to have lost those taken-for-granted facial muscles that enable us to smile, laugh, frown, gasp. Her emotions were difficult to control; sometimes she laughed inappropriately. All her life she had tried to lose weight; without effort, the weight now dropped off her because she was not able to swallow many foods. Food was pureed: though it may have tasted the same, it was unrecognizable. Within months, she had gone from a size 16 to a size 10, never more apparent than the day she opened the door to me, finding it difficult to hold her balance while holding up her oversized trousers.

*Walking the walk of diagnostic reasoning.* At the consultation, my mother did not ask any questions or read the information provided about MND. I was grateful that the consultant neurologist and the MND nurse did not elaborate on her prognosis. Only grateful because I wanted to keep hope alive. That discussion might have included information on how she would soon experience loss of muscles impacting on her whole body. My mother, brother, and I traveled home from the hospital in silence. I believe we were experiencing what Brown (2003) defines as "existential shock." I continually questioned why the consultant had not elaborated on how the illness would progress. I considered how he might discuss the impact of MND on the person at the next consultation. Only there would not be a next consultation. She had chosen not to be a patient at the MNDA clinic—but to receive support from the community palliative care team. I understood why she made this choice. She had sat in the waiting room at the MNDA care center observing people further on in their illness and in wheelchairs. She did not want to experience that again.

The consultant had asked that she consider having a PEG tube inserted. This was sold to her as a technique to provide quality of life. I sat in silence, thinking, "What quality of life, when she will soon be unable to move?" "How will she cope with not being able to move or communicate?" We were living on borrowed time. The day following diagnosis, my mother asked me to contact her solicitor and arrange an appointment. There was an urgency to get things sorted—for example, to complete a living will, get papers in order, and make her wishes known. When the solicitor asked about her wishes for her funeral, my mother shrugged her shoulders and pointed to me, which indicated that this decision was mine. How would I know whether I was getting that one right? I decided to have this conversation again. The solicitor spent time alone with my mother while she crafted her final will and power of attorney. She made her needs, priorities, and preferences known through the use of the lightwriter. The solicitor was so understanding of her needs; perhaps she had done this all before. We made the return journey from the solicitor in silence. Discussions about life and death with your loved one are so difficult, especially when about finiteness. Who really wants to go there? I asked the palliative care team to provide support for these

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discussions, because she needed someone outside the family to talk with. In the days that followed, as we all attempted to come to terms with the thought of a future without her, she asked me whether I would have the PEG tube inserted. I replied that I would not.

*Life as before, but not as before.* My mother continued to prepare family meals and to drive, but only locally. Her spatial world was shrinking. Because she could only communicate through her lightwriter, being with others was embarrassing, and so she chose not to go to the Women's Institute meetings and to only take visits from her closest friends. Her sister would visit, and together they would go to the garden center for lunch.

The PEG tube was inserted two months after the initial consultation, by which time my mother was losing the ability to communicate through her lightwriter. Her hands were so weak she could no longer type, and she could no longer mobilize. She acquired a hospital virus, was finding it difficult to hold up her head, and was having difficulty breathing. She was now in need of "continuing" healthcare. Continuing healthcare involved 24/7 nursing care. The choice was to be discharged to a nursing home or to her own home.

Our being together would never be the same again. The home we once shared for so many family gatherings had been turned into a nursing home. The bedroom had a hospital bed with an airwave mattress, a gantry hoist, and a PEG feeder. The dining table where we shared so many family meals was now a nursing station, where notes were written and handovers done. The conservatory was a storeroom for the PEG feeder, syringes, medication, and incontinence pads. The home had lost its homely smells, replaced by medical odors. End-of-life drugs were on hand, although locked away. The human rights of freedom and choice were compromised, as extended family members had to seek permission to visit. Power of attorney ensured that my brother and I could be there 24/7 if needed, and that we were consulted for all medical and financial decisions. There were times when I wanted to run as far away from this lifeworld as I could, but I still had a mother, who was trapped in her body and in her own world.

Every hour of every day, I thought about how being trapped in her body and in her own world must have felt, and so I found ways of helping others understand her needs. Not being able to move those heavy edematous limbs: hands, arms, feet, legs, body, and head, I requested that physiotherapy prescribe a passive range of movements for the nurses to do daily, to relieve those heavy limbs. People living with MND retain their senses, which are possibly even more intense than before. My mother was hypersensitive to light, and so the curtains remained closed, the room dimly lit. Her sense of smell became more acute during an early stage of her illness trajectory. She could no longer tolerate wearing perfume, or to go to the hairdresser. It was unbearable for her to experience the smell of food cooking, when she could neither eat nor drink, and to have an itch she could not scratch. The loss of dignity: not being able to toilet herself anymore or raise awareness that her pad needed changing, lying still in one position, observing others come and go, listening to them tell their stories of life outside the four walls of what was now her lifeworld: the bedroom. I introduced a communication board with all her different needs and senses. Though communicating her needs was difficult, the nurses gave her the best possible care they could. My mother's needs could be understood by searching through the sensory board, and her blinking her eyes for yes and moving her head slightly for no.

*Observing existential suffering.* During the final months, my mother cried continually, though her physical and psychological pain were under control. What I thought I was observing was existential suffering. She did not want the lifeworld with MND anymore. Dignity and respect were paramount in this context. The whole family, nurses, carers, and palliative care team achieved so much together. I woke early on the morning of her death and rang for the nurse on duty. She told me to get there as quickly as I could, but to be careful. The nurse who helped our mother out of this world said, "You must keep talking to her; she can still hear you." I will never forget being there at her end of life with my brother, husband, and sister-in-law, as we watched a single tear fall down her face. The sun was shining and the birds singing. Our mother had made her end-of-life journey her own. Just as midwives usher babies into the world, the nurse in charge ushered our mother out of her lifeworld, and we were by her side.

*The demands of getting it right.* I continually reflect on whether we got our mother's needs, priorities, and preferences right. I take comfort in the fact that she was cared for at home and died with those who loved and respected her. I wish that I had been brave enough to have had those end-of-life discussions—when she could still communicate.

## REFERENCE

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## 3.3 LINKING NARRATIVE FOR PAPER 4

Early in my postgraduate studies, I discussed with the academic staff how my previously published, descriptive personal reflections could be developed. We agreed that Paper 2 could be further developed to extend the literature by exploring the meaning of supporting a loved one dying with MND. Bochner and Ellis (2016: 68) suggested:

> *Sooner or later, life brings each of us unanticipated and unwanted darkness, sadness, frustration, and loss. These moments leave their mark on us. One could say our bodies are tattooed by them, though not by choice. Heidegger (1962) referred to such moments as 'simplifying' insofar as they make us aware of what is extraneous and peripheral and the possibilities that exist to dedicate one's life to what is definitively essential. Neither Heidegger nor anyone else can tell you what is truly important for your life.*

Returning to my previously published work (Paper 2), I revisited reflections that had been painful. They took me back to the family home, to images of my mother lying in bed, locked in her body, unable to move and communicate, and to the sadness in her eyes which caused me both physical and emotional pain. The experiences left their mark on all my family. I consider it essential to present my personal and professional experiences of supporting my mother to die, for two reasons: firstly, to find release from past experiences and, secondly, given the limited autoethnographic studies on prolonged death and family loss, to have a positive impact on care provision in the future. These reasons intertwine and will be explored through this narrative.

The history of autoethnography dates back to the 1970s (Heider, 1975; Hayano, 1979) when the term was used to describe researchers who conducted and wrote ethnographies of their own culture but did not include their personal experience (Adams et al., 2015). However, Adams et al. (2015) suggested that the core ideal of autoethnography is to offer an account of personal experience to fill gaps in the existing literature and show how generalisation in research frequently masks important cultural nuances. It also helps to create texts that are accessible to academics and other audiences. Ellis (1993: 724) told the story of the sudden death of her brother and family loss and, in doing so, sought to engage readers in topics

that have been overlooked and to demonstrate a new form for representing these practices. Mathews (2019: 1), a mother and researcher, used autoethnography to help process grief[10] after the death of her son, and wrote 'pain started behind my eyes. I blinked a few times and kept writing. Tears well up stronger and spilled down my face, splattering on my keyboard.' Mathews suggested that her journal entries were lifeless, but they became a cathartic outlet, helping her to understand what she felt and why she felt that way. Then she discovered autoethnography, which triggered her brain 'out of inertia' and onto the path to 'becoming a thinking, functioning, adult again'. As Mathews suggested, autoethnography is a process of weaving personal experiences with academic research, to explore difficult issues such as death, grief and loss.

Similarly, Hocker (2011) explored the experience of her family as they accompanied their mother/wife to a log cabin where she chose to spend her last days away from medical care. The family took on the role of primary caregivers, and experienced anxiety as the illness progressed more quickly than they had anticipated. They learned that death has its own trajectory, and that others are only there to provide love and support during the process of dying.

This autoethnography (Paper 4) explores my experiences as my family accompanied our mother home, where she chose to spend the last weeks of her life with continuing 24-hour health care. Her illness progressed more slowly than we had anticipated. As Ellis (2007: 14) suggested, 'our stories about people who have died serve as memorials that keep our loved ones alive in our memories'. Ten years later, I sit here at my laptop, reviewing my published papers in order to write a commentary on my collected work, and consider that the reason I have continued with research is not just to bring personal experiences to knowledge, but to find a release. Bochner (2016: 282), reviewing his work for a volume, found he had a sudden urge to reopen the door he had closed, writing, 'Could one more conversation together [father and son] have shaped a different memory of who we were and what we meant to

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[10] Grief is the pain and suffering experienced after loss; mourning is a period of time during which signs of grief are shown (Humphrey and Zimpfer, 2008: 3).

each other?' Similarly, I ask if one more conversation [mother and daughter] could have shaped a different memory of dying with MND.

Ethical considerations are important to me, both as a healthcare professional and as a researcher. The context of these reflections raises confidentiality issues: even though the main character around whom the reflections are based is dead. Early in my postgraduate studies, I discussed with my family my intention to use our shared experiences of caring for our mother, and they gave their consent. As Bochner and Ellis (2016: 150) observed, 'the dead can't talk back, but others in the community, who were in a relationship with you and those who have died, will have feelings about, and reactions to, what you write.' Chang (2016) noted that it is extremely difficult to protect others intimately connected to the known character. I have done everything in my power to minimise hurt, and to protect the identities of those in my autoethnographic story (Bochner and Ellis, 2016). This involved careful selection of the events and experiences included as a means of protecting myself and others.

In writing this narrative, I was interested in other family members' experiences of supporting our mother to die. One said:

> *Mum's journey was what it was, because of you, your knowledge, your skills, your intervention and your tenacity. The rest of us were onlookers and supporters, but you were the lead, you showed each of us what to do; you challenged what the carers were supposed to be doing, and you questioned some of the professionals, and rightly so. Because of you, Mum had a better end of life than a lot of people, and she knew that. She was your Rock, and you were hers. (Anonymised family member[11])*

I sat for many hours, observing the nurses coming and going, doing what they do very well, that is, caring for their patient's basic human needs. Despite this, my mother was experiencing existential suffering[12] towards the end of her life. I had to challenge other professionals in

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[11] Reflective Journal Extract

[12] Existential suffering towards end of life correlates with concepts of hopelessness, being a burden to others, the loss of a sense of dignity, and the desire for death or loss of the will to live (Chochinov et al., 2006).

order to safeguard my mother. My experiences are not unique.  Quinney et al (2017) also suggested that nurse family carers are not prepared for being accountable and responsible for coordinating care. Being a professional carer means that there was no avoiding my knowledge of the disease's progression or the treatments, and this contributed significantly to my anxiety. In Paper 4, I have used autoethnographic stories to explore my struggles to support my mother to die in the way she wished and ensure that she was consulted in all end of care decisions. In the process of being a daughter and a healthcare professional in the MND care context, I experienced considerable losses.

## 3.4 PAPER 4

**Link to paper**:  https://doi.org/10.12968/ijpn.2019.25.6.284

**On journal website:**

HTML views            67

PDF views             65

Abstract views        351

**On ResearchGate:**     44
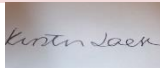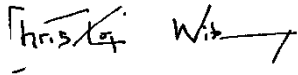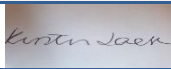
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## Research and Knowledge Exchange
## Graduate School
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**2. Title of PhD Proposal**

Interpreting End of Life Experiences in Motor Neurone Disease

**3. Title of Research Output**

Making her end of life her own: Further reflections on supporting a loved one with motor neurone disease

**4. Candidate's contribution to the research output**
**(State nature and approximate percentage contribution of each author)**

Denise Harris 80% Contribution
Dr Kirsten Jack 10% Contribution
Dr Christopher Wibberley 10% Contribution

**5. Co author(s):**

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**6. Statement by Director of Studies/Advisor**

I confirm that I have read the above publication and am satisfied that the extent and nature of the candidate's contribution is as indicated in section 4 above.

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|---|---|---|---|
| | (Director of Studies/Advisor) | | |

**7. Signature of Faculty Research Degrees Administrator**

| Signature: | Deborah Bown | Date: | 02.07.20 |
|---|---|---|---|
| | (Faculty Research Degrees Administrator) | | |

# Making her end of life her own: further reflections on supporting a loved one with motor neurone disease

Denise Andrea Harris, Kirsten Jack and Christopher Wibberley

## Abstract

**Background:** People can live for many months without knowing why their body is failing prematurely before being diagnosed with motor neurone disease (MND); a terminal neurodegenerative disease which can be experienced as 'devastating' for the person and their family. **Aim:** This study aimed to explore the meaning of supporting a loved one with MND to die. **Methods:** This study uses reflection and autobiographical story to connect with broader cultural, political and social meaning and understandings of dying. **Findings:** Four themes were identified relating to the end-of-life trajectory of MND. Loss of person (lived body experienced in silence); loss of relationships (lived relations are challenged); loss of home and loss of time (lived space and lived time take on new meaning); loss of future (dying—facing it alone). **Conclusion:** Dying with MND is a complex phenomenon. When a person can no longer move and communicate, relationships between those involved in end-of-life care are challenging. A person with MND needs the support from those acting as power of attorney to make their end of life their own, and they themselves need support to find meaning in their suffering. This autoethnographic reflection provides vicarious experiences for nurses and other healthcare professionals working with people with MND and similar conditions.

**Key words:** ● Autoethnography ● Family carers ● Motor neurone disease

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People can live for many months without knowing why their body is failing prematurely before they are diagnosed with motor neurone disease (MND), a terminal neurodegenerative disease, which can be experienced as 'devastating' for the person and their family (Harris et al, 2018). The disease can take away a person's ability to move and their ability to communicate, which presents challenges for all those involved in their care as they reach the end of life (Harris, 2017a). These challenges are exacerbated by the high levels of responsibility for those within the MND care triad: the person with MND, the family carer, and the healthcare provider (Hogden et al, 2017).

The person with MND experiences multiple losses and uncertainty (Harris, 2015; Harris et al, 2018). They experience being out of touch with others and unwelcome contact and physical interventions from healthcare professionals (Allen-Collinson and Pavey, 2014). This results in changes to how they experience the world and their family and significant others (Brott et al, 2007). The family carer also experiences the process of dying with MND which can take place over a long time-frame (O'Toole, 2011), resulting in anxiety and distress for the patient and an extensive burden for their carers (Whitehead et al, 2012). Other studies have suggested that caring is a relentless commitment (Aoun et al, 2013), resulting in multiple losses (Oliver and Aoun, 2013). Such losses include the loss of self and identity (Ray and Street, 2007), control, choice and increased isolation (Holkham and Soundy, 2018). Healthcare professionals experience challenges in managing MND, such as: building relationships with patients and families in their homes, preventing family carer burnout and breakdown, providing tailored care, and ensuring good working conditions in the

patient's homes (Lerum et al, 2017). Current evidence suggests that the person with MND and their family experience multiple losses, however, this present reflection further supports an understanding of how these losses are experienced and the choices made around dying. This study aims to extend the literature by exploring the meaning of supporting a loved one dying with MND, so it can enhance nurses' and other healthcare professionals' understanding of dying for this client group.

## Design

One of the authors (DH) supported by the other two authors, used an autoethnographic research design to reflect on memories of her mother's dying to develop a story that connected with the broader cultural, political and social meaning and understandings of supporting a loved one to die (Ellis, 2005; Maréchal, 2010). Bochner and Ellis (2016, p.68) suggested autoethnography involves returning to scenes that 'tarnished us, the ones hovering in our memories awaiting an opportunity for us to take pen in hand and write ourselves into a moment of transcendence, however fleeting', thus going beyond past memories and bringing forward meaning. The initial reflections have been re-visited to explore meaning, using existential philosophical ideas of: corporeality (lived body), spatiality (lived space), and temporality (lived time), relationality (lived relations), and mortality (death) (Heidegger, 1927/1962; van Manen, 2014). The term existential is often used to describe fear, anxiety, and other feelings that are caused by thinking about human existence and death (Collins Dictionary, 2019). This style of autoethnography (combining reflections and the literature) in a way that uses the literature as data, was influenced by the work of Wibberley (2012) and Bochner and Ellis (2016).

## Method

Chang (2016) has suggested that an autoethnographic study should: use authentic data, follow a reliable, transparent and ethical research process, resulting in an interpretation of the sociocultural meaning of the autoethnographer's personal experiences and engagement with the existing literature. This involved, for this study, returning to reflections already written as a timeline of events and experiences (Harris, 2017a). Reflections (written in italics) were grouped together—initially organising them under concepts articulated by van Manen (2014) such as lived relation, lived body and lived space and lived time. Subsequently, they

were developed through the identification of inductive themes. Questions were asked of the data, for example: how is the body, self and others, space and time, and dying experienced with respect to the phenomenon being studied? This enabled the autobiographical story to be connected to the broader cultural, political, and social meanings and understandings (Ellis, 2005; Maréchal, 2010).

## Ethical considerations

As no participants were recruited, a full ethics review was not required. In the process of autoethnography, others (family and professionals) are also intertwined in the shared experiences; and the ethical implications of protecting the self and others are considered as potential limitations of undertaking autoethnography. Thus no identifying features have been discussed. An open discussion of clinical incidents in the care setting would have brought another layer of meaning; however, it was acknowledged that the 'professionalism of colleagues should be expressed with due care to protect the integrity and reputations of that person' (Royal College of Occupational Therapists, 2015, p.26).

## Findings

The findings of this study were about one individual losing her ability to move and communicate, resulting in her becoming dependent on others; as a result of this her home became a clinical setting supporting her to die. Four themes were identified relating to the end-of-life trajectory of MND. Loss of person (lived body experienced in silence); loss of relationships (lived relations are challenged); loss of home and loss of time (lived space and lived time take on new meaning); loss of future (dying-facing it alone). The themes represent the phenomenon under study (Finlay, 2011), that is, the meaning of supporting a loved one with MND to die.

### Loss of person (lived body experienced in silence)

The body experienced in silence has particular significance, especially as DH's mother (the matriarch) lost her ability to communicate early into her illness trajectory. Within months following diagnosis she experienced loss of movement, she became dependent on others for her survival towards dying. NHS Community Services hired a team of nurses to provide essential 24-hour nursing care in her own home. DH's mother's body lost its muscle mass and lay

heavy and limp on the bed. Her eyes followed others around the room. She lay in silence unable to say whether she wanted to be repositioned on her pillow, or turned on the bed, or whether she wanted this existence anymore:

'That once-familiar voice was gone, communication replaced by a pen and paper in the early months and then by use of a light writer. I missed the phone calls giving me those words of wisdom, sometimes well received, and sometimes not. She still looked the same, though she seemed to have lost those taken-for-granted facial muscles that enable us to smile, laugh, frown, and gasp. Now she lay in silence waiting to die. Every hour of every day, I thought about how being trapped in her body, and in her world must have felt, and found ways of helping others understand her needs. The loss of dignity of not being able to toilet oneself anymore, or raise awareness that the pad needs changing; lying still in one position, observing others come and go. Listening to them tell their stories of life outside the four walls of what was now her lifeworld: the bedroom. Our being together would never be the same again.'

Bauby (2004) wrote about his experience of having had a brainstem stroke and finding himself unable to move and communicate, receiving 24-hour care. The speech and language therapist helped him to communicate his experiences of being 'locked-in' through the movement of one eyelid. He described his everyday experiences as being: 'paralysed from head to toe, the patient, his mind intact, is imprisoned inside his own body, but unable to speak or move' (p.12). Ray and Street (2006, p.35) described how family carers experience the 'visible body' as a constant reminder of the disease, and the 'dependent body' as in need of physical and emotional care. DH also observed her mother with MND 'locked-in', unable to move and communicate, as distressing for all those involved in care. She felt overwhelming grief for the loss of her mother.

