

Re-thinking our approach to care of the dying person with delirium, and their family: time for a new care paradigm

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Determining how best to care for delirious dying patients and their family is a clinical and research priority. Delirium is such a complex, distressing and poorly addressed syndrome that improving care will require evidence-based change at multiple levels (Lawlor et al., 2014). Yet it is our beliefs and attitudes towards the dying patient who is delirious that are arguably the most important to question and address if we are to improve care outcomes for these vulnerable patients and their families.

Delirium is a neurocognitive disorder and always abnormal for the person, independent of the setting of care, stage of life, or reversibility of the episode. Given the frequency of delirium in the last days of life, it may easily be perceived as a normal or even acceptable prequel to an expected death (Wright, Brajtman, Cragg, & Macdonald, 2015). Central to preventing and/or minimising the impact of delirium at the end of life will be a paradigm shift in hospice and palliative care settings, so that delirium is openly acknowledged as a syndrome, referred to as such, and not accepted as an inevitable final pathway for patients who are dying.

Escalating delirium from an inevitable syndrome to one that requires urgent attention would help to ensure that the dying patient who is experiencing cognitive and functional impairment continues to be treated as being present and worthy of optimal care. This shift in paradigm is particularly important as recent literature suggests that some clinicians perceive that dying patients experiencing delirium are somehow different to the person that they used to be; or even more alarming, to some extent already dead (Wright et al., 2015). Not acknowledging the presence of the patient may have been adopted by the clinicians in this study as a protective mechanism to minimise their own discomfort and uncertainty and/or as a strategy to ameliorate the family's distress. However, such a belief does little to address the dying patient's needs or acknowledge their personhood. Perceptions that the patient has already died when they have diminished capacity subtly implies that changes associated with delirium are expected, an acceptable part of dying and therefore futile to address. It may also contribute to delirious patients not receiving the level of respectful care and attention they

require and deserve, and cause family to feel discomfort and confusion as they seek to find ways to meaningfully connect with the person they love in their last days of life.

The emerging literature of ambiguous loss in dementia provides exemplars of how personhood may be maintained and resilience of family members better supported when delirium occurs for a person with advanced illness (Boss, 2009; Day & Higgins, 2016). This therapeutic approach acknowledges and addresses the loss when a living person is physically present yet psychologically absent, and may provide a better way to help grieving family find meaning, mastery, connection, hope and resilience during the delirious patient's last days of life (Boss, 2009). The need to find effective non-pharmacological and person-centred approaches to minimise the suffering of dying patients who experience delirium is becoming increasingly apparent, especially as emerging evidence calls into question current pharmacological approaches for managing this syndrome in palliative care (Agar et al., 2015).

As the crux of palliative care is to honour each person, who profoundly matters until they die (Twycross, 2016), our approach to care ought to be aligned with what dying patients and their families actually desire at the end of life. Patients want to be mentally aware, safe, and maintain a sense of one self (Spichiger, 2008; Steinhäuser et al., 2000). Demonstrating respect for the delirious person and understanding their needs and preferences is greatly valued by family as supportive care of both the patient and themselves at the end of life (Bolton, Loveard, & Brander, 2016); as is the provision of timely information and care, and professional caregivers who seek to understand what the delirious patient is experiencing. (O'Malley, Leonard, Meagher, & O'Keeffe, 2008).

As palliative care nurses, we are ideally placed ensure that the delirious patient always remains the centre of care and that their family have access to support and guidance that enables them to truly comprehend, interact with and hold on to the person they love, appreciate their final hours, and prepare for his or her impending death. These essentials of care provide a therapeutic framework for truly seeing and being with others in the suffering of delirium during dying, and are always worthwhile.

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