

Reflections on an international study of non-pharmacological caregiving activities at the end of life

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Earlier this year an interesting manuscript authored by Lindqvist *et al.* was published, “Complexity in Non-Pharmacological Caregiving Activities at the End of Life: an International Qualitative Study” published in PLoS Medicine, 9[2], 1-10. The manuscript provides depth and understanding to an experience we will all share; the end of life. The essence of humanity is captured in this work, through the collaboration of nine countries and sixteen facilities. Common human experiences in non-pharmacological caregiving activities (NPCAs) are revealed and patterns of care identified. As nurses ourselves, we were interested to note that the majority of data used in this manuscript came from statements by nurses. We recognised the diversity of NPCAs involved in end of life care and have provided some personal reflections on four of the categories described: ‘Carrying out or abstaining from bodily care and contact’, ‘Listening, talking with, and understanding’, ‘Creating an aesthetic, safe and pleasing environment’, and ‘Being present and enabling the presence of others’. We have added an additional category of ‘NPCAs for the family and staff’, as we felt this was a theme which came through strongly in the work.

Carrying out or abstaining from bodily care and contact

The details of basic bodily care outlined in this work add value to activities which are often unseen and tacitly known. The detailed exploration of mouth care, for example, illustrates the complexity and use of activities which not

only address physical needs, but also aid in the psychological concerns of the patient, the family, and the hospital staff. The revelation of seemingly trivial aspects of care, such as ensuring that the bin is emptied regularly (p.6), and creative use of pillows (p.4), emphasise and acknowledge the wide ranging NPCAs used by staff to facilitate comfort. Other nurses who cared for patients on a palliative care trajectory have similarly observed how a holistic approach and “the small things”, such as repositioning pillows and mouth care were important (1).

Listening, talking with, and understanding

Interpersonal interactions used by staff at the end of life were described in terms of what was said, how it was said, and what was not said. Readily apparent in the data was a thoughtful sensitivity to the situation and careful management of one’s personal approach and presence. “Chatting” (p.7) was acknowledged as an important NPCA. In previous research (2), chit-chat and social conversations were perceived by patients to be therapeutic. These interactions were felt to increase the personal value of the person and helped them to still feel part of the world. Chit-chat also facilitated the development of relationships between staff and patients, as well as families, which facilitated emotional comfort. Research with palliative care patients has revealed the importance of developing positive relationships between patients and staff in terms of making decisions at the end of life and minimising distress (3).

Creating an aesthetic, safe and pleasing environment

Focusing on the senses through the purposeful adjustment of environment to promote comfort for the individual nearing the end of life is described. Noise, activity, a technological focus and inability to support family have previously been found to preclude a dignified or peaceful death (4,5). In contrast, spaces that are welcoming and comfortable can enhance the wellbeing of patients at end of life, their families and the staff who care for them during this time of significant stress (6). Previous research has identified patients' perceptions of the physical discomforts in the hospital environment and emphasised the importance of the surroundings, the facilities and equipment, and a preference for being at home (7). Ideally end of life care should be performed at home, but in many situations this is not possible. It would seem important to consider the environmental effect on the patient and the family and make attempts to address this within the hospital setting.

Being present and enabling the presence of others

Presence is integral to caring. Defined as an interpersonal process, being present for another involves close physical attendance and emotional availability (8). This manuscript has captured the inherent comfort of human presence and rendered it visible. The intimacy of sharing the dying person's emotions without words by being there, perhaps with the gentle communication of touch, singing or reading aloud, is depicted. The courage required to be present without doing is acknowledged and the absence of intervention is recognised as a purposeful caring activity. In doing so, this manuscript illuminates tacit knowledge and activities so often taken for granted. Presence has been found to enhance mental and physical well-being. People who experience presence have reported increased feelings of security, coping and decreased stress and pain (8). It was perhaps not surprising then that this manuscript captured the increasing use of presence as a NPCA as death approached.

NPCAs for the family and staff

It is clear from the data presented in the manuscript that NPCAs can also include family and staff (p.6). The psychological impact of being with and caring for a

person who is dying is immense and needs to be carefully managed. Previous research has revealed the anguish experienced by some families who stayed with dying patients in hospitals (4,9). Strategies are needed to address the wellbeing of these persons. Hudson *et al.* (10) developed and tested a psychoeducational strategy for family carers and found that it increased preparation for death and addressed unmet needs.

Emotional and psychological implications for staff who provide end of life care have also been recognised previously (11). Nurses who work in hospitals have revealed their experiences of stress when lack of time and environmental constraints prevented them from adequately preparing dying patients and their families for approaching death (12,13). A recent study has revealed nurses' emotional distress when they felt unable to comfort patients who suffered with severe pain. Nurses were found to use NPCAs to alleviate their patients' distress and their own anxiety. The pleasure and satisfaction they derived when their patients' discomfort eased, was associated with a sense of empowerment that sustained and enriched the caring experience (14).

What is clear in this manuscript is that the quality of care experienced at the end of life has implications for the patient, their family and hospital staff. The identification of the silent activities used to promote comfort at this time is significant. The visibility of NPCAs in this manuscript will increase the quality of care at the end of life through education and further research. End of life care is difficult to research, both ethically and practically, yet this work has provided sound, relevant, and useful findings, as well as clear directions for future work.

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