### Loss of home and loss of time (lived space and lived time take on new meaning)

During DH's mother's illness, the family home became a clinical setting; with the lived in space altered by these adaptations. Thus, what was the family home took on a new meaning for all of those involved in the care triad. As a healthcare professional DH was used to the

culture of healthcare settings and the roles of those within such settings; and she could, with difficulty, accommodate the changes to the home—both in terms of environment and social expectations. For the rest of the family, these changes meant observing different cultural ways of being. DH's reflections bring forward how the home as a clinical setting lost part of its essential homely nature:

'The home we once shared for so many family gatherings became a clinical setting. The bedroom has a hospital bed with an airwave mattress, a gantry hoist, and a percutaneous endoscopic gastrostomy (PEG) feeder. The dining table where we shared so many family meals is now a nursing station, for notes and hand overs. The home has lost its homely smells, replaced by medical odours. End-of-life drugs are on hand, although locked away.'

Heidegger (1927/1962) suggested all places we inhabit offer us the possibility of home through how we 'dwell' there (Polt, 1999). DH's reflections bring forward how the home as a clinical setting lost part of its essential homely nature. So as Holkham and Soundy (2018, p.494) have suggested the family carers of people with MND experienced 'being captive' in their role. This experience of being captive meant her being there to ensure her mother was receiving person-centred care, as she understood it. As Ray et al, (2012) have suggested, family carers of people with MND experience concerns for the future, when plans are not communicated or enacted, thus reducing the capacity to 'preserve personhood'. However, her being there throughout the dying trajectory was challenging:

'There were times when I wanted to run as far away from this lifeworld as I could, but I still had a mother who was trapped in her body and her world.'

Heidegger (1927/1962) suggested that time has to be understood in terms of phenomena such as 'heritage, fate, and death' (Polt, 1999, p.110), thus including elements of past, present and future. DH reported how lived time was experienced in the following way: the past was embedded in our memories, the present was unrelenting, and the future was anticipated with anxiety. Similarly, Carlander et al (2011) suggested that for family carers of people with cancer or heart disease 'the future had become unplannable, the present is never-ending, and the past was seen in a different light'. Lived space

*Every hour of every day, I thought about how being trapped in her body, and in her world must have felt, and found ways of helping others understand her needs.*

and time for all those supporting a loved one to die, regardless of a person's diagnosis, takes on new meaning. Thus, the experiences of supporting a loved one to die, over a prolonged period, can be an overwhelming responsibility.

### Loss of relationships (lived relations are challenged)

DH described the loss of the relationship between mother and daughter, who trusted the care of her loved one to others (nurses and healthcare professionals). She reflected: being together would never be the same again. As a healthcare professional, DH had a prior understanding of the complexity of providing continuing healthcare in a person's home; alongside family members who have increased concern for their loved one. Reflections suggest a loss of relationships can also have a profound impact on family carers:

'The human rights of freedom and choice were compromised, as extended family members had to seek permission to visit the home. Power of Attorney ensured I could be there 24/7 if needed, to ensure that I was consulted for all medical decisions.'

Heidegger (1927/1962) suggested the world is a context for having meaningful human relationships, and defined human relationships as being governed by two separate phenomena: 'leaping in and leaping ahead'. Leaping in is a more common phenomenon, it involves doing something for someone else, thus relieving the need of the other to do it.

Leaping ahead is a less common phenomenon; it is directed toward the other's way of existing, thus it is authentic (Polt, 1999). The example given by Polt (1999) is a teacher who provides students with the answers, or a teacher who provides students with questions and encourages them to search for answers.

These philosophical ideas can be applied to nurses and other healthcare professionals in the acute hospitals who provide patients with care based on their knowledge, or nurses and other healthcare professionals who provide end-of-life care based on the person's lived through experiences. DH is suggesting if nurses and other professionals 'leap in' for the other, as in her mother's case, then the other is at risk of losing their past identities. To 'leap ahead' involves enabling the other to be recognised as a person until end of life without losing their identity, and the need to be involved in making choices (van Deurzen and Arnold-Baker, 2005; Kennedy, 2016).

### Loss of future (dying—facing it alone)

DH suggests a family carer experiences a loss of a future with their loved one. Their loved one, on the other hand, is facing dying and knowing that this is one of life's journey that has to be taken alone. The loss of communication meant DH's mother's words and gestures were no longer possible; although DH could catch her mood and feelings of despair through her eyes. For the nurses, carers and family members this was less obvious. Reflections act as a reminder of how difficult it was to observe a loved one experiencing suffering:

'We tried so hard to ease her suffering, and just being there was distressing. The regular night nurse said she is also traumatised by her continuous cries, and she calls it 'wailing'. I thought my mother wanted to die, but there was nothing we could do to speed up the dying process. I made an independent decision to ask for her to be admitted to the local hospice.

The hospice consultant visited, he spoke to my mother, and she stopped crying to listen. He discussed how the care she was receiving at home was no different than what she would receive in a hospice setting. He made recommendations to stop one medication that he believed was the cause of her distress, and made changes to the amounts of food and drink through the percutaneous endoscopic gastrostomy. He also recommended that palliative care is provided by preferred nurses who are known to the patient and family. He believed these changes would result in her experiencing peace. In the weeks that followed, my mother was more settled, and when the night nurse asked whether she was afraid to die, she shook her head for 'no'.'

Heidegger (1927/1962, p.251/295) defined being toward the end (death) as 'non-relational and not to be outstripped'. Non-relational refers to acknowledging that death is individual, and not be outstripped refers to its importance (Critchley, 2009). For this reason, people are encouraged to discuss and document their wishes and priorities for dying early into their illness trajectory while a person can still communicate (Harris et al, 2011; Preston et al, 2012). The importance of suffering at the end of life cannot be ignored (Bates, 2016). Murata and Morita (2006) suggested suffering is caused by 'loss of relationships (with others) loss of autonomy, (independence, control over future, continuity of self), and loss of temporality (the future)'.

Boston et al (2011) suggested that the way suffering is treated is not as well understood. As Andershed (2006, p.1162) suggested relatives can feel supported and experience peace of mind knowing that professionals are acting in their 'dying loved one's best interest'. Thus, it came as no surprise when the visiting hospice consultant discussed his recommendations with DH's mother, and she consented by blinking her eyes for 'yes'. As such, her mother was respected as a person, and given the freedom and responsibility for her dying, and she remained in control.

## Discussion

Palliative principles of care are essential to support a person with MND to die, regardless of the care context (Oliver and Aoun, 2013). Not everyone has a family to support them to die (Wintour, 2014), or will receive palliative care at their end of life (Dixon et al, 2015; National Council for Palliative Care, 2010). The findings of this autoethnographic study illustrate the complexity of achieving an ideal or good death. A good death is associated, in so far as is possible, with giving back control to the person to ensure the care they receive is following their wishes and preferences (Smith, 2000). In caring for her mother, the reality of person-centred care was illuminated for DH. These findings illustrate the complexity of person-centred care provision and how difficult it can be for nurses and other healthcare professionals to understand the end-of-life preferences. Having an ability to appreciate the unknowns about the end-of-life care preferences can facilitate knowledge development in this aspect of practice.

The findings of loss of person (lived body experienced in silence) indicate that family carers are observing their loved one locked-in their body, may have a profound impact on their emotional wellbeing. As Ray and Street (2007, p.41) suggested, family carers experience 'emotional labour' arising from the responsibility of caregiving, but feel that they have to regulate their own emotions for the sake of their loved one. As a family carer, DH was immersed in supporting her loved one to die and did not approach nurses and healthcare professionals to talk about her emotional response to observing a loved one locked-in. The loss is unique for each person (Ray and Street, 2007), and formal counselling is recommended (O'Brien et al, 2012). Anticipatory grief is recognised as an emotional response to the loss of a person before death (Royal College of Nursing (RCN), 2019). Therefore, nurses and other healthcare professionals could actively support family carers to talk about their emotional responses to the loss of a person.

The findings of loss of home and loss of time (lived space and lived time take on new meaning), contradicts the existing literature that suggests dying at home is a good experience. Soloman and Hansen's (2013, p.125) case study findings suggested that hospice care at home provided 'a richly familiar, quiet, and safe environment for being together over time'. DH's individual experience suggests lived space became an unfamiliar, busy, and anxiety-provoking environment for being together over time. It is recognised that community nurses can keep people at home, in recognition of their wishes and preferences (Nyatanga, 2019). To achieve dignity in dying, Henry and Hayes (2013) suggested delivering person-centred end-of-life care that is sensitive to the circumstances, wishes, and priorities of the person, their family, and friends. The call is for nurses and other healthcare professionals to have an awareness of self and others in the care setting. As documented in the end of life care strategy: 'how people die remains in the memory of those who live on' (Department of Health and Social Care, 2008, p.1).

The findings of loss of relationships (lived relations are challenged) suggest palliative and end-of-life care in the community can provoke strong emotions. Soloman and Hansen (2013, p.131) suggested their case illustrates what may be construed as 'an ideal or good death'. DH's experiences suggest that achieving a good death was difficult, and in the care setting her mother lost her past identities. McCormack et al (2018,) recognised the importance of knowing the person if person-centred relationships are to exist. Kennedy (2016) suggested that a way of getting to know a person is through life storytelling; this will help healthcare professionals view the patient receiving the end-of-life care as a person. Findings from this autoethnographic study suggest that nurses and other healthcare professionals could extend their focus of care from the present and future, to include the past, thus providing a whole-person perspective.

The findings of loss of future (dying—facing it alone), reflect how family carers may have anxiety for the future without their loved one, but at the same time, they do not want to see their loved one suffering. The RCN (2019) suggested that people at their end of life should be seen as individuals and involved in all discussion and decisions about their care. The person with MND at the end of life may still be

able to communicate their choices, for example, by blinking an eye (Doughty, 2012) and every effort should be made to support a person to make their end of life their own.

## Methodological considerations

The advantages of writing an autoethnographic-style paper are considered to be the way it allows the report of 'rich data' providing readers with a deeper understanding of a particular phenomenon (Pavlenko, 2002). The focus of this paper is the phenomenon of supporting a loved one with MND to die; however, it has to be acknowledged that shared experiences are unique to each person, and no two people will experience a phenomenon in the same way. Méndez (2013, p.282) referred to:

'the ease of access to data since the researcher calls on his or her own experiences as the source from which to investigate a particular phenomenon.'

However, it can be difficult for a researcher to return to past experiences to provide rich data for others.

DH feels, that it has been an 'existential struggle' to move life forward given the nature of past experiences (Ellis and Bochner, 2000, p.746), and not withstanding this particular limitation, it is because of past experiences that she came to this research in the first place and wrote it in order to make a difference for others. According to Holman Jones (2005, p.764):

'autoethnographers view research and writing as socially-just acts; rather than a preoccupation with accuracy, the goal is to produce analytical, accessible texts that change us and the world we live in for the better.'

In the process of conducting this autoethnography, the authors have reflected on past experiences and linked them with existential philosophical perspectives; and engaged with the existing literature on family care giving and dying. The intention was not to analyse this autoethnographic account as another language (purely theoretical), thus losing its meaning (Ellis and Bochner, 2000). Instead, it was to illustrate new perspectives on past experiences. The consumers of this autoethnography will determine whether it provides not only a description of personal experiences but also a 'sociocultural interpretation of such experiences' (Chang, 2016, p.444).

## Conclusion

Dying with MND is a complex phenomenon especially if the body is experienced in silence, so a person can no longer take part in decision-making about end-of-life care. People are dependent on others to act in their best interests, and this challenges relationships for all of those involved in end-of-life care. Palliative care perspectives are essential to support a person to die, regardless of the care setting, where lived space and time take on new meaning. DH acting as a power of attorney wanted to ensure that 'best interests determinations' reflected the specific guidance of the Mental Capacity Act, 2005, without which the other person's dying may have been taken away. Thus, people with MND need the support from those acting as power of attorney to make their end of life their own. IJPN

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## Key points

- Dying with motor neurone disease (MND) is a complex phenomenon, particularly when a person can no longer move and communicate; thus relationships between those involved in end-of-life care become challenging
- People with MND and their family experience: multiple losses (especially loss of identity); uncertainty; and other concerns. As the process of dying potentially takes place over a long time-frame, the potential for anxiety and distress is exacerbated
- A reflective approach to experience, which draws on broader social and cultural theory, may enhance the understanding of dying as a phenomenon.
- Autoethnography and other autobiographical accounts may provide vicarious experiences for nurses and other healthcare professionals working with people with MND, and similar conditions

## Continuing professional development: reflective questions

- Think of a patient you have cared for at the end of their life; reflect on what you knew of their life before you started caring for them. Were there opportunities you missed to learn more about their life and those of their significant others?
- Identify a condition such as motor neurone disease (MND), carry out a search using Google Scholar (or other appropriate search engine) for any autoethnographic accounts of this condition; or search more broadly for autobiographies of people with this condition
- Reflect on your role as a healthcare practitioner, working with other formal and informal carers and the patient, how can effective communication across all of those involved be achieved?

## Correspondence

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## 3.5 CONCLUSION

I came to this study with a preunderstanding of MND; this is not something that I can eliminate or bracket, as it is always present in the background, and I bring it into focus to further understand it (Koch, 1995). The two papers have contributed to knowledge by providing a descriptive personal reflection of supporting my mother through three phases of the illness, and my observations of MND care. The hidden thread linking these experiences together is my loss. In returning to previously published reflections to explore the meaning of supporting a loved one with MND as they die, the research identifies four themes relating to the end of life trajectory of MND. It must be acknowledged that no two illness trajectories will be the same. However, while all people with MND will undergo the same procedures of investigation and diagnosis, and have to make decisions regarding life-sustaining treatments, not everyone needs to experience existential suffering at end of life, if they are supported in talking about their losses and if they determine when they wish to die. As Mathews (2019: 8) suggested, 'the more perspectives we can gather, the better equipped we will be to understand our future losses and respond helpfully to those around us suffering loss.'

At the time of writing, there were no autoethnographic studies on the meaning of supporting a loved one with MND to die. Two substantial literature reviews exist on the role of being a family carer for a person with MND, which reveal the burden, distress (Aoun et al., 2012), loss of control, inability to choose and isolation (Holkham and Soundy, 2018). Soloman and Hansen (2013) explored the lived experience of one patient with ALS MND and her family carers. Their findings suggest that being at home with hospice care provides a familiar, private and safe context to be together, focussing on relationships; thus, the study explored experiences of a good death at home. What contributes to a good death at home is that a person with MND has self-determination, controlling their end of life. For example, they may be able to choose where to die, voluntarily foregoing food and drink when they are ready for death, with family supportive of their end of life plans. Personal experience suggests that a good death at home when a person is no longer able to communicate brings many challenges to be overcome. Not everyone dying with MND will have the capacity to control their end of life, or will have family carers to support them to die as they would wish, and this remains a concern (Harris and Fineberg, 2011; Preston et al., 2012).

Since this project began, the MNDA (2016: 24) professional guidance for end of life care has acknowledged that people with advancing MND have significant care needs, thus increasing the demands on family carers. The guidance also acknowledges that professionals may experience compassion fatigue, defined as 'emotional, physical and spiritual exhaustion from witnessing and absorbing the problems of others'. It is concerning that professional guidance is not informed by qualitative findings that explore the multiple losses for family carers (Harris et al., 2019). Thus, family carers do not receive bereavement[13] support from specialist palliative care professionals.

This reflection on the methodology is informed by the notion of the insider–outsider in qualitative research (Dwyer and Buckle, 2009). As an occupational therapist, I have always engaged in reflection, thus, reflecting on my preunderstandings before meeting with the participants seemed a natural course of action. My claim to be an insider is based on my experience of being both a provider and a receiver of MND care. I cannot claim to understand the physical experience of suffering from MND, but I do understand what it means to be a daughter and a professional in the context of MND care. Returning to my published reflections to explore the meaning of supporting a loved one with MND to die involves telling stories. As Koch (1998: 1189) suggested, 'the aim of telling stories (or creating a research product) is to gain another or a different understanding, which at its best can influence the way we care for clients.' The findings will not only enhance an understanding of the experience but will also assist me personally and help my family to overcome our shared losses.

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[13] Bereavement is the reaction to the loss of a close relationship (Humphrey and Zimpfer, 2008: 3).

# CHAPTER 4 PHENOMENOLOGICAL RESEARCH

## 4.1 LINKING NARRATIVE FOR PAPER 3

Papers 3 and 5 are both embedded in this chapter to illustrate the journey of becoming a phenomenological researcher. The design, in both cases, is based on a hermeneutic (interpretive) phenomenological approach (Heidegger, 1927/1962; Gadamer 1975), which seeks not simply to describe human experience as it is lived but to reveal the obscured and to stimulate consideration of the meaning of the phenomenon within personal situatedness (van Manen, 2014; Quinney et al., 2017). The two papers draw on the same data, but differ in the aims of their analysis. **Paper 3** answers the research question 'What does it mean to be a person living through the illness trajectory of MND?' and researches the phenomenon of existence after receiving a diagnosis of MND, in the context of receiving healthcare. (Harris, 2015: 1579). From the data, it emerged that people with MND live with uncertainty throughout the trajectory of their illness, and that the phenomenon of uncertainty required further examination. The aim of **Paper 5** was to explore 'the meaning of living with uncertainty for people diagnosed with motor neurone disease (MND)' (Harris et al., 2018: 2062). This narrative critically appraises how I sought to uncover the meaning of existence with MND through time, through a co-constructed approach.

A life-story approach to data collection enables participants to reflect and talk about their lived-through past, experienced present and anticipated future. This approach was chosen because Heidegger (1927/1962: 311) suggested that humans exist in a temporal structure (past, present and future). In undertaking the data collection for these two papers, even once I had decided to adopt a hermeneutic (interpretive) phenomenological approach, other decisions were still required, following the disclosures made to me by interviewees. In writing this narrative, I am returning to my reflective diary to recall an experience that continues to cause me concern:

> *I travelled for an hour to the first participant's home. I recall sitting in my*
> *car feeling anxious about using a life story approach for the first time. In an*
> *earlier communication, he had expressed a concern that the time frame of*
> *four weeks between interviews one and two may be too long. I assumed that*

*his MND might be progressing to the pre-terminal stage. Naturally, I was surprised when the participant opened the front door to let me into his home. He was extremely welcoming, and he offered to make me a cup of tea. I observed that he had issues with upper body movement, as he could not reach to get the milk out of the fridge. He introduced me to his teenage son, and then asked that he leave the sitting room, so that I could set up my digital recorder. Once set up I was ready to ask my question, 'Can you please tell me the story of your life, since you first thought there might be something wrong with you?' The participant began to reflect and talk about his past, and I learnt about his identities as a professional sportsman, businessman, father and more. His story naturally moved on to the experienced present, and I learnt that MND was having a significant impact on his body, as well as about the professionals who had been involved in helping him adapt to his physical changes. I noticed that he was getting fatigued, and we agreed to take a break.*

*On turning off my digital recorder, I entered into some further discussion on the timeframe between interviews one and two. He was keen to talk about how his disease had progressed and how he does not wish to live unable to move. He spoke of an M.P. who had left it too late to help himself. He has intentions of ending his own life (ways of doing this discussed), while he still has the upper limb strength to do so. He stated that he has documented in a living will that he is to have no life-sustaining treatments and that his consultant is aware of his intentions, as are his family. Because he presents as a man with mental capacity, I feel that taking his own life is something he is actively planning for some time soon. He has expressed a wish to complete the study, and a date and time have been arranged (2/52). I reflected on this conversation on my way home and decided to talk to my research colleague. We agreed that I talk with the MND consultant about his disclosure (see Paper 3: 1586). Hopefully, in doing so, I am not crossing the boundary of trust developed today between participant and researcher, especially as the consultant is aware of his intent. At interview two, I learnt*

*that he had an appointment with the hospice consultant. (Anonymised participant)*

The legitimacy of this reflection is informed by 'Gadamer's philosophical hermeneutics which does not show us what to do but asks us to question what is going on while researching.' (Koch, 1998: 1182). In this reflection, I am asking the reader to consider the communication between the participant and the researcher. The participant needed to share his experience of life in crisis. Listening to this participant's story was difficult, emotionally. I felt his sadness at not being able to support his teenage children into young adulthood, and his frustration at not being able to pursue his previous occupations, which gave him identity, purpose and meaning. I felt his despair that he did not want his family to experience him being locked in his body. The participant may have felt that I was paternalistic in deciding what information he could disclose. As Resnik (2015: 19) suggested, 'some rules that restrict individual autonomy can be justified on the grounds that they help to maximise the overall balance of benefits over risks in research'. Potentially, my general intention to safeguard participants was restricting individuals' autonomy to talk freely about their thoughts of suicide. As another participant pointed out:

> *It does in some way weaken your ability to have a full discussion in a written research paper of the way in which people's minds change over that period, or don't change, and, you know, I hope it is useful to record that and to include that as part of your study. I am just saying that in some places people would sometimes have stronger feelings that they would want you to record, but I don't necessarily have those strong feelings, but even my own feelings have changed from initial thoughts of Dignitas type routes to how you want to end it in the end.*

The MNDA's (2016: 7) professional guidance now acknowledges that 'it is legal for someone to take their own life [or to] refuse life-sustaining treatments which they feel are no longer helpful or have become a burden.' The ESRC's (2020: 1) guidance states that 'researchers will need to consider additional ethics, concerns, or issues arising from working with potentially

vulnerable[14] people.' Whilst the participants involved in my study all had the mental capacity to make informed choices about how and when they would wish their life to end (DCA, 2017), people with MND are considered vulnerable because of their disability (ESRC, 2020). As a researcher in occupational therapy, I would find it inappropriate to follow the MNDA guidance above, because I have a duty of care to those people with whom I work, and it is important that my practice is both ethical and lawful. Paper 3 was written to explore the phenomenon of existence after receiving a diagnosis of MND, in the context of receiving healthcare, using data collected in four life story interviews.

