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The need to consider 'temporality' in person-centred 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/late 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

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

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1 | INTRODUCTION

The overall aim of this paper is to provide practical insight into the way that those caring for a person with motor neurone disease (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 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.

2 | METHOD

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

- Descriptive personal reflections developed 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.

3 | MOTOR NEURONE DISEASE

MND is an umbrella term for a group of four rare, devastating neurodegenerative terminal diseases of middle/late 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 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 and 5 years; and for Progressive Muscular Atrophy 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. Brown¹⁸ 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-Hall²⁰ 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 life²³; however, despite this, care is often focused on functional deficits.¹⁸



4 | WHAT IS PERSON-CENTRED CARE IN MND?

One of our previous papers⁶ 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'.⁶ 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'⁴; 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 McCance²⁶ offered a theoretical model outlining the core concepts of person-centred care, which include practitioner prerequisites, 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 exclusion of the psychosocial and existential aspects of care.⁶ Hogden et al.¹² suggested a multi-disciplinary 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.

5 | 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, Hogden³⁰ suggested that models to support person-centred 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 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 model³¹ 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's³³ 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.

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

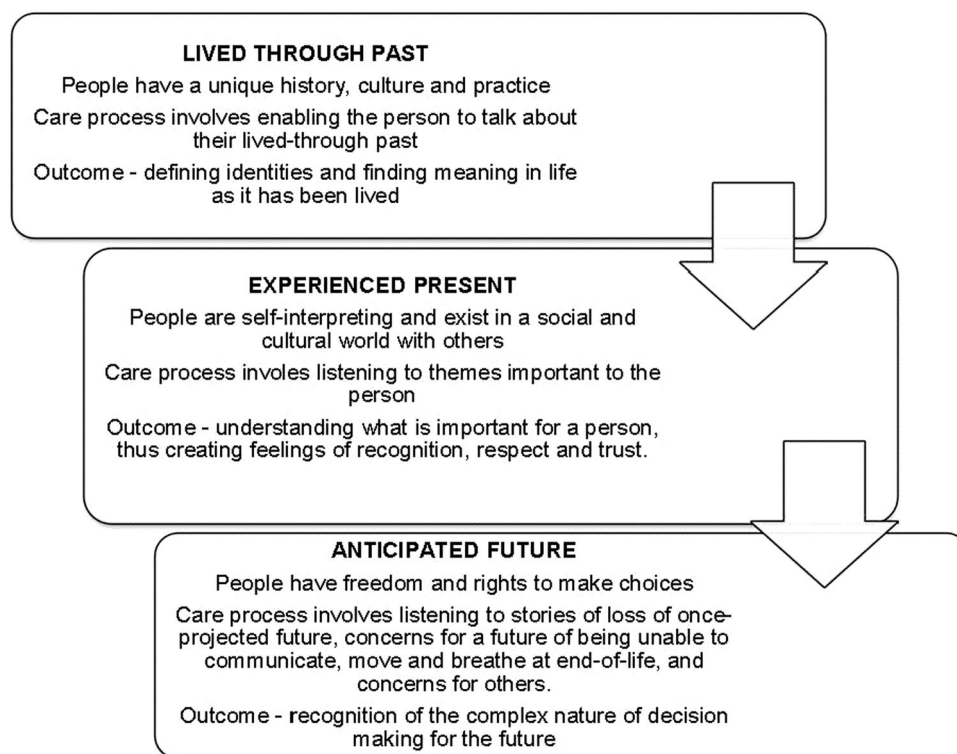


FIGURE 1 A temporal model of care to enable a new way of thinking about person-centred MND care.

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

7 | 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. Gale³⁹ 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

communication⁴⁰ and decision-making capacity at the end of life.^{41,42} Hogden³⁰ 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.

8 | 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

Caregivers and people living with MND often delay contact with professionals, postponing these encounters 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 well-being 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.

9 | 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.

10 | 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.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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