

home setting. Similarities and differences between papers were grouped using textual narrative synthesis.

Results Included papers (n=17) incorporated those focused on caring for people with advanced dementia (n=8), and those with moderate dementia (n=9). Family carers reported an experience of loss, burden and grief. Psychological distress was experienced due to internal conflict while caring. Although these experiences have a negative impact on general health, an improvement in the family carer's inter-relationships and the feeling of being useful were positive aspects of caregiving.

Conclusions Family carers' justifications and determinants for balancing challenges and possible distress to morals remain unclear. A complete description of all their experiences may be inadequate in conveying an acknowledgement of the illness within home-based caregiving. The caregiver-attributed personified value resulted in holding on to what remains of the care recipient for longer. Research is required to ascertain how family carers may proportionally balance their personified loss with their personified value earlier in the disease trajectory.

Impact Fear of losing a care recipient's personified value may affect how home-based caregiving is viewed by family carers and their willingness to accept or continue home-based caregiving.

7 CAREGIVERS' EXPERIENCES OF END-OF-LIFE CAREGIVING IN A HOME CARE SETTING

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Introduction Research has shown that most people want to die at home. In the Faroe Islands, home deaths make up 12% despite limited structural conditions. There is only home care during night hours in the capital and larger villages and an established palliative team do not have an outgoing function. The caring task relies heavily on family members.

Aims The aim was to provide inside into conditions that make home death possible in a small-scale society and describe family caregivers' experiences of providing end-of-life care in a private home setting.

Methods The study is qualitative. A phenomenological approach, inspired by Giorgi, was applied.

Results Two essential structures captured the experience of caring at home until death: 'Managing end-of-life care' and 'meaningfulness in a time of impending death'. It was mainly the family and especially family members with a health professional background and the district nurses who supported the caregivers in managing end-of-life care. By fulfilling their relative's wish to die at home, the caretakers found their caring task meaningful and experienced a closeness among family members during the palliative course. For caregivers in areas with no home care during night hours, this caused caregivers to feel insecure, especially about being able to relieve their relative's pain sufficiently.

Conclusions The willingness among family members to conduct end-of-life care for a relative is great despite limited structural conditions to support them. A way to increase the number of home deaths, could be if home care around the clock nationwide and an outgoing palliative care team were established.

Impact The study can be used to set further focus on the need to establish structured home care around the clock nationwide, and for the palliative care team to have an outgoing function.

8 SHIFTED DEATHS: THE USE OF HOME MECHANICAL VENTILATION FOR MOTOR NEURONE DISEASE (MND)

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Introduction As respiratory muscles weaken home mechanical ventilation can be used by patients with Motor Neurone Disease (MND) to help support breathing and prolong life. We know little about what it is like to die while ventilation is in place, to have ventilation withdrawn, how decisions about these end of life wishes are made, or how patients and families are supported through this experience and into bereavement.

Aims To explore the use of home mechanical ventilation at the end of life for people with MND

Methods Qualitative interviews with 31 bereaved family members involved in the care of someone with MND using ventilation at the end of life. Thematic analysis was applied.

Results Preliminary findings show that planned withdrawal of ventilation can provide families with an important element of control, allowing patients more choice about the timing and manner of death. Some patients initiated decisions about their wishes in advance allowing health professionals and family members to prepare. Others made more immediate decisions based on their currently quality of life. Family members often reported having little knowledge and understanding of how dying would occur. Some participants felt the ventilation had kept the patient's body alive beyond the point of a natural death, blurring the nature of the death.

Conclusions Ventilation can have a profound impact on the death of the person with MND and subsequently, those close to them. For some this can be traumatic and poorly understood but when planned and implemented well, can be satisfying and cherished.

Impact This is the first work to explore the use of ventilation at the end of life for those with MND. It illustrates that more information and discussion with patients and families, is needed. This work will make an essential contribution to building an evidence based to guide healthcare professionals, inform families and support decision making.

9 A CROSS-CULTURAL VALIDATION OF THE GOOD DEATH QUESTIONNAIRES IN INDONESIAN

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Introduction The concept of Good Death is essential in palliative care. Palliative care supports patients to die with dignity and without suffering. Since patients, families, health professionals, and communities may have diverse perspectives on death, it is imperative to assess Good Death's perception, which can also be culturally bounded. This assessment can be