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[14] Vulnerability may be defined in different ways and may arise as a result of being in an abusive relationship, age, potential marginalisation, disability or due to disadvantageous power relationships within personal and professional roles (ESRC, 2020: 1).
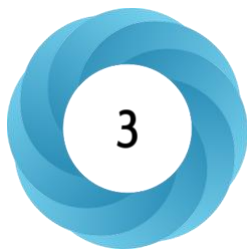
## 4.2 PAPER 3

Harris, D.A. (2015). 'Lived-through past, experienced present, anticipated future: Understanding 'existential loss' in the context of life-limiting illness.' *Palliative and Supportive Care* (Cambridge University Press) 13 (6): 1579–94.

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- Harris, D. A. (2016). 'Existential concerns for people with motor neurone disease: Who is listening to their needs, priorities and preferences?'. *British Journal of Occupational Therapy*, *79*(6), 391-393.

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### 2. Title of PhD Proposal

A Lifeworld Approach to palliative and supportive care

### 3. Title of Research Output

Lived-through past, experienced present, anticipated future: Understanding "existential loss" in the context of life-limiting illness

### 4. Candidate's contribution to the research output
#### (State nature and approximate percentage contribution of each author)

Denise Harris 100% contribution

### 5. Co author(s):

I confirm that the contribution indicated above is an accurate assessment of the contribution by the candidate to the research output named in section 3.

| Name | Signature | Current e-mail address |
|---|---|---|
| | | |
| | | |

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I confirm that I have read the above publication and am satisfied that the extent and nature of the candidate's contribution is as indicated in section 4 above.

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# Lived-through past, experienced present, anticipated future: Understanding "existential loss" in the context of life-limiting illness

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## ABSTRACT

*Objective:* Motor Neurone Disease (MND) is a rare, devastating neurodegenerative disease of middle/later life, usually presenting in the sixth and seventh decades (McDermot & Shaw, 2008). People have to wait many months to receive a diagnosis of MND (Donaghy et al., 2008), and during this period they have already experienced the degenerative nature that characterizes MND (Bolmsjö, 2001). However, information on the meaning of life with MND through time is limited. The aim of the present research was to answer the research question "What does it mean to be a person living through the illness trajectory of MND?" and to research the phenomenon of existence when given a diagnosis of MND and in the context of receiving healthcare.

*Method:* Hermeneutic phenomenology, inspired by the philosophers Heidegger and Gadamer, informed the methodological approach employed, which asked people to tell their story from when they first thought something untoward was happening to them. The hermeneutic analysis involved a five-stage process in order to understand (interpret) the lifeworld[1] of four people diagnosed with MND, and a lifeworld perspective helped to make sense of the meaning of existence when given a terminal diagnosis of MND.

*Results:* The concept of "existential loss" identified in relation to MND was the loss of past ways of being-in-the-world, and the loss of embodiment, spatiality, and the future.

*Significance of results:* The concept of existential loss requires closer attention by healthcare professionals from the time of diagnosis and on through the illness trajectory. The study findings are conceptualized into a framework, which when used as a clinical tool may prompt healthcare professionals to focus on their patients' existential loss and existential concerns. This research adds to the existing literature calling for a lifeworld approach to healthcare.

**KEYWORDS:** Existential loss, Martin Heidegger, Hans-Georg Gadamer, Existential-hermeneutic phenomenology

## INTRODUCTION

The purpose of this research was to understand the meaning of existence when a patient is diagnosed with a life-threatening illness, in this case motor neurone disease (MND). People living with this disease often retain an active mind but are increasingly unable to move any of their muscles, and death usually occurs within months in the case of progressive bulbar palsy (PBP) MND, and three to five years for amyotrophic lateral sclerosis (ALS) MND (Motor Neurone Disease Association, 2000; Oliver, 2002). British research in this area of interest has focused on care values for MND (Brown, 2003), on whether life is biographically disrupted when living with MND (Locock et al., 2009), and on how people talk about living with MND (Brown & Addington-Hall, 2008), with each of these studies

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[1]Lifeworld—being-in-the-world (Finlay, 2011; Polt, 1999).

identifying existential concerns for people living with MND.

MND is a relentlessly progressive disease with no curative treatment, and the recommended clinical management of MND is palliative care throughout the disease trajectory (Oliver, 2002). However, whether a person receives palliation in the United Kingdom may be dependent on their geographical location (Oliver, 2002), as well as the presenting symptoms (Motor Neurone Disease Association, 2013a; 2013b). In the United Kingdom, the recommendation for care of people with MND is medical and functional. Those who experience a loss of speech, loss of respiratory function, or are in their terminal phase are referred to the palliative care services (Motor Neurone Disease Association, 2013a; 2013b). People may prioritize their existential concerns ahead of their medical and functional needs, yet all have a need for palliative care services from the time of their diagnosis to affirm the meaning of life and death as a normative process (WHO, 2002). This paper discusses what it means to be a person living through the trajectory of MND, a life-limiting illness. The literature review provides an overview of the empirical research of living with MND, receiving healthcare, and the impact on self and identity. The section on the understanding of existential hermeneutic phenomenology outlines and justifies the methodological approach taken and the method adopted and developed for this research, including the ethical considerations and hermeneutic analysis, and provides a critical evaluation of the research. Extracts from the stories on the meaning of existence with MND from four participants are presented. Finally, the Discussion and Conclusions section appraises the findings in relation to the existing literature and guidelines, and provides recommendations for a lifeworld approach to healthcare for people living with MND and other life-limiting illnesses.

## LITERATURE REVIEW

### What is Motor Neurone Disease?

Motor neurone disease (MND) is an umbrella term for a group of age-related neurodegenerative disorders of unknown etiology. Motor neurons transmit electrical signals from the brain (upper motor neurons) and the spine (lower motor neurons) to muscle groups within the body in order to generate movement. The upper motor neurons situated in the higher brain area (motor cortex) send signals down the spinal cord to connect at different junctions with the lower motor neurons, which in turn send signals to the muscles to initiate movement of the arms and legs (Talbot & Marsden, 2008). In MND, motor neu-

rons progressively degenerate and eventually die (Talbot & Marsden, 2008).

Little is understood about the causes of MND following extensive examination of the environment or the life histories of people living with the disease. Some of the suggested risk factors include: exposure to insecticides, heavy metals, electromagnetic radiation and solvents, a history of fractures and other traumas, athleticism, and military service; however, these risk factors remain unconfirmed. Talbot and Marsden (2008) state that only 2 to 3% of patients with familial MND carry mutations in the gene encoding superoxide dismutase (SOD1), and in 90% of patients it is obvious that they do not have any genetic basis for their disease. It remains a possibility that genetic variations, acting in concert, increase the risk of developing MND (Talbot & Marsden, 2008). Other potential genes thought to be involved are TDP-43 and FUS (Oliver, 2002). Of course, this may be a significant concern for people diagnosed with MND and may determine whether they risk passing the disease on to other generations (Bolmsjö, 2001).

In the most recent epidemiological research carried out in the United Kingdom, Alonso and colleagues (2009) analyzed the general practice research database for the period of 1990 to 2005, and found that 830 new cases of MND (360 in women; 470 in men) were recorded. Talbot and Marsden (2008) state that MND is a relatively rare disease, which means that healthcare professionals infrequently encounter people living with MND. For example, one in 1000 death certificates record MND as the cause of death, in comparison to stroke, which affects one in three, and cancer (all types), which affects one in four. There is no evidence to suggest that MND is becoming more common, though increasing life expectancy will impact on the number of people being diagnosed with MND.

At the time of diagnosis, a person learns that MND is a life-threatening disease with no known cure (Leigh et al., 2003), and they are usually offered the drug Riluzole, which has been shown to increase survival times by up to 3–4 months (McDermot & Shaw, 2008). A person may learn at the time of diagnosis that they have one of four types of MND: amyotrophic lateral sclerosis (ALS), progressive bulbar palsy (PBP), progressive muscular atrophy (PMA), or primary lateral sclerosis (PLS) (Talbot & Marsden, 2008; Motor Neurone Disease Association, 2000; 2013).

### Discourses on Living with MND

People may receive a diagnosis of ALS-type or PBP-type MND, and, depending on the type of MND diagnosed, they may have months or years to live (Motor

Neurone Disease Association, 2013b). Research in the United Kingdom has focused on care values in MND (Brown, 2003), on whether life is biographically disrupted when living with MND (Locock et al., 2009), and on how people talk about living with MND (Brown & Addington-Hall, 2008). These studies have identified that being diagnosed with MND is an "existential shock" (Brown, 2003), a "biographical abruption" of a previously planned life (Locock et al., 2009), and a "fracturing narrative," telling of their loss and fear of the future (Brown & Addington-Hall, 2008), with each of these studies identifying existential concerns for people living with MND. In studies conducted outside the United Kingdom, people talk about their existential concerns for life and death (e.g., Bolmsjö, 2001), and, while this is the only research publicly available, more studies may exist.

## Management of Illness: A Philosophical Perspective

> Greek physicians had observed the body cannot be treated without at the same time treating the soul. It is further suggested that perhaps even this is not enough, that it is impossible to treat the body without possessing knowledge concerning the whole of being. (Gadamer, 1993, p. 793)

The diagnosis of illness is determined from knowledge gained within the natural sciences; however, once given a diagnosis, a person with an illness is then defined by a social state of affairs and a psychological/moral state of affairs (Gadamer, 1993). Gadamer is referring to the concept that, once a person is diagnosed, they then become involved in a social network, such as the United Kingdom healthcare system. Gadamer notes how people were previously reliant on their family doctor (general practitioner, GP) to provide social, psychological, and moral support, whereas today GPs are often unable to provide such levels of support. Consequently, we are more likely to be reliant on the practical experiences of clinicians, who see their patient in the clinical stage, "and therefore do not understand the patient and their history, and care becomes 'unavoidably abstract'" (Gadamer, 1993, p. 21). He argues that healthcare practice has become objectified in terms of the multiplicity of data, and that personhood has been lost. Although Gadamer refers to the healthcare practice of some 30 years ago, his insight has meaning for healthcare practice in the 21st century. A patient diagnosed with MND is a prime example: first, the patient visits their GP because they have noticed something untoward is happening to them; they then undergo a number of clinical investigations (brain scan, nerve testing, breathing tests), and all the information concerning the person is collated into a computerized system, and the relevant data are then applied to the person presenting to the consultant with the disease. Gadamer questions whether the unique value of the person is acknowledged during this process.

## The Multidisciplinary Team Approach in the 21st Century

People living with MND require help to manage their symptoms from a multidisciplinary team of healthcare professionals (Motor Neurone Disease Association, 2011). Thomas (2010) refers to patients receiving healthcare in the United Kingdom as being involved in a different social system (the NHS), and involvement in this social system means receiving healthcare from a range of healthcare professionals working in a variety of settings (Oliver, 2002). Oliver highlights the number of professional services that may be involved in the management of MND: (1) neurology services; (2) MNDA care centers; (3) research centers; (4) community services; and (5) palliative care services. This brings into question whether people receiving healthcare from so many different services experience a continuity of care, and patients with MND receiving healthcare have reported deficiencies in the organization of healthcare services (Brown et al., 2006).

## The Professional Paradigm

All healthcare professionals have their own professional paradigms and work within shared policy frameworks and practice guidelines that determine how their care is delivered. In the management of MND, Brown (2003) found that "professionals appreciate the debilitating effects of MND, but their practice prioritizes their functional roles over emotional support. This situation is often created through external constraints but leaves professionals in a constant state of tension" (p. 215). Brown (2003) further reported that healthcare professionals were unsatisfied with the care they delivered to patients with MND.

The MND Association (MNDA) has introduced the "Services Required Along the Year of Care Pathway" (Motor Neurone Disease Association, 2013a). While it is not clear why this is only directed toward the first year of the illness trajectory, this pathway offers guidance for healthcare professionals to manage a patient living with MND. The care pathway recommends referral to different healthcare services based upon milestones (generic needs at and after diagnosis), and the needs based on loss of function include the use of arms, ability to walk, ability to manage personal hygiene and care, speech, ability to swallow,

respiratory function, cognitive function, and palliative care prior to death. What is clear from this pathway is that the care delivered is very much focused on management of the medical and functional needs of people living with MND, and not their spiritual and emotional needs. Referral to palliative care services is noted only for those who have experienced a loss of speech, respiratory function, and are nearing the end of life, and the pathway does not identify the need for a person diagnosed with MND to be put onto the palliative care pathway at the time of their diagnosis. Similarly, this care pathway does not acknowledge the significance of MND as an "existential shock" (Brown, 2003), or a "biographical abruption" (Locock et al., 2009) at the time of diagnosis, and the loss of movement as "existential suffering" (O'Toole, 2011). However, the care pathway does suggest that practical, emotional, social, and financial support is available via the MND Association (MNDA) throughout the course of the disease, and people are able to contact an advisory line in order to access this support. The emphasis on the MNDA to provide emotional support removes this responsibility from the healthcare professionals.

## Discourses on Receiving Healthcare

The current available literature suggests that the needs of people living with MND are not being met because the care tends to focus on the functional needs of the person living with MND (Brown, 2003; Hughes et al., 2005; van Teijlingen, 2001). Brown (2003) argues that people need to be acknowledged independent of their disease; however, the currently available evidence suggests that people are not being acknowledged in this way because the care people do receive is based on objectified care pathways, which are focused on the person and their disease and do not acknowledge the patient in a wider temporal frame or beyond their illness context. However, a few studies have focused on the meaning of existence with an MND, a life-limiting illness, through time.

## METHODOLOGY AND METHODS

### Research Design

This research adopts an existential hermeneutic phenomenological approach (Heidegger, 1927/1962). Heidegger terms human existence as "Dasein" (being-in-the-world, being-there) (Moran, 2000), and he asked questions about experiencing and understanding, such as what does it mean to be a person? The unit of analysis is the experience of the situation and the person; what is shared history, culture, practice, and language. Interpreters participate in

making data, with the understanding that their interpretation can only make explicit what is already understood. To accomplish this, Heidegger introduced the idea of the "hermeneutic circle," whereby the researcher brings their own background and frames of meaning to the hermeneutic circle of understanding, and these cannot be "bracketed," ignored, or forgotten, as they are contextualized life events (Koch, 1995). Gadamer (1975) recommends engagement with one's own presuppositions, defined as preunderstandings, prejudices, and beliefs, in order to understand the meaning of ourselves and others. Schwandt (2000) states that a researcher adopting this position for their study is taking a non-objectivist view of the meaning. Brown (2003) also framed her study on Heidegger and Gadamer's hermeneutic phenomenological perspectives, though it focused on care values.

The existential hermeneutic phenomenological approach adopted in this study captures the meaning of existence through time, the lived-through past, the experienced present, and the projected future. Alternative phenomenological perspectives were considered when designing this research, including Merleau-Ponty's meaning of existential phenomenology, which emphasizes the body as the primary site for knowing the world. He maintained that the body and that which it perceives could not be "disentangled" from each other. However, this perspective was rejected because the focus on the body is inappropriate for people with a progressive deterioration of motor neurons now controlling their lifeworld. Furthermore, the approach of hermeneutic phenomenology offers a sensitive approach to this research, and a way of understanding a person in a wider temporal frame, beyond their disease context; the participant is both the expert and an authority on his or her own life.

For this study, a life story approach was designed, using one-on-one interviews that asked the question "Can you please tell me the story of your life (...) since you first thought there might be something wrong with you?" This method of data collection is consistent with Wengraf's approach (2001) and the hermeneutic phenomenological approach. A hermeneutic phenomenological approach recognizes that we live our life in stories, and that the stories we tell are important for our identity, as they tell us who we are (Widdershoven, 1993, in Atkinson, 1998). The life story interview was conducted through a series of three separate interviews, where the timeframe between interview 1 (parts A and B) and 2 (part C) was 4 to 6 weeks, depending on individual circumstances. This interval was employed to enable interpretation of the data gathered during the first interview, and the themes that emerged

**Table 1.** *Participant demographics*

| Name (Changed) | Age | Marital Status | Number of Children | Employment | Type of MND | Diagnosed | Areas Affected |
|---|---|---|---|---|---|---|---|
| James | 55 | Married | 2 (aged 21 and 16) | Self-employed | ALS | 18 months | Upper motor neurones |
| Martin | 68 | Married | 3 (adults) | Self-employed | ALS | 14 months | Upper motor neurones |
| Charles | 57 | Married | Twin boys (aged 21) | Retired sales manager | ALS | 2 years | Lower motor neurones |
| Maureen | 70 | Single | 0 | Retired carer | PMA | 10 years | Upper motor neurones |

were explored in the second interview to gain a "fusion of meaning" (Gadamer, 1975). Three further questions were asked during the second interview in order to gain a deeper understanding of the life being lived.

An information sheet and consent form for the study were read to the participants before they provided written or oral consent to take part. Three of the participants were unable to sign because of a loss of motor function in their upper body, and instead they were asked to provide oral consent in the presence of a witness, and this was recorded in writing. Process consent was appropriate for this study, and this was achieved by checking at each stage of data collection whether the participant still wanted to participate in the study. Consent was also obtained before commencing the second interview (Munhall, 1991, in Addington-Hall, 2002).

## Sample

As the purpose of hermeneutic phenomenology is to interpret the lifeworld experience of people, the sampling method had to select people who would contribute to providing an insight into the phenomenon of existence when given a diagnosis of MND and in the context of receiving healthcare. Thus, for the purposes of the present study, maximum variation purposive sampling was applied to recruit four participants with an accepted diagnosis of MND (all types) (see Table 1). Maximum variation purposive sampling was employed to ensure that a range of experiences from different stages of disease progression were included in the sample (Wengraf, 2001). The participants were recruited from one geographic area in the United Kingdom. According to Patton's (1990) understanding of maximum variance purposive sampling, such data and their analysis will produce high-quality detailed descriptions of each case; this not only provides individual uniqueness, but also shared patterns across the cases, emerging from heterogeneity. This process of sampling is in line with interpretive philosophy because it promotes inclusion of people with unique and diverse experi-

ences, and similar studies have successfully used a small sample size to examine the experiences of chronic disease (Finlay, 2003; Gullickson, 1993; Koch, 1995; Robertson-Malt, 1999) and life-threatening illness (Brown, 2003). A story approach allowed for in-depth exploration of rich material, and the quality of the data provided by the four participants was sufficient for the purposes of this study.

## Analysis

Hermeneutic phenomenology has no specified method of interpretation to offer researchers (Finlay, 2011), although Heidegger introduced aspects of existence to understand (interpret) a person in their lifeworld. Cohn (1997) interpreted Heidegger's ontic[2] and ontological[3] aspects of existence, and those he considered important have been used here as a framework to interpret the participants in their lifeworld. Finlay (2011, p. 135) offers justification for the use of such a framework:

> The explicit focus on lifeworld dimensions offers phenomenology a clear pragmatic framework that is well anchored in phenomenological philosophy (and so justified). The framework is one that guides methodology and upon which researchers can hang their understanding.

Gadamer offered the "hermeneutic circle" as a process of coming to understand (interpret) the being of something, for example, a text, the phenomenon, or a participant in the research context (Finlay, 2011). Fleming and colleagues (2003) interpret Gadamer's meaning of the hermeneutic circle as gaining understanding of the parts in order to understand the whole. The present study has brought forward these two philosophical positions to understand (interpret) the meaning of existence.

