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Making Her End of Life Her Own: Further reflections on supporting a loved one with motor neurone disease.

Denise Harris, Kirsten Jack, 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, potentially experienced as 'devastating' for the person and also their family.

Aim. This study aimed to explore the meaning of supporting a loved one with MND to die.

Design. Autoethnography based on existential philosophical perspectives.

Methods. Reflection and autobiographical story have been used to connect with broader cultural, political and social meaning and understandings of dying as a phenomenon.

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). These themes are reflected on, alongside relevant literature to illuminate the meaning of supporting a loved one with MND to die.

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.

The significance of the results. This autoethnographic reflection potentially provides vicarious experiences for nurses and other health care professionals working with people with MND, and similar conditions.

Key Words: Autoethnography, Family Carers, Motor Neurone Disease, Palliative and End of Life Care, Reflection.

Key Points:

- Dying with 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 health care professionals working with people with MND, and similar conditions.

CPD 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 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 health care practitioner, working with other formal and informal carers and the patient, how can effective communication across all those involved be achieved?

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, potentially experienced as 'devastating' for the person and also their family (Harris et al., 2018). This 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 towards dying (Harris, 2017). 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, uncertainty and other concerns (Harris, 2015; Harris et al., 2018). The person with MND experiences being out of touch with others and the unwelcome touch by health care professionals (Allen-Collinson and Pavey, 2014); and this results in changes to their world and that of 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 excessive burden for their carers (Whitehead et al., 2012). Other study findings have suggested that family caring is a relentless commitment (Aoun et al., 2013), resulting in multiple losses (Oliver and Aoun, 2013). Such losses include that of loss of self and identity (Ray and Street, 2007) and control, choice and isolation (Holkham and Soundy, 2018). Health care 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 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 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 health care 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 broader cultural, political and social meaning and understandings of supporting a loved one to die (Ellis, 2004; 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, utilising 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, following 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, lived space, 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, 2004; Maréchal, 2010).

Ethical considerations

As no participants were recruited, and past notes were revisited, a full ethics review was not required. In the process of doing autoethnography, others (family and professionals) are also intertwined in our shared experiences; and the ethical implications of protecting 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 ~~context~~ 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' (COT, 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 the home became a clinical setting while 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. The National Health Service (NHS) Community Services hired a team of nurses to provide essential 24-hour nursing care in her own home. DH's mother's body had 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 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 handovers. 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 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 health care professionals). She reflected: *our being*

together would never be the same again. As a healthcare professional DH had a pre-understanding of the complexity of providing continuing health care 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 health care professionals in the acute hospitals who provides patients with care based on their knowledge, or nurses and other health care 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 (Kennedy, 2016; van Deurzen and Arnold-Baker, 2005).

Loss of future (dying - facing it alone)

DH suggests a family carer experiences loss of future with their loved one. Their loved one is facing dying – and knowing this is one of life's journey that has to be taken alone. The loss of communication meant her mother's words and gestures were no longer possible; she 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 PEG. 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 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). Morita and Murata (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 (2005, 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; NCPC, 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 health care 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 well-being. 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 health care 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 (RCN, 2019). Therefore, nurses and other health care 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 the 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 health care 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' (DOH, 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 a way of getting to know a person is through life storytelling; this will help health care professionals view the patient receiving the end of life care as a person. Findings from this autoethnographic study suggest that nurses and other health care 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 Royal College of Nursing suggested that people at their end of life should be seen as individuals and involved in all discussion and decisions about their care (RCN, 2019). Respecting that 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), 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' and so provide 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 our shared

experiences are unique to each of us, 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 notwithstanding this particular limitation, it is because of past experiences that she came to this research in the first place and wrote 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 doing autoethnography, we have reflected on past experiences and linked them with existential philosophical perspectives; and engaged with the existing literature on family caregiving, dying. The intention was not to analyse this auto-ethnographic account as another language (purely theoretical), thus losing its meaning (Ellis and Bochner, 2006). 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).

Conclusions

Dying with MND is a complex phenomenon because especially if the body is experienced in silence and so a person can no longer take part in decision making. People are dependent on others to act in their best interests, and this challenges relationships for all 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) (DCA, 2007a), 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.

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