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Letter to the Editor

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Dear Sir/Madam,

Motor neurone disease (MND) is a progressive neurodegenerative disease with no known cure. At the time of diagnosis, a person has already experienced the degenerative nature of MND and the subsequent losses and uncertainty of life with the disease (Harris, 2015; Harris et al., 2018b).

Loss and uncertainty are recognized as existential concerns for people who are diagnosed with a terminal illness, such as cancer (Hench and Danielson, 2009). Breitbart (2017, 509) raises awareness that people facing death need support to explore their existential guilt, as a way to accepting a life that has already been lived in order to face death with “peace and equanimity.” It is important that we address the existential concerns of the terminally ill if we are to prevent people experiencing life in crisis and considering suicide or hastening death (LeMay and Wilson, 2008). Saracino et al.’s (2019) review acknowledges several best practices relating to psycho-oncology at end of life. However, in relation to MND care, there are still gaps in thinking that need to be addressed.

MND care should be provided through a multidisciplinary team (MDT) approach that is person-centered, focusing on the physical, emotional, social, and spiritual needs of the person (Foley, 2011). Those MDT professionals who are more adept at addressing the existential concerns of people with MND are psychologists or palliative care professionals (Hogden et al., 2017). It is known that psychologists are underutilized in MND care (Harris et al., 2018a) 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 from life in crisis.

The person with MND’s experience of their end of life may be vastly different from the way the provider of care experiences it, and the provider of care must be mindful of this. I propose a temporal model of care as a way of thinking about person-centered 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 their conversation on what is important for the person. This may be 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 (Harris et al., 2021).

Conflict of interest

The author declares no conflict of interest.

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