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[2]The ontic approach is concerned with the particular ways in which a person is in the world (Cohn, 1997).
[3]The ontological approach is concerned with the intrinsic features of being that are "given" and inescapable (Cohn, 1997).

## Stage 1: Gaining an Understanding of the Stories

The present study adopted a story approach for gathering data. Heidegger (1927/1962) holds that all being through time is temporal; this involves the past, which is carried along by a present, which is already anticipating the future. This philosophy has been applied to the present study as described below (see also Table 2). Heidegger and Gadamer understood that gaining understanding of the whole should be the starting point of interpretation, because the meaning of the whole will influence the understanding of the parts (Atkinson, 1998; Fleming et al., 2003). The process involved:

1. Iterative listening to the stories and organizing them into temporal themes (past, present, and future).

2. In the first stage of the data collection process (interview 1), the participant was asked to tell their story from when they first felt something untoward was happening to them.
   a. This was naturally told as their experienced past, and was color-coded in blue.

3. In the second stage of the data collection process (interview 1), the participant was asked to elaborate on the meaning of their experiences.
   a. Where stories still related to the past, these were also color-coded in blue.
   b. Stories related to their experienced present were color-coded in pink.
   c. Stories related to their anticipated future were color-coded in green.

4. In the third stage of the data collection process (interview 2), the participants were asked three broad questions to enhance their stories.
   a. The responses to these questions have been combined with the earlier stories (of past, present, and future).

5. Stories that were repetitive or less relevant to the research focus were omitted.

**Table 2.** *Heidegger's aspects of temporality applied*

| Experiencing MND from the Time of First Noticing that Something Untoward Was Happening | Experiencing MND in the Present | Projected Future Living with MND |
|---|---|---|
| Past | Present | Future |

## Stage 2: Interpretation of the Meaning of Existence

Atkinson (1998) recommends having a perspective broader than one's own in order to understand a story fully. Heidegger's (1927/1962) different aspects of existence offers a philosophical framework in which to understand what it means to be a person living through the illness trajectory of MND. The aspects of existence (lifeworld dimensions) used for this stage of analysis included: being-in-the-world; being-with-others; temporality; spatiality, thrownness; embodiment; mood; and mortality. The process involved:

> Dividing the text into meaning units, which were then condensed, and organized into aspects of existence. The condensed statements are presented to bring closer attention to the metaphors/words/sentences used by the participants to emphasize their lifeworld experiences. (Finlay, 2011)

See the examples presented in Table 3.

## Stage 3: Sense of the Whole Story (Expanded)

It is understood that the meaning of the parts helps us to understand the meaning of the whole (Heidegger, 1927/1962; Gadamer, 1975), and this philosophy has been carried forward by a number of researchers (Atkinson, 1998; Benzein et al., 2001; Fleming et al., 2003). The process involved:

1. Grouping together the existential themes.
2. Paying closer attention to the condensed statements in order to understand the meaning of the whole story.

The lifeworld experiences of one participant are provided as an example of how the past is carried along by a present that is already anticipating the future (see Table 4) (Heidegger, 1962).

## Stage 4: Identification of Passages

The final stage involves identification of passages (excerpts) that are representative of shared understandings between the researcher and the participants—the fusion of two horizons (Fleming et al., 2003). The research findings for this study have been co-created in dialogue, and I understand that another researcher with a different history, culture, and practice would have impacted differently on the participants, and is very likely to have heard a different story (Finlay, 2011). The process involved: identification of passages (excerpts) selected to bring forward what it means to be living through the illness trajectory of MND. The example provided in Table 5

**Table 3.** *Philosophical framework analysis*

| Meaning Unit | Condensed Statement | Aspects of Existence |
|---|---|---|
| Well, my condition started in October 2009, was the first indication I had a brain thing not right. I lost my tennis racket out of my right hand, while I was playing tennis, and I thought hmmm. | First indication I had a brain thing not right | Embodiment |
| Well, in actual fact I would prefer you to have your whole brain and neck scanned, but I didn't get that message until after (…) because I think I was seeing him on the Thursday, and I was actually having the scan the following Monday. | I would prefer you to have your whole brain and neck scanned | Being-with- others |
| I was diagnosed the first week of October, I think, in 2010. So it took a year. But you know, it's a difficult one to diagnose at the early stages. But, of course, it wasn't my neck. Sadly, it was a bit more serious. | So it took a year. Sadly, it was a bit more serious | Being-with-others; Thrownness |

**Table 4.** *Meaning of the whole story (James)*

| Condensed Statements | Aspects of Existence |
|---|---|
| I used to run around in the wintertime, blowing a whistle. In the summertime, I'd be playing cricket, or playing tennis. | Past ways of being-in-the-world |
| From being an active person to hopeless care currently. | Mood |
| In spite of best mental efforts, this has beaten me. | Mood |
| Am I going to see the end of the football season; this is a tricky one. | Mortality |
| Making a plan for the disease is actually keeping your head fixed on the fact that you've got limited time available to do so. | Mortality |
| Lifeworld experience | |
| This participant's story tells of existential loss because of his past ways of being-in-the-world, his mood in the experienced present tells of how he has been beaten by MND, of his present situation, and how he is anticipating his future: "It's a funny old situation. You sort of— It's like being in— It's like being on death row without knowing when the executioner is going to pop in." | |

**Table 5.** *Identification of passages*

The only thing I'm doing at the moment is I'm watching my son play football. I used to actually referee football matches. I mean, I'm a level 1 football referee.

So I used to run around in the wintertime, blowing a whistle. In the summertime I'd be playing cricket, or playing tennis. In fact, I played tennis all year round. In fact, it was on a— We play every Friday evening indoors, and we have been doing for twenty-odd years. And, as I say, it was losing my racket out of my right hand that indicated to me that something wasn't right.

It's such a huge change in your lifestyle, from being an active person, running around, and being a bit of a hopeless case currently.

So— In spite of my best efforts to (…) Mentally— And I suppose as a competitive sportsman you always— you always feel that you have power— positive mental thought you can get—you can get by it. Er— This has beaten me.

is taken from one participant's meaning of existence now that he is no longer a being in the world of sport.

A reflective diary and fieldnotes were kept throughout the course of the study and were drawn upon and utilized in the ethical consideration of this study. Addington-Hall (2002) highlights the methodological challenges of researching the healthcare experiences of palliative care patients. She points to issues that relate to the identification of patients in the first instance, and then to the following ethical concerns: physical problems; vulnerability; autonomy; cognitive impairment; and changes in the physical condition of the patient. The consultant and his team identified the participants in the first instance, and they chose the study participants because they met the inclusion criteria; those that did

not have the mental capacity to consent were excluded. The criterion of avoiding harm is a basic ethical principle in the design of any study; however, as Hollway and Jefferson (2000) state: "Can we assume that it is necessarily harmful to experience being upset or distressed? It can be reassuring and therapeutic to talk about an upsetting event in a safe context" (p. 87). Researchers using a life story approach understand that they must adopt active listening principles, which involve giving a person time to express their emotions (Wengraf, 2001). Active listening principles are also applied in the context of occupational therapy (OT), and they were applied in the research context in the same manner. Harm must be evaluated independent of distress (Hollway and Jefferson, 2000), and the participants were informed during the process of gaining consent that, should they disclose the risk of harm to self, the researcher is legally obliged to report this information to their consultant/GP in charge of their care or their next of kin (COT, 2010). Participants consenting to be interviewed at the neurological center might experience fatigue following their visits to healthcare professionals, and for this reason the interviews were conducted in their homes, at times convenient for the participants, in order to reduce the risk of fatigue. It was also understood and explained to participants that, should they become fatigued during the interview, they would be given the option to continue another day. The lone-worker policy was put in place, and the personal details of each participant were sent to the research supervisor, only to be opened in case of an emergency. Contact was made with the supervisor at an agreed time, allowing two hours for each interview.

## RESULTS

The findings from the participants' stories of the meaning of existence through the trajectory of MND include the many aspects of existence. The importance of their lived-through past, experienced present, projected future, and anticipated future is situated in the concept of "existential loss": the loss of past ways of being-in-the-world, loss of embodiment, loss of spatiality, and loss of future. The significance of "existential loss" is illustrated through the seven themes that emerged during the analysis: "being thrown into the world of MND," "loss of embodiment," "loss of spatiality," "mood," "being-with-others," "facing their own mortality," and "facing their loss of temporality and spatiality." On the basis of these findings, a conceptual framework recommending a lifeworld approach to care as a clinical tool has been developed.

### Being Thrown into the World of MND

The "givens" of existence Heidegger terms our "thrownness" into the world, into events and conditions we do not choose and cannot control; thus, we do not choose the place where we are born, our parents, [and] the circumstances of our life (Cohn, 1997, p. 126). The participants did not choose to be thrown into the world of MND; however, they did choose to face up to their condition and to remain where possible in control of the "givens of existence." Alternatively, they could have denied their condition or allowed their circumstances to control them. Allowing their condition to control them may have resulted in a number of attitudes, such as idealization, resentment, confusion, and a feeling of paralysis (Cohn, 1997). The findings suggest that Martin and Maureen were more positive about living with MND, although they did not consider their life ideal:

My past history has probably given me the resolve to fight the disease in the best way I can. (Martin)

I came home, and it didn't seem to bother me. I didn't come home and sit and think, oh you know! (Maureen)

While James and Charles had developed attitudes of resentment because MND was impacting on their past and future lives:

The interesting thing is, of course, the stock answer, when people ask how long they've got, is three to five years, and I'm never certain whether that three to five years is from diagnosis, or from actual onset of the disease. So just being silly, if you think the first noticeable symptom occurred in October '09, I must have had— I must have had the disease prior to that, and— Let's say June, and since that time, as I say, the rate of degradation, or degeneration, has been relentless. (James)

When news suddenly comes out of the blue and it very much was so, er—The period after that you are in tatters really, both yourself and your immediate family. (Charles)

A sense of paralysis is life ruled in the shadow of loss (Cohn, 1997), although this is not to be confused with experiencing paralysis because of the loss of upper and lower motor neurons and its impact on movement. It may be that for James life is ruled in the shadow of loss, and as such he is making resolute choices:

You sort of— it's like being in— It's like being on death row without knowing when the executioner

is going to pop in. Anyway, we shall be sorting that one out.

These study findings are not unique, as Bolmsjö (2001) also identified important ontological aspects of being related to thrownness, a fear of not being in control of current and future lives. Similarly, such fear is reflected by Charles:

> But for instance, simple things like sleep— I normally sleep very well, but you are forever waking up thinking I am dying. What is this all about?

## Loss of Embodiment

Embodiment relates to the physical, psychological, social, and spiritual ways of being (Heidegger, 1962; Inwood, 1997). The currently available evidence acknowledges the remarkable degree of variance in the presentations of MND (Talbot & Marsden, 2008). Such variance is due to the type of MND diagnosed and the progressive nature of each type (Motor Neurone Disease Association, 2013b), and the physical symptoms include rapidly progressive muscle weakness (atrophy), fasciculation, muscle spasticity, dysarthria, dysphagia, and dyspnea (Leigh et al., 2003). The medical view of types of MND and symptoms does not inform us about how the physical symptoms that are being experienced. Brown (2003) focused on the impact of MND on the person in their present state: "bodily deterioration coupled with a loss of social and communication outlets forces a person to turn inward, to face death in an increasingly difficult day-to-day life." The participants in this study described the impact of MND on the embodied self in their spatial world as degrading, humiliating, and cruel, due to an altered self-image and a fear for physical safety.

> But, of course, it is a very degrading disease. I mean, I can't do such basic things for myself, and you feel humiliated. I mean, you can't feed yourself. You can't go to the toilet yourself properly. (Martin)

> But also, cruel as it is, it is less cruel if you have got a partner, or a full-time carer who cares, if you see what I mean. (Charles)

Despite the different aspects of loss that appear more profound for each participant, there are shared patterns of experiences across the cases. For example, embodiment is now experienced as altered self-image and fear for physical safety:

> When you are actually in this situation, you don't quite know what you look like, and I say that in a

slightly humorous way, but because my wife has been dressing and sort of brushing my hair and everything, and there's no mirrors at wheelchair height in the bedroom or anything, I suddenly realized what I looked like with my ventilation on. But she showed me, and I said, "Bloody hell, I look a right state." (Charles)

> But I have never had on some of them good clothes because I know how my shape has gone. And when you look at yourself, you think, "Oh no," you know. I do buy bits, tops, and that because I don't want to go out like that, you see. (Maureen)

> I am frightened of going anywhere on my own. I mean I can't pull money out of my pocket for instance so— my bus pass or whatever. So you are really totally dependent on—Well, I am now. (Martin)

> But I would say the last twelve months, two years I've started having a lot of falls, so then I had to stop going because they were worried. (Maureen)

Because there is no existing study that has understood the ontic/ontological aspects of existence with MND, similarities are drawn here to Ashworth (2006) in relation to existence with Alzheimer's, which is understood by the patient as "embodiment just is." Ashworth goes on to define what he means by this statement: "The body may seem to need no particular protection from the gaze of others and may not be vulnerable to negative assessment—indeed, praise about her appearance is not sought" (Ashworth, 2006, p. 220). These findings bring together stark differences between these two neurological diseases and the experienced impact on the body, without suggesting that any one of these neurological conditions is any more debilitating than the other.

## Loss of Spatiality

If an existence is being-in-the-world, it is "spatial," and as such part of a wider context to which it is related (Heidegger, 1962; Cohn, 1997). In their spatial world, the participants discussed the need to be with others for their survival, and also the need for aids and adaptations for their physical safety. Both are a constant reminder of their loss of control and increased dependency. In their spatial world, they have accepted health and social care professionals, not through choice, but for survival. Spatiality is dependency and a limited choice:

> Yeah. Social services come in twice a day to help with shaving, washing, dressing, cooking breakfast, doing my teeth. (James)

Anyway, we have had a fantastically intricate [Bio-Bidet] fitted, because hand dexterity for toileting isn't great. (James)

It's probably a good time to look at the total cost of (…) situation, and in a way it links back to this thing about whether you do harm to yourself. I think that one's life does have a value, and if it suddenly was going to cost, we have a house that's worth, take a figure of three hundred thousand, and you end up having to spend ten thousand pounds on a through-floor lift from one floor to another, and fifteen thousand for a totally new bathroom. Then the cost when you have passed away for those things to be cleaned up, tidied up, to make good— to sell the house, if you had any income at all— Sorry if you have any capital at all, you could end up spending that sum of money. (Charles)

The carers have to stay overnight because sometimes my breathing equipment can drop out, and they are here because I can't put things back, you know, pick up or anything. I never wanted them, but I would be lost without them. (Maureen)

Ashworth (2006) described spatiality for a person living with dementia as follows: "The rescheduling or re-routing of a local bus service, or a change (at the behest of planners and developers) to a familiar place, can shrink the world." The spatial worlds of people living with dementia and those living with MND are not too different; the argument here is that both neurological conditions involve changes to the embodied self, although these changes are notably different in symptoms and effect, yet both conditions result in the shrinking of a spatial world. A person living with dementia and a person living with MND has no choice but to accept care if they are to survive in their spatial world. Control was seen to be an issue for only one of the participants: Maureen had limited control over accepting overnight carers, but without accepting them she would not survive in her spatial world.

### Mood

We now discuss understanding (interpreting) the participant's mood in relation to their lifeworld. Heidegger (1962) holds that we are always in one mood or another, and that this is how we understand ourselves. Two of the participants said they were not depressed but that they were sad, and people diagnosed with MND have been perceived to be at risk of depression because of the effects of MND on everyday functioning (Hogg et al., 1994). According to the American Psychological Association (2014), depres-

sion is more than just sadness, and people with depression may experience a lack of interest and pleasure in daily activities, significant weight loss or gain, insomnia or excessive sleeping, a lack of energy, the inability to concentrate, feelings of worthlessness or excessive guilt, and recurrent thoughts of death or suicide (American Psychological Association, 2014). The participants described weight loss, insomnia, and a lack of energy, but they did not relate feelings of worthlessness, though they did talk about recurrent thoughts of death. Two participants discussed recurring thoughts of assisted suicide, again not because they were depressed but because of their emotional response to their existential "given":

I am quite religious, and of course I've— I would certainly never consider going to Switzerland or anything like. (Martin)

It's worth documenting that people do consider a Switzerland-type of approach initially. (Charles)

The variance in mood/attitude to their existential "given" is evident:

It's such a huge change in your lifestyle, from being an active person, running around, and being a bit of a hopeless case currently. (James)

I have never felt any depression for the full period, because depression to me is usually defined as a medical condition. But what I do feel is incredibly sad that I won't be around to see things in the future and to enjoy my retirement with my family, etc. (Charles)

I mean, you have got to be positive and move forward. (Martin)

But I won't give in, in that way. (Maureen)

Brown and Addington-Hall (2008, pp. 205–206) similarly captured expressions of distress in their fracturing and enduring narrative, and also expressions of finding positive meaning in life in their preserving narrative.

### Being-With-Others

This section involves understanding (interpreting) what the healthcare professionals are doing to help people with their expressions of distress. We have a choice as to whether we are with others or not (Heidegger, 1962; Cohn, 1997), but being diagnosed with MND means that people do not have a choice but to be associated with healthcare professionals

for their diagnosis, management of symptoms, and survival. For three of the participants with ALS-type MND, their involvement with healthcare professionals began to intensify in the second year of the illness trajectory, and much later for one participant with PMA-type MND. Brown (2003, p. 215) states that the need for "professionals and carers to interact with people with MND as 'being human in extremis' cannot be overemphasized. Keeping the focus on the person rather than the disease appears so simple, yet so challenging." Similarly, Bolmsjö (2001, p. 504) states that "in the absence of a curative treatment, it is the individual rather than the disease that must be cared for." The study findings here concur with those of Brown (2003) and Bolmsjö (2001) by suggesting that, from the point of diagnosis, the focus of care and treatment is on the person living with MND. The participants commented on the care they received from the multidisciplinary team at the MNDA care centre and in the community, which in the main focused on the management of their medical and functional needs:

> They're obviously very keen to ask me about my swallow, and my breathing. And we all know the reason for that. [Clears throat] I have lost [sigh] a stone and a half in weight. (James)

> Well, to be honest, they are only monitoring it. That's all they are doing. For instance, they have been monitoring my blood gas levels and things like that, and any assistance I need on breathing, although my lungs are okay. They only suggested putting a peg in my stomach and things like that. (Martin)

The participants' experiences of receiving healthcare are consistent with the MNDA (2013) practice guidelines. However, care that focuses on the medical and functional needs of the person in the present does not focus on their emotional response to the existential loss of past, nor to the existential loss of future.

## Facing their Own Mortality

This section of the discussion concentrates on understanding (interpreting) participants' emotional responses to facing their own mortality:

> We are never a "finished" item, or a totalized entity in our lifetime; we are always ahead of ourselves in the process of becoming, until we become no more. We do not make our choices, or choose ourselves, once and for all: we are faced with choosing and re-choosing as we project ourselves toward our deaths. Furthermore, by virtue of the interconnectedness of the ecstasies, every choice impacts on

and is affected by, all three dimensions of temporality. (Weixel-Dixon & Strasser in van Deurzen and Arnold-Baker, 2005, p. 229)

For Heidegger, the three dimensions of temporality are expressed as follows: the past is carried along into the present, which is always anticipating the future, while the process of facing death is filled with anxieties due to certainties and uncertainties. For example, the certainties included the knowledge that their illness will progress further before they die, and some of the uncertainties are not knowing how long they have left to live and how they will die. In the present, they are anticipating their future:

> The interesting thing is, of course, the stock answer, when people ask how long they've got, [which] is three to five years, and I'm never certain whether that three to five years is [counted] from diagnosis, or from actual onset of the disease. So just being silly, if you think the first noticeable symptom occurred in October '09, I must have had— I must have had the disease prior to that, and— Let's say June, and since that time, as I say, the rate of degradation, or degeneration, has been relentless. (James)

> There was a period when I just had a bit of a chest infection, early January, and you start to think, "Oh, I can't breathe," this that and the other, and you think, "I might not be around in three months," and you start to panic. (Charles)

> I mean, I do try and ask them, er— you know, when I am going to die, and is it going to be pneumonia, is it this? And they all seem to be very reluctant to communicate that. (Martin)

> When I went back to [the hospital] and when I was talking to [the nurse] she said, "Well, I am surprised that you have spoken like this," things about when you die and all that, because of how it comes. She said, "I am amazed that you have asked these questions." So you see, I am just beginning to open up. My sister was with me. (Maureen)

McPherson et al. (2007) found that people have a fear of becoming a burden when they are nearing the end of life, and this was discussed by one participant, but was not recorded, and so for confidential reasons cannot be discussed. Another participant was dealing with his fear of becoming a burden, and he had organized some respite care, which involved him going into a hospice to give his wife a break from caring. This same participant discussed being in the process

of documenting his needs, priorities, and preferences in an advance directive (living will):

> There will come a time when you think, "I've had enough," and, therefore, that will be probably the time to stop feeding, stop this [points to non-invasive breathing machine], and please make me as comfortable as possible in the period while I fade away type of thing. (Charles)

The findings suggest that discussions about the end of life are being left until people are in the second year of their illness trajectory. A key recommendation of the End-of-Life Care Strategy for England (2008) is for an explicit discussion around death if a person is likely to die within 12 months (Department of Health, 2008). The findings here may indicate that the timeliness for such end-of-life discussions is consistent with practice guidelines. Beauchamp and Childress (2001) advocate the timeliness of the information given in relation to maleficence and beneficence. Maleficence refers to cases in which it is considered harmful to overwhelm the patient with information when they may be unwilling or unable to understand the information, while beneficence refers to actions that should benefit people. There is a fine line to follow for people with MND between maleficence and beneficence, and it is argued that not discussing needs, priorities, and preferences early on in the illness trajectory may mean that people lose their ability to communicate and sign the appropriate documentation (Preston et al., 2012). All of the participants involved in the present study were able to understand the information about how their illness trajectory was likely to progress toward the end of life, and how providing information on their illness trajectory might outweigh any risk. Although all of the participants could still communicate, three were no longer able to sign this important end-of-life documentation. The present findings suggest that discussions about needs, priorities, and preferences are occurring too late in the illness trajectory. Doughty (2012) reported on the landmark decision in which a judge at the Court of Protection approved a contested living will. A patient living with MND wished for his ventilation machine to be turned off when he no longer had any quality of life, and he had discussed and documented his needs, preferences, and priorities in an advance directive (a legally binding document) when he could still communicate and sign the documentation.

Bolmsjö (2001) also identified important ontological aspects of being related to mortality, such as thoughts about death creating anxiety, suicidal thoughts, and thoughts of euthanasia. The findings of this study reveal three different opinions on the value of life and views on euthanasia via the Dignitas route. James is determined to act; for Martin, it is not an option; and Charles acknowledges that this was once a possible option, at least in the initial stages following diagnosis, although he also stated:

> But generally, if you start looking at other people and think, "God, am I that bad?" And if they have symptoms that— obviously, they are able to speak, which I don't know, for instance, what my attitude would be going back to a will to live, if I lose my speech. (Charles)

These are powerful words spoken by a man who lives in "hope" to live long enough to see his boys home from university, and in his own words, "to know that we are getting on all right."

## Facing the Loss of Temporality and Spatiality

Understanding (interpreting) the participant's loss of temporality and spatiality from an existential therapeutic perspective is the focus of this section. Medard Boss (1903–1990) was a Swiss psychiatrist who adopted Heidegger's view on being-in-the-world to inform his own practice (Cohn, 1997). Boss suggests that the loss of temporality (past, present, and future) and spatiality can result in melancholia,[4] because the experience of loss is not just anticipated—it is a fact (Boss, 1994, in Cohn, 1997). Boss provides reasons for what happens to patients experiencing melancholia: "Of the three temporal existential extensions of past, present, and future, the first and third are almost totally covered up in such patients, so much so their existence is practically reduced to the present" (Boss, 1994, in van Deurzen & Arnold-Baker, 2005, p. 192). The present findings suggest that the participants are experiencing mixed degrees of a loss of temporality and spatiality; though they may not be depressed, they may be experiencing melancholia (their physical and emotional response to MND). The following are examples of loss of temporality and spatiality that appeared more profound for each participant:

- James talked about his past ways of being-in-the-world of professional sports as loss, his present is likened to being a prisoner on death row, and he can no longer see his future. He had expressions of distress that need acknowledgment and treatment.

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[4]In a modern context, "melancholy" applies only to the mental or emotional symptoms of depression or despondency; historically, "melancholia" could be physical as well as mental, and melancholic conditions were classified as such by their common cause rather than by their properties (Berrios, 1988)

- Martin talked about his loss of past ways of being-in-the-world of business, and loss of embodiment and spatiality. Despite such losses, he is grateful for living on borrowed time and being able to plan for his future. He has made resolute choices not to go into a hospice, but to die at home, or at the office, or in the car. He has identified that his wishes, priorities, and preferences need to be discussed and documented in an advance directive while he can still communicate, though he is no longer able to sign the documentation.

- Charles does not focus on his loss of past or loss of embodiment and spatiality in the present; however, he is experiencing a loss of a once-projected future alongside his family with incredible sadness. Despite this, he has hope to see his boys home from university and settled. He is in the process of discussing and documenting his end-of-life plans in an advance care plan/advance directive.

- Despite Maureen's loss of past ways of being-in-the-world of retirement, and loss of embodiment and spatiality, she remains positive and has recently started discussing her future and has planned her funeral. Although Maureen finds it difficult to talk about her future, her wishes, priorities, and preferences need to be discussed and documented in an advance directive while she can still communicate, though she is no longer able to sign the documentation.

## DISCUSSION AND CONCLUSIONS

### Discussion

The present study findings bring to the literature an understanding that people living through the illness trajectory of MND do experience existential loss of temporality (past, present, and future) and spatiality. At the time of data collection, they did not perceive that they were depressed; however, they relate other expressions of distress that need to be recognized by healthcare professionals (McLeod & Clarke, 2007). The findings have been conceptualized into a framework, which when used as a clinical tool will prompt multidisciplinary healthcare professionals to focus on the key areas of a patient's lifeworld. These key areas are: (1) lived-through past, experienced present, and anticipated future; (2) their emotional response to the existential "given" of being diagnosed with a life-threatening illness; and (3) the meaning of their existence. The application of this lifeworld approach to healthcare recognizes such individual and social concepts as: (1) the individual is recognized as a self-interpreting being

with a history, culture, and practice; (2) the individual is a self-interpreting being with rights to make choices; (3) the recognition of being with others (in their social and cultural world); and (4) the individual has freedom and rights: freedom from unwanted medical intervention and rights to stop life-sustaining treatments. The overriding care principle for this lifeworld approach to healthcare is minimizing the loss of past ways of being-in-the-world, the loss of embodiment, the loss of spatiality, and the loss of future. For recommendations for a lifeworld approach to healthcare, see Table 6.

A further explanation of the lifeworld approach and how this may potentially be utilized as a clinical tool in healthcare practice is offered here. The three key areas of existence serve as a dialectic approach to enable a person diagnosed with MND to reclaim the meaning of their life as lived, as experienced, and as anticipated. The purpose of this dialectic approach is to guide multidisciplinary healthcare professionals on the key area(s) of existence that are important to a patient. This process involves enabling a person to come to terms with the inherent contradictions of human living, and allowing them to reclaim their personal freedom (van Deurzen & Arnold-Baker, 2005) and gain control over the direction of their healthcare. The lifeworld approach used as a clinical tool for people diagnosed with MND may also be used as a clinical tool for people diagnosed with other life-limiting illnesses. The timing of this study is appropriate, as a review into end-of-life care services in England has been launched. As Henry (2014, p. 8) states, "We only have one chance to get it right for people who are dying, but despite some excellent practice, many people are not currently getting the care and support that is right for t**hem**." Freedom to make choices is the key message of the lifeworld approach as a clinical tool.

### Conclusions

The purpose of the present study was to gain an understanding of living with MND, receiving healthcare, and the impact on self and identity, in order to contribute to caring policy and practice. The aim was to answer the research question "What does it mean to be a person living through the illness trajectory of MND?" and to study the phenomenon of existence when given a diagnosis of MND in the context of receiving healthcare over time. The four participants provided eloquent stories of their unique existence from the time they first noticed something untoward was happening to them until the present day. These stories have helped us understand that the focus of the management of MND is currently medical and functional, and it is only when

**Table 6.** *Lifeworld approach to MND: A clinical tool*

| Four Key Areas of Lifeworld | Existential "Givens" | Meaning of Existence | Individual and Social Concepts | Care Principle | Recommendations for Lifeworld Approach to Healthcare | | |
|---|---|---|---|---|---|---|---|
| Lived-through past | Loss of past ways of being-in-the-world and being-with-others. | People are involved with things, projects, and people that they "care" about. | Individual is a self-interpreting being with a history, culture and practice. | Minimizing loss of past ways of being-in-the-world. | Listening to a person's story of living with their life-threatening illness. | Help a person to acknowledge that their past ways of being-in-the-world have been meaningful and purposeful. Help a person to explore conflicts. | |
| Experienced present | Loss of embodiment (physical, psychological, social, and spiritual ways of being). | People experience illness on their bodies in different ways, such as degrading, humiliating, and cruel because of altered self-image and fear for physical safety. | Individual is a self-interpreting being able to make choices. | Minimizing loss of embodiment. | Listening to a person's concerns for their loss of embodiment. | Focus on the themes that may emerge as important to a person. This may not involve a medical and functional approach to care. | Help a person to explore conflicts in relation to their existential "givens" by referring to an existential counsellor |
| Experienced present | Loss of spatiality (self in their world as before). | People are part of their wider cultural context; they may experience dependency and limited choice. | Individual is a being-with-others (in their social and cultural world). | Minimizing loss of spatiality. | Listening to a person's needs, priorities and preferences while recognizing they may also be considering the needs of significant others. | A person may wish to make what are considered unwise decisions, refer to the Mental Capacity Act (2005) and best interest checklist. | |
| Anticipated future | Loss of a once projected future anticipating certainties of being-toward-dying, and uncertainties of when and how they will die. | People anticipate their future because of their lived-through past, and experienced present. | Individual has freedom and rights: freedom from unwanted medical intervention and rights to stop life-sustaining treatments. | Minimizing loss of future. | Listen to their existential concerns for the future, facilitate information giving if a patient has a willingness to interpret choices and the ability to make rational decisions. | Help a person discuss their existential concerns, and to document their needs, priorities, and preferences for end-of-life care in an advance care plan/advance directive. | |

healthcare professionals consider that a patient is in their last year of their illness trajectory, or when they are experiencing respiratory loss, that they are referred to the hospice services for palliative care. This study has uncovered some important issues in relation to people having the right to discuss and document through a "living will" their needs, preferences, and priorities while they can still communicate and sign the documentation. The participants are experiencing existential loss: the loss of past ways of being-in-the-world, the loss of embodiment, the loss of spatiality, and the loss of future. Yet, despite experiencing existential loss, the four participants had not been given the opportunity to explore their loss until the second year of their illness trajectory, when they were referred into the hospice service for palliative care. Although none of the participants reported being depressed, two stated that they were sad. One participant may be ruled by the shadow of his loss, past ways of being-in-the-world of sports, and the loss of future with his family; in the present, he is making resolute choices, and he had independently sought counseling from the hospice services.

The findings from this study help us to make sense of what it means to be a person living through the illness trajectory of MND. The findings are conceptualized into a framework, which was used as a clinical tool, to prompt healthcare professionals to focus on the four key areas of existential loss: the loss of past ways of being-in-the-world, the loss of embodiment, the loss of spatiality, and the loss of future, and their emotional response to the existential "given."

## LIMITATIONS OF THE STUDY

One limitation of this study is the inability to take the findings back to the participants for their thoughts on the researcher's interpretations, as three of participants died before completion of the interpretations. I do not claim that all people living with MND will experience existential loss or that all people are not in receipt of healthcare that takes account of their loss of past ways of being-in-the-world, loss of embodiment, loss of spatiality, and loss of future, as these findings are taken from a small sample consisting of just four individuals. A story approach requires considerable time to be spent on examining the detailed nuances (Brown & Addington-Hall, 2008), and in the present study it took time to examine the differences between the four presentations of MND and the different stages of their illness trajectories. Although it has taken extra time to describe and interpret, such a level of information does add to the current body of knowledge. Interpreting the individual participant stories at a phenomenological level involves iterative listening, which was emotionally

draining, but deep respect was given to the in-depth stories recounted, and it was considered worthy of the time and emotion in order to understand participants' stories at a phenomenological level. The participants came to this study wanting to make a difference for other people diagnosed with MND. They told their stories, and I listened and interpreted them to understand the meaning of their existence; I took their stories to a deeper level than I had anticipated. Some may argue that using Heidegger's ontic and ontological aspects of existence to interpret participants' stories may overly structure and constrain the analysis (Finlay, 2011), but in response to such arguments, I would state that there is no existing evidence that has focused on both the ontic and ontological aspects of existence for a patient diagnosed with MND.

## ACKNOWLEDGMENTS

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## 4.3 LINKING NARRATIVE FOR PAPER 5

Early in my postgraduate studies I had discussed with academic colleagues how the participants had described facing death with MND as filled with anxieties, due both to certainties and uncertainties, such as the certainty that MND will progress further before the person dies, and uncertainties over how long they have left to live, or how they will die. However, there is limited knowledge available on the existential concerns of uncertainty. Paper 5 reports on a hermeneutic (interpretive) phenomenological study exploring the meaning of uncertainty for people who are diagnosed and living with MND. Finlay (2011: 229) suggested:

> *It is important with phenomenological analysis to take time to dwell with the raw data such that implicit, layered meanings come to the fore. At its best, the process of doing the analysis becomes an embodied lived experience in itself. It is not just a cognitive, intellectual exercise. When I am well immersed in an analysis, I am there sensing, moving, empathising, responding and resonating with my whole body-self. In a sense I am re living the experiential accounts and 're-membering' (re-embodying) what was said.*

I had two years to dwell and to re-live the experiential accounts of existence with MND, in particular remembering (re-embodying) what was said. 'It's like being on death row without knowing when the executioner is going to pop in' was a comment that haunted me, and that I came back to again and again, because people with MND are experiencing life in crisis. Despite the involvement of a multidisciplinary team of professionals, they are experiencing uncertainty over how long they have left to live, and how they will die, and none of the professionals are open to having those discussions.

Asking additional research questions of existing qualitative data can generate new knowledge and increase the use of data sets (Hinds et al., 1997). Other researchers working on MND have also returned to collective data sets because the low incidence of MND makes data collection difficult (Locock and Brown, 2010; Ozanne et al., 2013; Ray, Brown and Street, 2012). Locock and Brown (2010: 1498) explored the experience of peer support for people with MND and

their family carers. The findings suggested that people are shocked and saddened at seeing others further on in their illness trajectory and, therefore, choose not to use peer support. Only one participant involved in this study talked about using the MNDA peer support groups early in his illness trajectory and he, too, found it distressing to see people deteriorate. Ozanne et al. (2013) conducted a secondary analysis to illuminate how people with MND create meaning despite the disease and found that meaning and strength are achieved through the presence and support of family and friends. Ray et al. (2012: 466) examined the ways in which family carers experienced the death of a relative with MND. The findings suggest that the end of life plan is not always communicated, which can impact on the preservation of personhood. Three of the four participants were in the process of discussing their end of life plans with hospice professionals. Paper 5 was written to bring to knowledge everyday experience and how this leads to uncertainty for people diagnosed with MND.

## 4.4 PAPER 5

**Harris, D.A.,** Jack, K. and Wibberley, C. (2018). 'The meaning of living with uncertainty for people with motor neurone disease.' *Journal of Clinical Nursing.* 27: 2062–2071.

**Link to paper:** https://doi.org/10.1111/jocn.14350

**Journal website:**

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| Altimetric score | 5 |
| Tweeted | 8 |
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| HTML | 793 |
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| Abstract | 547 |

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**This paper is cited by:**

- Flemming, K., Turner, V., Bolsher, S., Hulme, B., McHugh, E. S. and Watt, I. (2020). 'The experiences of, and need for, palliative care for people with motor neurone disease and their informal caregivers: a qualitative systematic review.' *Palliative Medicine.* 34(6): 708-730

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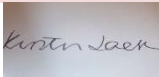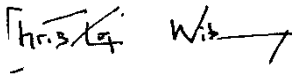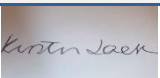
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# Research and Knowledge Exchange
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# Form **RDPUB (ROUTE 1 AND 2)**

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*This form is to accompany an application for registration for PhD where the PhD is by Published Work. A separate form should be completed for each publication that is submitted with the proposal and should accompany the RD1 form.*

| 8. The Candidate | | | |
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**9. Title of PhD Proposal**

Interpreting End of Life Experiences in Motor Neurone Disease

**10. Title of Research Output**

The meaning of living with uncertainty for people with motor neurone disease

**11. Candidate's contribution to the research output**
**(State nature and approximate percentage contribution of each author)**

Denise Harris 80% Contribution
Dr Kirsten Jack 10% Contribution
Dr Christopher Wibberley 10% Contribution

**12. Co author(s):**

I confirm that the contribution indicated above is an accurate assessment of the contribution by the candidate to the research output named in section 3.

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**13. Statement by Director of Studies/Advisor**

I confirm that I have read the above publication and am satisfied that the extent and nature of the candidate's contribution is as indicated in section 4 above.

| Signature: | *Kirsten Jack* | | Date: | 26/6/2020 |
|---|---|---|---|---|
| | (Director of Studies/Advisor) | | | |

**14. Signature of Faculty Research Degrees Administrator**

| Signature: | Deborah Bown | | Date: | 02.07.20 |
|---|---|---|---|---|
| | (Faculty Research Degrees Administrator) | | | |

**ORIGINAL ARTICLE**

WILEY *Journal of* **Clinical Nursing**

# The meaning of living with uncertainty for people with motor neurone disease

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**Aims and objectives:** To explore the meaning of living with uncertainty for people diagnosed with motor neurone disease (MND).

**Background:** Motor neurone disease is a progressive neurodegenerative condition resulting in multiple needs, arising from the complex nature of the disease trajectory. People with MND are often required to make decisions for symptom management and end-of-life care. Research into the lived experience of MND has previously highlighted the following: the shock of receiving such a diagnosis and prognosis; subsequent concerns relating to the future and loss; and the existential suffering for a person with MND. The lived experiences of MND accentuate the devastating nature of the disease, and this can impact upon how people respond to care.

**Design:** Hermeneutic (interpretive) phenomenology: suitable for studying lifeworld experiences.

**Method:** Life story interviews were conducted with four participants and subjected to interpretive analysis.

**Results:** Three phases of the MND illness trajectory emerged: "body failing prematurely and searching for answers," "body deterioration and responses to care" and "body nearing its end and needing to talk." These phases highlight the phenomenon under study, all relating to uncertainty for people living with MND.

**Conclusions:** This study showed that people with MND are living with uncertainty and other concerns throughout their illness trajectory. People are having to turn to palliative care professionals who are more able to meet their concerns than those caring for other aspects of their disease.

**Relevance to clinical practice:** Motor neurone disease is a complex disease, and it is important that professionals continue to provide holistic care throughout the illness trajectory. The identification of three distinct phases of the MND illness trajectory will help nurses and other professionals to better understand the meaning of uncertainty and other concerns for people with MND.

**KEYWORDS**
body experiences, concerns, motor neurone disease, palliative care, uncertainty

# 1 | BACKGROUND

Communication of the diagnosis of motor neurone disease (MND) is "daunting" for both neurological consultants and individuals (Aoun, Breen, Edis et al., 2017; p. 368), and anxiety before a diagnosis can be increased as a result of experiences during a long period of investigation (Bäumer, Talbot, & Turner, 2014), with the median time from onset of symptoms to diagnosis being 15.6 months (Donaghy, Dick, Hardiman, & Patterson, 2008). When a person receives a diagnosis of MND, they learn whether they have the inherited (familial) form of MND, which occurs in only 5%–10% of people diagnosed; or the more common sporadic form of MND, where the disease develops through a combination of genetic susceptibility and environmental factors. They also learn that MND is a progressive and terminal disease resulting in the degeneration of motor neurones, which can affect their movement, speech, respiration and swallowing (Bäumer et al., 2014) and may also affect their cognition and/or behaviour (Goldstein & Abrahams, 2013). The rate of progression and symptoms experienced vary, and this is dependent upon the type of MND diagnosed. The types of MND include amyotrophic lateral sclerosis (ALS), progressive bulbar palsy (PBP), progressive muscular atrophy (PMA) or primary lateral sclerosis (PLS) (Talbot & Marsden, 2008). A person diagnosed with PBP MND may experience a rapid decline and die within a few months, whereas an individual diagnosed with ALS MND may experience a slower decline and die 3 years after symptom onset (Mitchell & Borasio, 2007). MND results in complete dependency on others, especially towards end-stage care (Dawson & Kristjanson, 2003), and individuals find themselves having to be involved with many healthcare professionals.

Research into the lived experience of MND highlights feelings of uncertainty before diagnosis because of fear of the unknown (Ozanne & Graneheim, 2017). Receiving a diagnosis of MND can be shocking (Brown, 2003) and be perceived as a death sentence (Locock, Ziebland, & Dumelow, 2009). People experience the loss of motor ability early into their illness trajectory, and this impacts on their occupational roles (Brott, Hocking, & Paddy, 2007), resulting in their experiencing MND as a disruption to their lives (Locock et al., 2009) and having concerns regarding their losses and their future (Brown & Addington-Hall, 2008; Foley, Timonen, & Hardiman, 2012), and feelings of uncertainty throughout their illness trajectory because of not knowing when or how they will die (Harris, 2015). Family carers report that the long illness trajectory of MND can create existential suffering for a person with MND (O'Toole, 2011) and an excessive burden for their family carer(s), which coupled together may exacerbate a "patient's desire to hasten their death" (Whitehead, O'Brien, Jack, & Mitchell, 2011, p. 368). The lived experiences of MND accentuate the devastating nature of the disease, and this can impact upon how people respond to care.

Motor neurone disease is recognised as a complex and complicated disease (Hogden, Foley, Henderson, James, & Aoun, 2017; MNDA, 2015), and it results in people having to be involved with MND professionals who are disease specialists (Ozanne, Graneheim, & Strang, 2013). Hogden et al. (2017, p. 210) suggest people with

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**What does this paper contribute to the wider global clinical community?**

- Motor neurone disease is a complex disease, and it is important that professionals continue to provide holistic care throughout the illness trajectory.
- The identification of three distinct phases of the MND illness trajectory will help nurses and other professionals to better understand the meaning of uncertainty and other concerns for people with MND. This may help to avoid palliative care patients in general experiencing life as a crisis and having to seek support from hospice professionals too late into their illness trajectory.
- These results further support the concept of providing education for nurses and other professionals on improving the dialogue relating to concerns, in particular uncertainty, and the need for early referral to palliative care professionals.

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MND are "often required to make decisions for symptom management and end-of-life care. Symptom management includes: gastrostomy, invasive ventilation and non-invasive ventilation, to provide improvements in quality of life, as the disease progresses." Gale (2015, p. 251) suggests thinking about the future with further losses and planning for end of life is "serving the agenda of the health professional at the expense of the patient." Studies of the lived experiences of MND care have suggested that people were generally dissatisfied with the focus of their care (Bolmsjö, 2001; Brown, 2003; Brown, Lattimer, & Tudball, 2005; Hughes, Sinha, Higginson, Down, & Leigh, 2005; Van Teijingen, Friend, & Kamal, 2001). Although professionals acknowledge the debilitating impact of MND on a person, the focus of care is functional rather than emotional (Brown, 2003). The call is for professionals to change their priorities and to carefully listen to individual accounts of their lived experiences, thus treating the person as an "individual rather than a patient" (Bolmsjö, 2001, p. 503).

Miles and Asbridge (2013, p. 286) also acknowledge the need for modern medicine to respect the whole person, stating: "the patient is a person with dimensions which extend well beyond the purely physical and which include the psychological, emotional, existential/spiritual and social components of human existence." Ozanne et al. (2013), Ozanne and Graneheim (2017) propose a solution through respecting the whole person with MND and suggest the need to involve MND professionals who are specialists in the disease together with specialists in palliative care. Connolly, Galvin, and Hardiman (2015) also recommend the integration of palliation for people with MND to alleviate distressing physical, psychosocial and existential concerns. Henoch and Danielson (2009, p. 228) explored the existential concerns of people with cancer, which they classified into the two main themes of the "struggle to maintain self-identity" and "threats to self-identity."

Some of the components relevant to "threats to self-identity" included "bodily changes, uncertainty, loss of meaning, loss of control, loss of relationships, and fear of dying." There are parallels to be drawn for people with cancer and people with MND, as they are diagnosed with a terminal illness/disease, resulting in existential concerns (Bolmsjö, 2000, 2001). The aim of this study was to explore the meaning of living with uncertainty for people diagnosed with motor neurone disease (MND).

## 2 | METHODS

### 2.1 | Design

This research is part of a hermeneutic phenomenological project concerned with the meaning of living with MND. The initial study undertaken to answer the research question: "What does it mean to be a person living through the illness trajectory of MND?" and a study of the phenomenon of existence when given a diagnosis of MND in the context of receiving health care. The concept of "existential loss" identified in relation to MND was the loss of past ways of being-in-the-world, and the loss of embodiment, spatiality and the future (Harris, 2015, p. 1579). From the data, it emerged that people with MND are living with uncertainty throughout their illness trajectory, and it was determined that this required further examination. To meet the aim of the current research, hermeneutic (interpretive) phenomenology was used as a methodology, as this is suitable for studying lifeworld experiences (Finlay, 2011). Finlay (2011, p. 89) suggests "both descriptive and hermeneutic (interpretive) designs may be used to explore how everyday experience shows itself in the lifeworld, i.e., as embodied and lived through time/space and in relationships with others." Descriptive phenomenology as a methodology offers researchers an approach through which to explore body experiences and a researcher "brackets" their existing presuppositions (experiences and beliefs) of a phenomenon to promote validity (Husserl, 1989 cited in Allen-Collinson & Pavey, 2013). Hermeneutic (interpretive) phenomenology as a methodology offers an approach through which to explore the body experience and how this impacts upon everyday lives, and a researcher brings their prior presuppositions of a phenomenon to the "hermeneutic circle" of understanding (Finlay, 2011; Heidegger, 1927/1962). Thus, they are open to a new and evolving understanding of something, such as a "text," "phenomenon" or "participant" in the research context (Finlay, 2011; Gadamer, 1975; Heidegger, 1927/1962).

### 2.2 | Participants

Four people with MND were recruited from the MNDA Care Centre in the North West of England, with the inclusion criteria that individuals had an accepted diagnosis of MND (all types), over 18 years of age (no upper limit), had been receiving treatment from a range of professionals and had been receiving care and treatment for 3–6 months. Individuals were excluded from the study if they did not have the mental capacity to provide their informed consent. An MND consultant and nurses provided the study information sheet to people attending the clinic and asked whether they contact the researcher (DH) if they wished to discuss and be involved in the study (Harris, 2014). The participants contacted the researcher to express their wish to be involved, and interviews were conducted at a time and location convenient to them, either in their home or at their place of work.

### 2.3 | Data collection

Data were collected in 2012. In the initial study, the researcher (DH) asked: "Can you please tell me the story of your life.… since you first thought there might have been something wrong with you? Please begin wherever you like. I will not interrupt you; I will listen to you and only write down some notes. When you finish I may ask you some questions to clarify some points." The researcher (DH) returned to the themes described in the first stage of the interview to explore and gain a deeper understanding of the participants' lived experiences. Data from the first interview were audio-taped and analysed before carrying out the second interview. All participants attended a second interview, which was again at an agreed date/time, when a summary of their lived experiences was discussed, thereby providing an opportunity to add or remove any detail(s). The researcher then asked three open-ended questions to induce further discussion.

### 2.4 | Analysis

Interpretive description guided the analysis (Finlay, 2011), and this involves the concept of returning to the whole-parts-whole to facilitate the process of understanding (Fleming, Gaidys, & Robb, 2003; Gadamer, 1975; Heidegger, 1927/1962). Fleming et al. (2003, p. 118) suggest "gaining understanding of the whole text should be the starting point of analysis, because the meaning of the whole will influence understanding of every other part of the text." The current analysis process involved the following:

1. Returning to the individual philosophical framework analysis.
2. The identification and extraction of excerpts that represent a participant's description of the everyday experiences and how this leads to uncertainty for people diagnosed with MND.
3. Producing a description to reinforce the initial interpretation.
4. Going back and forth between participant descriptions, initial interpretations, themes and forming patterns of the coherent whole.
5. Noting similarities and differences across all the individual excerpts.
6. Grouping together the experiences of the "body failing prematurely and searching for answers," "body deterioration and responses to care" and "body nearing its end and needing to talk"; these illuminate the patterns that represent the phenomenon under study (Finlay, 2011): the meaning of uncertainty for people with MND.

## 2.5 | Plausibility of Interpretations

To promote a level of self-awareness, the researcher (DH) reflected on her prior understandings of MND and experiences of supporting her mother living through the illness trajectory of PBP MND, before data collection commenced, and those evolving during the study. To ensure that interpretive closure was not reached prematurely, the interpreted stories were taken back to the participants, and the researcher held regular discussions with other professionals acting as supervisors for the initial study (Harris, 2014). To ensure the researcher's (DH) interpretations are both plausible and justified (Finlay, 2011), extensive excerpts are provided. The knowledge claims have been validated in dialogue with other professionals who are co-editors of this paper (Finlay, 2011).

## 2.6 | Ethical considerations

Permission to undertake the study was obtained from the researcher's University Research Ethics Panel, the NHS Health Research Authority and the local NHS Research and Development (approval No. 11/EE/0364). The information sheet and consent form sought approval for participation in the study, primary and secondary analyses and related publications. Pseudonyms have been used throughout when referring to the participants involved in the study to ensure anonymity. The criterion of avoiding harm was a basic ethical principle in the design of this study. Hollway and Jefferson (2000, p. 87) state "Can we assume that it is necessarily harmful to experience being upset or distressed? It can be reassuring and therapeutic to talk about an upsetting event in a safe context." If participants started to get upset, the researcher (DH) gave them time to express their emotions and made them aware of support services available to them.

## 3 | RESULTS

The results of this study highlight three aspects of the illness trajectory of MND: "body failing prematurely and searching for answers," "body deterioration and responses to care" and "body nearing its end and needing to talk." These bring to light the patterns that represent the phenomenon under study (Finlay, 2011), the meaning of uncertainty for people with MND. Other existential concerns, including bodily changes, loss of meaning, loss of control, loss of relationships and fear of dying and death, can be found throughout their stories.

## 3.1 | Body failing prematurely and searching for answers

The body failing prematurely and searching for answers from neurological professionals. The similarities drawn, the participants are living with uncertainty of what condition they may have. Thereafter, their experiences of investigations and diagnosis were varied. James, a professional sportsman, took himself back to the significant sporting events occurring at that time and being uncertain as to why he needed to be admitted into hospital for investigations:

*So on the last day of the Ryder Cup, I remember it well, I found myself being admitted to [Name of hospital] neuro ward for more electro-nerve tests. And then on the following day I think I had a lumber puncture, and then I had a brain scan, MRI brain scan, and was then diagnosed with MND.*

*I could probably have done them all in a day, or a day and a half. But obviously it had to fit in with all the test equipment, and the time involved, and the scheduling of the department.*

*When I was in [Name of hospital] being diagnosed there was an awful lot of people came in to look at me, because I think I have quite physical fasciculations, which are a diagnostic indicator of things not going well.*

Martin first noticed something untoward was happening to his body when he dropped his pencil whilst drawing. His GP recommended he go private for neurological investigations and consultancy as changes to his body had a profound impact on his role as a managing director/architect:

*The first time I suspected there was something wrong, was I am or I was left handed, whereas now I am not any handed of course, but I was left handed. But I started dropping things and being clumsy with my right hand, um I knew it was out of character; actually I have been blessed with a lot of skill, in being able to do anything mechanical with my hands for drawing.*

*So I arranged for a private consultation with (name of MND consultant) at the (name of hospital), which I got one in 2/3 days. He then arranged for an MRI scan on the Friday evening and the results then to be analysed on the Monday morning.*

Charles was out walking his dog when he first noticed his foot drop. His physiotherapist referred him for private investigations and consultancy. The consultant's approach to diagnosis was potentially insensitive, as the period after was experienced as life in crisis because of Charles' loss of future relationships with his family:

*I had taken early retirement, at quite an early age, at 53, and therefore I enjoyed some years of retirement before diagnosis. So therefore can be a little bit more philosophical about life, than had it hit me when working, and suddenly life had to change all of a sudden, to give up work, and to give up that particular income stream, and for my whole life to change. So that probably did make it easier to er... cope with it.*

*Rightly or wrongly I was still covered by some private health that did make a difference, that was Thursday and I was expecting an answer by Monday morning.*

*The guy said 'You have been told on your own, go away and talk to your wife, and come back next week or ten days later when you have looked at the internet and found out everything.' He said 'Don't look at the worst bits, because you know what the internet is like, it always gives you the worst things.' He said 'You know it is not good but come back and...' He said 'We will book a double session,' whatever that was, so we just went back... [Wife] and I to talk to the consultant in his rooms in a very relaxed way, and giving every single question you can think of.*

*When news suddenly comes out of the blue and it very much was so, er... The period after that you are in tatters really, both yourself and your immediate family.*

*But even my own feelings have changed from initial thoughts of Dignitas type routes to how you want to end it in the end.*

Maureen endured many months of investigations involving a number of hospital admissions, and she experienced a loss of control during the process of investigations and diagnosis, resulting in uncertainty regarding what it all meant:

*I had to go home and then come back in about a month later. Then I went in and then they did a lot of tests, like all the nerve ends of your body, and all that, and a lot of other tests. You know I can't just remember all of them, but I had a lot of tests. I had a full scan and then I went back, and then they said we'll have you in for five days. Anyway they did all tests on me and that five days lasted for about eight weeks.*

*And then I had all the students around me seeing, because you've got to let people learn, haven't you? I don't mind that.*

*And when (name of MND consultant) said 'Do you want the good news or the bad news?' I said 'I will have the bad news first.' He said 'You've got what they call motor neurone, do you know about it?' I said, 'No, I've never heard of it.' And then he said 'You can lose, you can lose your speech, your walking,' he said you can lose everything except your brain. I never asked about your eyes, but he said you can lose everything but your brain; that keeps going.*

## 3.2 | Body deterioration and responses to care

Body deterioration and responses to care from MND professionals vary depending on whether a person accepts life with MND. The similarities are, however, that the participants are living with uncertainty as to how their care will be managed:

*But you know they keep on talking about managing my symptoms. I don't suffer any pain, so I'm not totally certain what symptoms we have that need managing.* (James)

*I am supposed to be under (name of head MND consultant) at (name of hospital), I have never seen (name of head MND consultant) ever, and the doctor that I usually see is (name of second MND consultant).* (Martin)

*Now when I go to the MND centre I don't spend very long with those individuals because I have really got everything I need locally. So the teams have, NHS related professionals have been excellent.* (Charles)

The progressive nature of MND means involvement with a multi-professional team of professionals who carry out their individual assessments of need, and this approach was experienced as enlightening, overpowering and annoying:

*Well I suppose it's a bit of shock being in a situation where you have to be on the receiving end of quite a lot of healthcare. It suddenly makes you wake up to the... either the supreme efficiencies, or deficiencies of the NHS as a healthcare provider. And that er... that definitely has raised a few eyebrows.* (James)

*Receiving healthcare, some people find it overpowering we have had someone visit every day this week, if you include yourself as a health professional. Take yesterday, the district nurses rang, we have had the speech and language therapist, and the lady from the MND association come to see me. I have been to the hospice on Monday.* (Charles)

*I had the speech therapist, and she assesses your food and how you eat, and what I eat. She came about a fortnight ago. I very rarely see a social worker, and I am a bit annoyed with them. I don't want to see them. I have the nurse and my physiotherapist. I have a new OT, I am just beginning to get used to, but I have to keep mithering and mithering for things. I don't want me home being like hospital, I definitely don't.* (Maureen)

The progressive nature of MND means people have no choice but to accept care from formal carers for their survival, although how they respond to this relationality is different for each person. The formal care received via social services was essential for attending to basic human needs; however, James raised concerns regarding threats to maintaining his self-identity, such as managing his daily insulin, as he will be dependent on district nurses to administer it, thus adding yet another professional coming to his home each day; he stated:

*The problem is, you see, you have got social services looking after the personal care side of things, which they are*

*doing, and then you've got the medical practitioner... You know, when I get to a stage, should I ever get there, that I'm not in a position to self-administer my insulin then the care people can't do that, somebody else has to come in and take care of that, which considering what is involved strikes me as a real sledgehammer to crack a nut.*

Maureen, a retired carer, had a prior understanding of the provision of day care. She describes a loss of relationship with a carer, who was like a daughter, coupled with loss of control of self in her world, adds to her frustration:

*I think it was when I worked on [Home Help], some of them didn't have families, I used to feel sorry for them, and I used to go in my own time, you know, at night, or back if they were on their own.*

*My day care is getting better, because like when my first carer left, she went to Australia, she was like my daughter. She always said I was like a second mother. And she did care. But now they just come and do, and feed you, and all that.*

*But now I am getting that way, that if there's a few in and they are talking, I feel as though I am getting worked up. And I am getting more worked up when I have to phone people over complaints and that, I am getting worked up very much, but I was never like that.*

Maureen had experienced a number of hospital admissions, resulting in her spending long periods of time in an acute setting, and having to make decisions on essential medical interventions, such as noninvasive breathing equipment and overnight carers, as without them she could not survive. Thus, Maureen is struggling between needs and wants; she knows that she needs the care but does not want the care:

*I was in [name of respiratory hospital] for a long time, they wouldn't let me come home until I decided that I'd have to have night care, and I didn't want it. I didn't want it.*

*I'm on a ventilator overnight, but I've had the mask over my nose, but now I'd rather have the things in my nose because I can breathe better and I don't feel closed in. I have night carers now.*

*Anyway I had to decide then I'd have it because... everything went wrong in my body, you know, everything went wrong.*

*And that is why they are here, because if it comes out they have to be here to put it back, or if I choke two or three times where I have to have it off a bit to get right to sit up, because I feel as though I am choking.*

*I never wanted them [overnight carers], but I would be lost without them.*

## 3.3 | Body nearing its end and needing to talk

The body nearing its end and needing to talk with palliative care professionals occurs in the second–tenth year of illness trajectory. Similarities can be drawn, in that all the participants are living with uncertainty as to how they will be supported to die with MND. James prioritises his need to talk because of a loss of meaning and frustration as he comes to terms with dying:

*Erm... I am getting on with life it's the only way to go. And of course that's being amply demonstrated by the fact that the football season has started, Grand Prix season has started, football season is boiling up to a fantastic climax, and you just think to yourself, well, hm, am I going to see the end of the football season? Or am I going to see the.. Who knows? This is a tricky one.*

*But the snag is, as I think I mentioned earlier, in this instance, maybe my positive mental attitude has been beaten by the fact that I can't stop this disease, this degeneration from continuing. And maybe that's not a good basis on building a solid positive mental attitude. It's a bit like building a house on quicksand, it doesn't matter how solid the building is, and if you haven't got a decent foundation we're never going to succeed. And I suppose, if I'm honest, I am probably phlegmatically resigned to my fate, rather than fighting it from every corner. But that's... you know, that's with the wisdom of two years hindsight.*

*It's a funny old situation. You sort of... it's like being in... It's like being on death row without knowing when the executioner is going to pop in. Anyway, we shall be sorting that one out.*

*Well, funnily enough, one of the things that erm [Name of consultant], at my last clinical appointment, put me... gave me a referral to [Name of hospice consultant], I think he's in palliative care at the hospice, and has a clinic at [Name of hospital], but bearing in mind it's April, I haven't heard a dicky bird since. If they don't get on with it I'll be a name on a list of deceased patients, rather than somebody that is on a palliative care list.*

James had concerns for his wife and children after his death and searched for counselling services who would understand about their loss, and he self-referred to the hospice Macmillan nurse:

*I did go to my GP surgery to find out about counselling services, or what was available for my wife, and my*

*children, after my death, and the first foray into that wasn't hugely successful. I think if you weren't a single mum with an alcohol narcotic problem it was quite difficult to put somebody in the right pigeon hole, but eventually I found them myself, through the specialist Macmillan nurse.*

*And more importantly to me, which I thought was probably significant, she's obviously working at the hospice, so she has had quite a number of years in dealing with patients with a terminal illness, which obviously makes my visits to her, as far as I'm concerned, a lot more grounded than they would be with a counsellor that just deals in general counselling.*

Martin raised his concerns that MND professionals who specialised in the disease are not open to having discussions about the terminal stage of the disease:

*I mean I think people... Because it is a terminal disease are always a bit frightened, they have to have somebody with them at first, they are frightened of being politically incorrect. Which is... You know they are frightened of ticking the wrong box. Of course he doesn't bother now, I... I'd rather he speak frank and open.*

*I mean so many people, and I find it probably a little bit disappointing with some of the staff from the occupational therapy, they are frightened to mention the word 'terminal.'*

Martin appreciates not needing to forward plan an appointment to talk to his hospice consultant about his condition, although he notes the problems of other professionals not wanting to talk about dying:

*Well, really there is not much I can do for you, you know he said 'but I would be better off passing you over to the hospice.'*

*But I have got nothing but praise for the hospice in every respect. I suppose it's a bit of a problem for doctors, um they are used to being able to find a cure for somebody, but (name of consultant) at the hospice had been very good, and rather than make an appointment I just give him a call when I want to see him.*

*I mean a lot of people don't want to talk about it, but it certainly doesn't worry me talking about it. Well we are all going to die, and I think it will come to every one of us. I suppose we have just been told it is going to... And it is a rather painful death, so...*

Charles focuses on talking to the hospice professionals about his loss of future with his family, future support and making plans for the future:

*There is actually a local Macmillan nurse who has got expertise in MND and she has come, she is a lovely lady and she is going to be great for me as time goes by.*

*So in the end certainly we are in the midst of putting together the... the/Living Will type thing, personal directive.*

*But what I do feel is incredibly sad that I won't be around to see things ... and to enjoy my retirement with my family.*

Maureen only goes out of her home once a week to hospice day care, where she is talking about completing an advance care plan, knowing that her religious faith will help her to face the fear of dying and death:

*Because now they give you books to write everything down. But you have got to accept things haven't you. I always say well my faith helps me and things like that, you know.*

## 4 | DISCUSSION

The results show that people with MND go through three significant body experiences impacting on their everyday lives: body failing prematurely and searching for answers, body deterioration and responding to care and body nearing its end and needing to talk. Lerum, Solbraekke, Holmøy, and Frich (2015) also raise awareness of three phases of MND: (i) diagnosis, (ii) ongoing change and decline and (iii) chronic or terminal. The results of this study focus on categorising MND as a terminal disease from diagnosis, because people with MND are living with uncertainty and other existential concerns relating to their bodily changes, loss of meaning, loss of control, loss of relationships and dying and death.

During the first phase of the illness trajectory of MND, the theme *body failing prematurely and searching for answers* indicated that a quick diagnosis can lead to living with the uncertainty of what it all means, whilst a longer wait for diagnosis means living with the uncertainty of what condition an individual may have. Consequently, both quick and slow diagnoses can lead to uncertainty of different kinds. One of the issues that emerges from these results is that people with MND are at risk of experiencing life as an existential crisis following a quick diagnosis, and one participant described this period as "life in tatters," relating to difficulty with a loss of future with family, and consideration of a Dignitas approach. Similarly, other studies have shown that people are living with uncertainty before diagnosis and living with a fear of the unknown after diagnosis (Ozanne & Graneheim, 2017). Fear of the unknown may arise because a person newly diagnosed with MND learns that they have a progressive and terminal disease which will lead to the loss of movement, speech, breathing and swallowing (Bäumer et al., 2014).

Other study results suggest that a prolonged time to diagnosis and the way a diagnosis is delivered can result in adverse consequences (O'Brien, Whitehead, Jack, & Mitchell, 2011), such as long-term emotional stress (Aoun, Breen, Oliver et al., 2017). Emotional stress at the time of diagnosis and the period afterwards has been described as "shock, fear of the future, denial, anxiety for family, loss of future, anger, isolation, sadness, and guilt" (MNDA, 2013, p. 23). A study by Aoun, Breen, Edis et al. (2017) suggests that neurologists need to improve their skills relating to responding to the emotions of individuals newly diagnosed with MND. The results of the present study suggest that people experience their body failing prematurely before being diagnosed with MND, and they have a need to talk to a neurological consultant about their concerns of uncertainty and loss of future.

In the second phase of the MND illness trajectory, responses grouped under the theme *body deterioration and responses to care* are varied, depending on whether body deterioration is rapid or slow, and people are living with the uncertainty of "managing" their condition. Cohn (1997, p. 13) states that a "person has the freedom to accept or deny the conditions of their existence" and also "a person can choose how to respond to being with others such as choosing involvement or isolation." The study results suggest that accepting life with MND results in the continuity of life, but not as before, until a person can no longer conceal the fact that their body has deteriorated beyond recognition. Choosing involvement as a response to care meant that individuals had their symptoms monitored re nutrition/hydration and respiratory distress, and their needs were assessed for essential social and medical care, which potentially resulted in a loss of the control of self. Hogden et al. (2017, p. 210) suggest "the consequences of avoiding decision making, for example, for nutrition/hydration or respiratory distress, can impact the patient's health and quality of life." Other studies suggest people "engaged with services on their own terms to be in control of care but equated living with ALS to a life of unremitting loss which included loss of control" (Foley, Timonen, & Hardiman, 2014, p. 118). The study results reveal that people are at risk of experiencing life as an existential crisis approximately two years into their illness trajectory, and one participant described life as "being a prisoner on death row," because the present and future were uncertain. Other researchers have reported that physical losses associated with MND place a person's existence on hold (Ozanne et al., 2013). The desire to hasten death has been associated with a loss of control (Bolmsjö, 2001), being unable to accept the disease (Cipolletta, Gammino, & Palmieri, 2017), and hopelessness and fear of becoming a burden (Whitehead et al., 2011). This study has revealed that people experience their body deteriorating and have a desire to talk to MND professionals about their concerns of uncertainty, loss of control and loss of meaning; however, they are being referred on to palliative care professionals for this aspect of their care.

The third phase of the illness trajectory, encompassed by the theme *body nearing its end and needing to talk,* refers to the involvement of palliative care professionals because of living with the uncertainty of how they will be supported to die. Participants were referred to the palliative care professionals in their second–tenth year of illness trajectory. Palliative care professionals understand that the phenomenon of dying involves the affirmation of life and regard dying as a normal process (WHO, 2002). Sigrist (2009) suggests the affirmation of life involves finding meaning in life, reflecting on past and present relationships and completing unfinished business. The MND Association (2016) recommend professionals have open discussions about the progressive nature of MND and dying and death to enable people to exercise choice and remain in control of their preferences for end-of-life care. Connolly et al. (2015, p. 435) suggest that early and open discussions of end-of-life issues may "obviate the introduction of unwanted interventions and use of technologies." The participants did not talk about having such early and open discussions of end-of-life issues, although two of the four participants were using technologies to help them survive. One participant raised his concerns about attempting to have open discussions with MND professionals and stated: they are frightened to mention the word "terminal." Other study results suggest that people with MND experience anxiety over dying and death, and recommend referral to palliative care professionals at the time of diagnosis (Ozanne et al., 2013). Goldstein and Abrahams (2013) note that a diagnosis of MND prioritises the need to talk to palliative care professionals early in the illness trajectory because people are at risk of cognitive decline and behavioural changes. Cognitive decline impacts on the ability to communicate advance decisions to refuse treatments (ADRT) or the withdrawal of treatments (MNDA, 2016; NCPC, 2011). This study raises awareness of how people experience their body nearing its end and the need to talk to palliative care professionals about their concerns of uncertainty and fear of dying and death. Talking to palliative care professionals may also enable people with MND to complete unfinished business, find meaning in life and reflect on past and present relationships with others.

## 5 | CONCLUSIONS

The aim of this study was to return to the everyday experiences of people living with MND and how this leads to uncertainty for people diagnosed with MND. The findings show that people with MND are living with uncertainty and other concerns throughout their illness trajectories. The effects of this can result in people experiencing life in crisis at different stages of their illness, resulting in the desire to hasten death because of various losses. People are having to turn to palliative care professionals who are more able to meet their concerns than those caring for other aspects of their condition. MND is a complex disease, and it is important that professionals continue to provide holistic care throughout the illness trajectory. The identification of three distinct phases of the MND illness trajectory will help nurses and other professionals to have a better understanding of the meaning of uncertainty and other concerns for people with MND. The uncertainty that surrounds all phases of MND tends to be overlooked by those caring for people with MND. This research extends our knowledge of existential concerns and how people are being referred to

professionals who are specialists in palliative and end-of-life care too late into their illness trajectory, when additional risks associated with a loss of mental capacity and loss of speech may impact on their ability to talk about their concerns and plan for their future.

## CONTRIBUTIONS

Initial study design: DAH; current study design: DAH, KJ, CW; data collection and analysis: DAH; and manuscript preparation: DAH, KJ, CW.

## CONFLICT OF INTEREST

The authors declare that there is no conflict of interest.

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## 4.5 CONCLUSION

This conclusion relates to both Paper 3 and Paper 5. My situatedness as a phenomenological researcher was a strength that forged my understanding, informed my judgement and provided me with the skills to understand the meaning of others with MND, although this did create methodological challenges as discussed in the narratives. The two papers have contributed to knowledge, in that the designed method of data collection and analysis enabled a sensitive methodology for researching the phenomenon of existence with MND through time. The findings from this study have contributed to the further development of caring policy and practice for the health needs of people living with neurological conditions in the County of Lincolnshire (Ray et al., 2018). I returned to the individual philosophical framework analysis to explore the meaning of uncertainty for people diagnosed with MND. The findings uncovered three phases of the MND illness trajectory. The similarities across the data included uncertainty regarding their future condition, how their care would be managed and how they would be supported to die. The differences in the uncertainties faced can be found in the individual participants' excerpts. These findings have been cited in a systematic qualitative review (Flemming et al., 2020: 724), which suggested, 'across the papers, the last days of life were commonly the first-time individuals and carers had discussed specialist palliative care support, with the exception of one paper.' This single paper (Paper 5) found that it is unusual for people to receive specialist palliative care support in the months before their death.

Since this study began, the knowledge regarding MND has progressed to interpret the ways in which the disease can impact significantly on the motor neurones and cognition. Turner (2016: 214) suggested that MND is a disease that 'moves beyond the motor neurone' because up to 50% of people with MND are known to have mild cognitive impairments. Thus, professionals monitor the progression of MND in terms of limbs, bulbar and respiratory muscle weakness, and whether the disease has spread to the brain. Connelly et al. (2015: 435) called for the clinical management of end of life to incorporate the 'palliation of distressing physical, psychosocial, and existential distress'. The issue of existential distress at end of life is still current, as a retired teacher living with MND is campaigning to legalise assisted dying in the UK so that he and others can be in control of the end of their lives (Clark, 2019).

The aim of palliation is to minimise the barriers to a good death and support family carers in their bereavement (Aoun et al., 2018). Henoch and Danielson (2009) share concerns as to how healthcare professionals working with people with terminal cancer may best support each individual's well-being. Since each person's well-being will differ, there is no standard template suitable for all. The participants involved in this research project were experiencing significant loss, uncertainty and other existential concerns, which impacted on their well-being, and professional interventions were not targeted at these concerns. There are still few evidence-based approaches designed to enhance well-being for people with MND.

The hermeneutic phenomenological approach in research, acknowledges that researchers come to the study with some existing understanding of the phenomenon. Laverty (2003: 21) suggested that 'the researcher and the participant work together to bring to life the experience being explored'. This chapter critically appraises how I have enabled people with MND to interpret their lives and find meaning in their experiences through a co-constructed approach, and the challenges that ensued. I have remained open to developing an understanding of the meaning of existence and uncertainty when diagnosed with MND, and to searching for the deeper meaning of experience (Finlay, 2011). Searching for a deeper meaning of the experience of MND has been extremely time-consuming and emotionally challenging. The reward has been the acceptance of these two papers in peer-reviewed journals and knowing that the findings are now being used to inform care policy and practice. It has made this research journey worthwhile.

# CHAPTER 5 PROPOSING A PERSON-CENTRED CARE MODEL

## 5.1 LINKING NARRATIVE FOR PAPER 6

*…So a template that is good for patient A, might be crap for patient B, or patient C, for that matter* - James.

Embedded in this chapter, **Paper 6** aims to provide practical insights into the way that professionals caring for a person with MND can recognise, respect and respond to that person's temporality: that is, recognise the person that they have been, that they are now and that they will be in the future. This narrative will explore the rationale for proposing a person-centred care model. As Miles and Asbridge (2019: 208) suggested, 'multiple deficiencies exist within the current care models for MND and much work, therefore, remains to be done to ensure a maximum impact of care processes on the experience of illness and on clinical and social care outcomes'.

Miles and Asbridge (2019) provided a commentary on the work of Aoun et al. (2018) and Aoun (2018), who identified the need for a person-centred approach in the care of people with MND. Aoun et al. (2018: 326) used a postal survey to report on a person-centred model of care – the MND Advisory Service. The MND Association's motto is 'Until there is a cure, there is care'. The findings suggest that people with MND and their families feel supported, and are able to make informed decisions. The authors raised concerns that this service is reliant on charity funding. In a later paper, Aoun (2018: 675) called for palliative care for people with MND and their family carers to be integrated into the care plan from the point of diagnosis to bereavement. The three outcomes of palliative care are 'quality of life, quality of care, quality of death' and these can be achieved through several processes: focussing on the person and not only on the illness; therapeutic interactions; communication throughout the course of the illness; care goals; and advance care plans. The complexity of MND care needed to optimise quality of life for people with MND and their family carers should not be underestimated.

The proposed person-centred care model is based on philosophical ideas of freedom towards death:

*Anticipation reveals to Dasein its lostness in the they-self and brings it face to face with the possibility of being itself, primarily unsupported by concernful solicitude, but of being itself, rather, in impassioned freedom towards death – freedom which has been released from the illusions of 'they', and which is factical, certain of itself and anxious (Heidegger, 1927/1962: 311)*

I have interpreted these ideas as follows: in the present, a person pursues current interests and projects their future. They continue doing so until they realise that something untoward is happening to their body. A person diagnosed with MND learns that there is no known cure, and, therefore, they anticipate their death. MND creates many additional concerns, however, because a person is aware that their body will deteriorate further before they die, and they must make choices regarding life and death. In anticipation, Heidegger (1927/1962) is suggesting that acknowledgement of being towards death can bring 'sense, meaning and orientation to our lives' (Cooper and Adams, 2005: 81). Others have acknowledged that healthcare professionals have difficulty talking with patients about death (Miles and Asbridge, 2019a).

After publishing papers 1, 2 and 3, I chose to return to work as an occupational therapist with the same NHS Trust that had been my previous employer and had provided palliative and end of life care for my mother. I was covering for a colleague who was on maternity leave. My caseload had many patients diagnosed with various types of terminal illness or conditions, including seven people with MND, of different types and at different stages of their illness. The NHS Trust ensured that all those diagnosed with MND received palliative care from the time of their diagnosis and throughout their illness trajectory. The focus of care was on optimising the quality of life for patients. I would visit these patients in their own homes and take time to understand the person in a wider temporal frame and beyond the context of their illness. What I learnt, through this new way of understanding the person with MND, was that they were not concerned about the degenerative nature of their condition, but about the others in their world. They wanted the visiting professional to enable them to talk about their concerns, and for the professional to listen. While it would be unethical to share

examples of patient care here, I can report one participant's concerns about recommendations made to him by an occupational therapist:

> *It is probably a good time to look at the total cost of the situation and, in a way, it links back to this thing about whether you harm yourself.  I think that one's life does have a value, and if it suddenly was going to cost, we have a house that is worth taking a figure of three hundred thousand. You end up having to spend ten thousand pounds on a through floor lift from one floor to another, and fifteen thousand for a new bathroom. Then the cost, when you have passed away, for those things to be cleaned up, tidied up, to make good and sell the house. If you had any income at all, sorry, if you have any capital at all, you could end up spending that sum of money.  I just would not have done so. It would have involved spending ridiculous amounts of anything you have ever saved over your life, to prolong your life for, say, a shortest, potential period.  You lose the wish to continue that.*

This view made me reflect on my past experience as an occupational therapist, where I may have made similar recommendations. Of course, the aim at the forefront of any such recommendation is to preserve the person's quality of life. Professionals need to recognise what is important to the person, which may not be themselves in the present, but others in the future. Paper 6 presents the collective findings, developed into a person-centred care model.
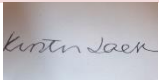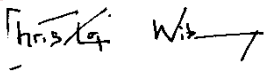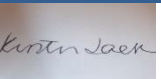
## 5.2 PAPER 6

**Harris, D. A**., Jack, K. and Wibberley, C. (In Press, 2020). The need to consider 'temporality' in person-centred care of people with motor neurone disease (In press). Accepted Manuscript, 4th June 2020, *European Journal for Person Centered Healthcare*.

## PhD BY PUBLISHED WORK (ROUTE 1/2): CONTRIBUTION TO PUBLICATIONS

*This form is to accompany an application for registration for PhD where the PhD is by Published Work. A separate form should be completed for each publication that is submitted with the proposal and should accompany the RD1 form.*

| 1. | The Candidate | | | |
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**2. Title of PhD Proposal**

Interpreting End of Life Experiences in Motor Neurone Disease

**3. Title of Research Output**

The need to consider 'temporality' in person-centred care of people with motor neurone disease (in Press)

**4. Candidate's contribution to the research output**
**(State nature and approximate percentage contribution of each author)**

Denise Harris 80% contribution
Dr Kirsten Jack 10% contribution
Dr Christopher Wibberley 10% contribution

**5. Co author(s):**

I confirm that the contribution indicated above is an accurate assessment of the contribution by the candidate to the research output named in section 3.

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**6. Statement by Director of Studies/Advisor**

I confirm that I have read the above publication and am satisfied that the extent and nature of the candidate's contribution is as indicated in section 4 above.

| Signature: | *Kirsten Jack* | Date: | 26/6/2020 |
|---|---|---|---|
| | (Director of Studies/Advisor) | | |

**7. Signature of Faculty Research Degrees Administrator**

| Signature: | Deborah Bown | Date: | 02.07.20 |
|---|---|---|---|
| | (Faculty Research Degrees Administrator) | | |

ARTICLE

# The need to consider 'temporality' in person-centered care of people with motor neurone disease

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## Abstract

**Aims and objectives:** The overall aim of this paper is to provide practical insight into the way that professionals caring for a person with motor neurone disease (MND) can recognise, respect and respond to that person's temporality; that is, the person that they have been, that they are now, and that they will be in the future.
**Background:** MND is an umbrella term for a group of four rare, devastating neurodegenerative terminal diseases of middle/later life. Previously, we have acknowledged the importance of different time-periods in the trajectory of MND as an illness, for example, during the diagnosis stage through to end of life and decision-making at that time. Living with MND can cause anxiety at all stages of the disease trajectory especially as it can be difficult for people living with MND to communicate their desires and concerns to professionals and carers. It is important that professionals continue to provide holistic care throughout the illness trajectory and the aim of this paper is to explore past research about caring for someone with MND in relation to the concept of person-centred care.
**Method:** The paper is based on the concatenated exploration of the findings of a hermeneutic phenomenological project. Thus, this discursive paper links elements/studies which have been published previously to develop a model of person-centred care for people with MND which recognises and respects their temporality.
**Conclusions:** We suggest MND has a significant impact on a person's lifeworld. The proposed person-centred care model focuses on understanding (interpreting) a person in a wider temporal frame and beyond the context of their illness. The expected collaborative outcomes are that: a person is acknowledged as more than a 'patient with MND' and that a professional is providing person-centred care based on individuality of the person, through a temporal lens. This requires a collaborative approach between the person, others, and professionals. Such person-centred care, focused on individuality, may prevent a person experiencing life in crisis and suffering towards the end-of-life.

## Keywords

Heiddeger, hermeneutic phenomenological method, models of care, motor neurone disease (MND), person-centered care, temporality

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## Introduction

The overall aim of this paper is to provide practical insight into the way that those caring for a person with MND need to recognise, respect and respond to that person's temporality; that is, the person that they have been, that they are now, and that they will be in the future. This is based on Heidegger's (1927/1962) suggestion that time has to be understood in terms of phenomena such as 'heritage, fate, and death' [1], including elements of past, present and future; thus to ignore a person's past and future, is confining that person to the present [1].

This paper pulls together a connected series of study findings and the relevant literature to demonstrate the need to consider temporality as an important aspect of person-centred care. We employ a concatenated exploration of the findings of a hermeneutic phenomenological project. "The expression *concatenated exploration* refers at once to a longitudinal research process and the resulting set of open-ended field studies that are linked together, as it were, in a chain leading to cumulative ... theory" [2]. Additionally, over the time period of the studies, other literature has

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added to the understanding of the hermeneutic phenomenological project; and so the "accretive nature of properly executed, concatenated exploration" [2] has led to an understanding that is greater than the parts of the individual studies within the project. Thus, the current paper represents the practical application of the knowledge gained throughout and across the project, to propose ways in which care can be improved through reflection on temporal aspects of the person being cared for.

## Method

This discursive paper links elements/studies which have been published previously:

- Descriptive personal reflections developed in order to engage with the primary researcher's presuppositions as part of the hermeneutic process [3].

- More developed reflection focusing on loss of person (lived body experienced in silence); loss of relationships (lived relations are challenged); loss of home and loss of time (lived space and lived time take on new meaning); loss of future (dying - facing it alone) [4].

- Interpretive analysis focusing on the themes of: being thrown into the world of MND; loss of embodiment; loss of spatiality; mood in relation to their lifeworld; being with others; facing their own mortality; and facing their loss of temporality and spatiality [5].

- Interpretive analysis focusing on three aspects of the illness trajectory of MND: the body failing prematurely and searching for answers; body deterioration and responses to care; and body nearing its end and needing to talk [6].

While different issues were identified across the studies, what underpinned these identified issues were aspects of the perceived lack of consideration of temporality within the provision of care. Lack of consideration of temporality in care is possible across a number of conditions; but certain characteristics of MND, notably the concomitant reduction in/of the ability to communicate effectively and the ability to control the body in general, renders temporality of particular importance.

## Motor Neurone Disease

Motor Neurone Disease (MND) is an umbrella term for a group of four rare, devastating neurodegenerative terminal diseases of middle/later life [7]. Cases of MND below the age of 30 years have been linked to genetic mutations [8]. The prognosis for the different types of MND varies: for Progressive Bulbar Palsy (PBP) MND - which accounts for approximately 20% of cases - it can be months; for Amyotrophic Lateral Sclerosis (ALS) MND - which accounts for approximately 75% of cases survival is between 2-5 years; and for Progressive Muscular Atrophy (PMA) MND which accounts for approximately 5% of cases survival can be up to 10 years [9,10]. Primary lateral sclerosis (PLS) is not fatal and progresses more slowly than other types of MND [9]. Thus while the progressive nature of MND is unpredictable and depends upon the type, the terminal aspect of MND (with the exception of PLS) is not [11].

A person with MND and their family will face many challenges during the progression of the disease including: physical problems (dysarthria, loss of mobility, respiratory failure and dysphagia) and psychosocial problems (loss, bereavement, depression and family distress) [12,13]. For some, cognitive and behavioural changes may occur [14]. However, around 50% of people with MND are unaffected by cognitive changes [15], making their experiences of loss more painful. Family members and significant others have to observe the overwhelming effects of MND on the ever-changing body of the sufferer.

Information on the temporal aspects of life with MND is relatively limited although other aspects are explored in more detail. Locock *et al.* [16] described the disruptive effects of MND and described diagnosis as a 'biographical abruption' of life while Brott *et al.* [17] explored the occupational disruption of living with MND. Brown [18] explored the disparity between patient needs and care delivered and emphasised the need for the professional focus to be on a person rather than their disease. Foley *et al.* [19] explored the meaning of quality of life when diagnosed with MND and highlighted the importance of faith, control and dignity, and the desire to maintain identity. Brown and Addington-Hall [20] explored how people with MND talk about living and coping with the condition, especially how they live and cope with the loss of movement and speech.

Existential concerns of people with MND have been explored in some studies [18,21,22]. Suffering has also been observed by those caring for people living with MND towards their end of life [23]. The evidence suggests that people living with MND who are experiencing loss of movement and speech have existential concerns and carers have observed suffering at the end of life [23]; however, despite this, care is often focused on functional deficits [18].

## What is person-centred care in MND?

One of our previous papers [6] intrinsically acknowledged the importance of different time periods in the trajectory of MND as an illness. In a separate paper it was noted that "lived time was experienced in the following way: the past was embedded in our memories, the present was unrelenting, and the future was anticipated with anxiety" [4]. However, as a result of our previous findings, we have suggested that "motor neurone disease is a complex disease, and it is important that professionals continue to provide holistic care throughout the illness trajectory" [6]; the findings have not however, been linked explicitly to the concept of person-centred care.

The concept of person-centred care is not new although there is confusion about what it is and how it is supposed to be practiced [24]. Kogan *et al.* [25] suggested that person-centred care moves the care focus away from a biomedical approach in favour of one supporting personal choice and autonomy. They described some key domains which include, holistic care, respect and value, choice, dignity, self-determination and purposeful living. McCormack and McCance [26] offered a theoretical model outlining the core concepts of person-centred care, which include practitioner pre-requisites, the care environment, processes and outcomes. However, along with a lack of definition, there are multiple barriers to the implementation of person-centred care such as, staff culture, time constraints, vulnerability of people, and professionals' belief that they already provide it [27].

Healthcare is known for doing 'to' and 'for' people, rather than doing 'with' them [28]. Indeed, the emphasis on disease management in MND has traditionally been on the management of physical symptoms and functioning with an exclusion of the psychosocial and existential aspects of care [6]. Hogden *et al.* [12] suggested a multidisciplinary approach to person-centred care in MND that addresses the broad range of needs although they highlighted that issues may arise between acute care, rehabilitation and palliative care teams, because of differing philosophies of care.

## Temporality

MND seems to present specific challenges to the support of person-centred care and people living with this disease have particular problems, for example, in relation to communication difficulties [29], which will have a direct impact on the expression of wishes and desires. Indeed, Hogden *et al.* [30] suggested that models to support person-centered approaches to decision-making in other chronic diseases and cancer care are insufficient when applied to the care needs of people living with MND. The authors suggested a dynamic model to guide person-centred decision-making for example, in Amyotrophic Lateral Sclerosis (ALS). They acknowledged the cyclical nature of decision-making, suggesting that people may choose to defer decisions, (wait and see) or change their

mind about decisions already made. Timing is an important factor in these stages, which may occur during a single consultation with a professional or over a longer period.
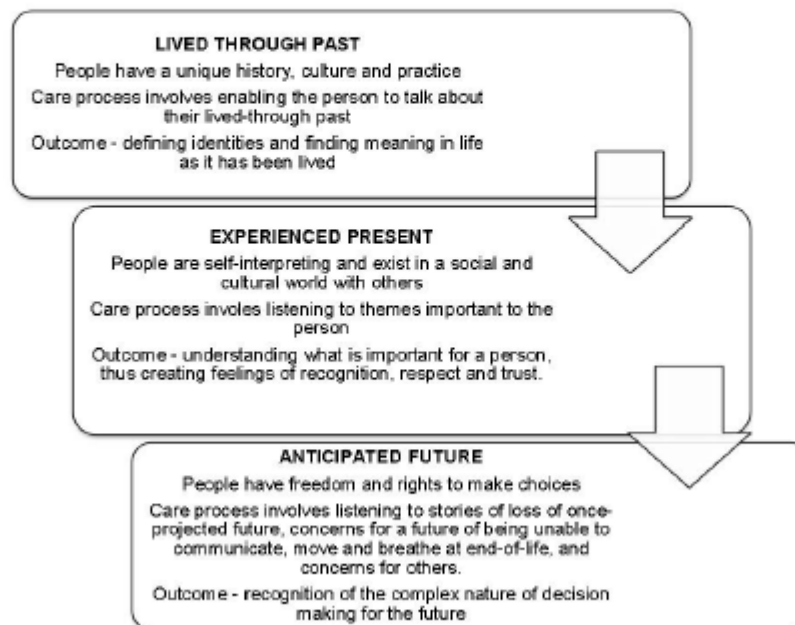
King *et al.* [31] highlighted the difference between MND and other diseases, in that change is ongoing over time. Disease progression might slow but in terms of functioning will decline then once functionality is lost, it is not regained. Thus, there are no periods of remission or respite. King *et al.*'s model [31] highlighted the importance of timely interventions from professionals to support people not only with practical issues, but also to acknowledge the psychological nature of the disease and provide appropriate interventions. Connolly *et al.* [32] described the importance of early and open discussions of end-of-life concerns with people living with MND and their carers. Allowing time for reflection and planning is reassuring and can help avoid unwanted and inappropriate interventions.

As documented within our published work to date and existing MND focused person-centred decision-making models, we suggest that the issue of time is important for two principal reasons. First, the often-swift decline in the ability to communicate places a sense of urgency on the therapeutic relationship (to ascertain wants and needs). Second, is the recognition of the person's wider temporal frame; just as important as caring for someone in the present, is an acknowledgement of who they were in their past, how they could be in the future and how this influences the care they require [4]. Having the ability to care for a person with MND in a wider temporal frame and beyond their current illness context is important for the delivery of person-centred care. As Heidegger suggested, to ignore a person's past and future, is confining that person to the present [1,4] therefore restricting the possibilities for truly person-centred care. This is in line with Dewing's [33] call for a reassessment of person-centred nursing frameworks to take account of body and time (corporeality and temporality) if claiming an 'allegiance' with personhood.

In the care of a person with MND, corporeality and temporality are particularly important when considering the nature and progression of the illness. Someone who is living with MND might engage with deeper modes of temporality because of their anticipated future, they reinterpret and redefine their past [34]. Acknowledging a person's past supports understanding of who they are in the present and who they want to be in the future. The importance of temporality when providing person-centred care for people living with MND is explored below and a way of thinking to support practice will be advanced.

## Experienced present

The presentation and progression of MND will vary greatly from one individual to another, meaning that each will have particular requirements as the disease progresses [35]. Delays in diagnosis can be distressing and the variation in time before diagnosis has been demonstrated in previous research to be a cause of considerable

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**Figure 1 A temporal model of care to enable a new way of thinking about person-centered MND care**



LIVED THROUGH PAST
People have a unique history, culture and practice
Care process involves enabling the person to talk about their lived-through past
Outcome - defining identities and finding meaning in life as it has been lived

EXPERIENCED PRESENT
People are self-interpreting and exist in a social and cultural world with others
Care process involes listening to themes important to the person
Outcome - understanding what is important for a person, thus creating feelings of recognition, respect and trust.

ANTICIPATED FUTURE
People have freedom and rights to make choices
Care process involves listening to stories of loss of once-projected future, concerns for a future of being unable to communicate, move and breathe at end-of-life, and concerns for others.
Outcome - recognition of the complex nature of decision making for the future

dissatisfaction [5,6]. Additionally, satisfaction and confidence in the ability of the neurologist increases when more time is spent at diagnostic appointments [36].

Just as there are variations in disease presentation and progression, the need for information will vary depending on the stage of disease progression [37]. Following the initial shock of diagnosis, each day involves decision-making about how to live with the disease and associated loss of function. Living with MND might be viewed as a negative experience although day-to-day life can still have meaning and can hold positive experiences [31]. Understanding the individual is important, as it can support them to negotiate their way through the disease trajectory in the present and inform care in the future. In a disease which has no cure, focusing on person-centred care in the present takes on an important meaning and understanding day to day concerns, needs and preferences can inform this undertaking [38]. Practising in this way respects a person as a self-interpreting being, existing in a social and cultural world with others. The care process involves listening to what is important for a person, thus creating feelings of recognition, respect and trust [38].

## Anticipated future

A person with MND may wish to talk about their anticipated future and how to exert choice over the timing of death and achieve clarity over the legality of these options [11]. The timing of end-of-life discussions and

decision-making is a contested area of MND practice. Gale [39] has raised concerns in this context given that it is asking a person to think ahead to a time of future loss. Others prioritise end-of-life discussion and decision-making because of the risk to verbal communication [40] and decision-making capacity at the end-of-life [41,42]. Hogden [30] suggested a reflexive process, one which acknowledges and is responsive to inevitable change. Person-centred care in MND involves listening to stories of loss of a once-projected future, concerns for a future of being unable to communicate, to move and to breathe at end-of-life and concerns for others. Recognition of the complex nature of decision-making for the future, is an important element of person-centred care provision for those with MND.

## Lived-through past

Up to 50% of people living with MND experience symptoms of cognitive decline [43]. For those whose cognition is not affected, the communication of memories can be important when supporting holistic care provision and understanding the person as they once were. However, professionals can struggle to build relationships as caregivers often desire a task-orientated approach to care in an attempt to maintain some control over the disease trajectory [44].

Care givers and people living with MND often delay contact with professionals, postponing these encounters

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until they are exhausted [45]. This makes opportunities to build relationships difficult and opportunities to provide quality care (based on knowledge of the person as they once were) can be lost. Where opportunities present, learning can be taken from the care of older people. Biographical work is acknowledged as respecting the intrinsic worth of a person, particularly in the context of decision-making [26,46]. In palliative care, life review can improve the emotional wellbeing of the patient with terminal cancer, especially when a person feels out of control of their situation and is unable to adapt to change or distressed by previous life events [47]. Acknowledging the importance of the past recognises that a person with MND has a unique history, culture and practice. The care process involves professionals enabling the person to talk about their lived-through past. The expected outcome is a person living with MND who will be defining their identity and finding meaning in life as it has been lived.

## A temporal model of care

Based on the hermeneutic phenomenological project findings and relevant literature discussed earlier, we propose a temporal model of care as a way of thinking about person-centred care through a temporal lens (see Figure 1). Central to this model are three aspects of temporality - lived through past, experienced present and anticipated future.

The utilisation of this temporal model of care would support healthcare professionals to focus their conversation on what is important for the person, which may be their lived through past, or their experienced present, or their anticipated future. A person diagnosed with MND, or any other terminal illness will, through this model, be encouraged to direct the focus of conversation. We suggest that one approach is to encourage the temporal model of care, and to use narrative (life story) to focus on the lived through past, as this is recognised as providing connectedness to others, and continuity of self. Thus, past identities of a person can be respected right up until the end of life. Additionally, the model of care can be used to focus on the anticipated future, to use advanced care planning and directives, providing freedom for people to make choices and remain in control of their future. A temporal model of care will therefore enable professionals to view care in the present, while taking into account the past and future.

## Conclusion

MND has a significant impact on a person's lifeworld. The person-centred care model proposed here focuses on understanding (interpreting) a person in a wider temporal frame and beyond the context of their illness. The expected collaborative outcomes are that a person is acknowledged as more than a 'patient with MND' and that a professional is providing person-centred care based on the unique individuality of the person, through a temporal lens. This requires a collaborative approach between the person, others, and professionals that may prevent a person experiencing life in crisis and suffering towards end-of-life.

We suggest that these findings provide insight into the need to consider temporality when caring for people living with MND. This is important as it can support a change in person-centred care and culture for people diagnosed and living with MND. MND care, when solely focused on the present, can have a detrimental effect on people who are living with loss, uncertainty and other concerns. The need to consider temporality as an important aspect of person-centred care provision is thus amply demonstrated.

## Conflicts of Interest

The authors declare no conflicts of interest.

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## 5.3 CONCLUSION

My situatedness as a healthcare professional was the inspiration for pursuing research to contribute to the further development of MND caring policy and practice. The findings of the research are brought together to develop a person-centred model of care which emphasises the need to acknowledge the temporal aspects of caring for a person with MND and their family or significant others. This paper adds to the literature calling for a community-centred approach to caring, dying and grieving (Hilbers et al., 2018; Miles and Asbridge, 2019). The philosophical position underlying my proposed person-centred model of care acknowledges that being-towards-death is individual. Heidegger (1927/1962: 303) wrote:

> *Death is Dasein's own most possibility – non-relational, certain, and as such indefinite, not to be outstripped.*

I have interpreted the philosophical idea of being-towards-death as follows. Death is an individual experience. Death is non-relational because the individual must face death alone; while supported by family or significant others, they must make that final journey alone. Death is certain when a person has been diagnosed with MND, but there is uncertainty as to when this will happen. Death is not to be outstripped; it is as important as life. I suggest that the importance of a person diagnosed with MND being recognised as being-towards-death is extremely significant for caring, dying and grieving.

The final phase of this research project was to link the research elements and studies which have been previously published. Thus, the final paper (in press) represents the practical application of the knowledge gained throughout the research project, to propose ways in which care can be improved through reflection on the temporal aspects of the person being cared for. This, predominantly, hermeneutic (interpretive) phenomenological research project created opportunities to learn from the experiences of others and its success lies in a greater familiarisation with the underlying philosophical ideas (Neubert et al., 2019), thus, understanding (interpreting) how MND threatens existence for the person and their family.

# CHAPTER 6 FUTURE RESEARCH

I came to this research concerned with how MND threatens existence for both the person diagnosed with it and their family. The philosophical underpinning for this research includes an understanding that every person is a unique individual, who already existed in the world before being diagnosed with MND. Despite this, a person entering the world of MND care is at risk of losing their individuality, seen only as a patient with symptoms. My research findings suggest that a person will probably have started experiencing the degenerative nature of MND before diagnosis, with consequential losses and uncertainty throughout the illness trajectory. Not everyone will accept life and death with MND. There is scope to improve support, to enable people to discuss their losses and uncertainty from the time of their diagnosis and throughout their illness trajectory, and to support family carers and significant others in bereavement. This requires a new way of seeing a person in a wider temporal frame, and beyond the context of their illness. My future challenge will be to use the findings to inform education, practice and research.

## 6.1 EDUCATION

My research findings could inform education in health and social care at all levels, as there are calls for more holistic, person-centred approaches to care (Miles and Asbridge, 2019a). As Neubauer et al. (2020) suggested, phenomenology can help students learn from the experiences of others. I found it difficult to interpret the different philosophical ideas associated with phenomenology to develop a methodology for research and believe that this is extremely difficult without the support of others who have knowledge and skills in this area. In the UK, a limited number of universities provide education on interpretive phenomenology as a research methodology. My insights could support developments in nursing, and other health and social care, professional education to navigate their way through the philosophical ideas involved, and to develop their own unique studies.

## 6.2 PRACTICE DEVELOPMENT AND RESEARCH

The difficulties of delivering person-centred palliative and end of life services are acknowledged (McCormack, 2018). MND care should be provided through an interprofessional approach that is person-centred, focusing on the physical, emotional, social and spiritual needs of the person (Foley, 2011). Professionals who are more adept at addressing the existential concerns of people with MND are psychologists or those with a palliative care background (Hogden et al., 2017). It is known that psychologists are underutilised in MND care (Harris et al., 2018), and that people with MND are not usually referred to the palliative care specialist until the last weeks of their life (Flemming et al., 2020). This is too late for those who are suffering with life in crisis.

The person at end of life might have very different requirements to those that the care provider might think they have? For example, to the care provider, the medical needs might be a priority whereas the person with MND might prioritise the relational aspects? I propose a temporal model of care as a way of thinking about person-centred care through a temporal lens. Central to this model are three aspects of temporality – lived-through past, experienced present and anticipated future.

The use of this temporal model of care will support professionals to focus on the relational aspects of care. This might include conversation about their lived-through past, or their experienced present, or their anticipated future. A person who has been diagnosed with MND, or any other terminal illness, will, through this model, be encouraged to direct the focus of conversation. MND care is complex, but the complexity can be reduced if those who provide MND care interpret the person's end of life experiences.

At a regional level, I plan to network with Lincolnshire (NHS) Care Trust, U.K. to explore the possible implementation of the proposed person-centred care model at the MNDA Care Centre and to support staff in its use. At a national level, I plan to publish and disseminate a letter to the editor which summarised my opinion about MND care, which was grounded in my research (Harris, 2021 in review). At an international level, I plan to present Paper 6 at the 2020 MNDA Virtual Symposium. Another approach considered is the implementation of a

programme of practice development to further develop person-centred care in MND. I would implement and evaluate the person-centred care model through evidence-based practice sessions and questions relating to the experience of caring for a person with MND until the end of their life.  A further possible area of study is to explore the experiences of nurses and other health and social care professionals in caring for a patient at end of life, using the proposed person-centred care model.  The participants would be recruited from two MND care centres in the U.K.

## 6.3 FINAL THOUGHTS

The lived experience of being a postgraduate researcher has spanned a decade (July 2010 to July 2020) and has felt like a roller coaster ride. Imagine riding on a ghost train, climbing into the carriage, knowing that it will be dark and frightening, full of twists and turns and then, when it comes to an abrupt end, wanting to do it all again. Whilst sitting in the carriage, I opened a closed door which had hidden past painful experiences. As the carriage moved very cautiously along the track, I experienced surprising twists and turns, which involved a continual circular movement as I developed an interpretive thought process and voice. Suddenly, the experiences of loss and grief were put into a shared context, and my journey was no longer a solitary one. This journey has ended, and I am keen to start a new ride, to further develop relational care for people living with MND.

I came to this research project to explore the lifeworld experiences of MND using both phenomenology and autoethnography. My competence and confidence in using such methodologies has grown, as has my identity as a researcher. This project started with the assumption that interpretation always involves reflection on historical awareness, and that a person's experience and sense-making can be found in their life-story. I have asked people with MND to tell their stories of living through the illness trajectory of MND, as well as telling my own story of being a professional family carer. Thus, I have reflected, articulated and interpreted various illness experiences (Boer, 2016). The publications are brought together in this thesis to demonstrate that my work forms a coherent and significant contribution to knowledge. The analytical commentary critically explores the relationship between the researcher and participant, the published work and the current body of knowledge in the

field of end of life in MND. Thus, it supports my academic identity in calling for a rethink on the way person-centred care is delivered.

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