

SESSION 7B SPIRITUAL CARE AND MEANING IN LIFE

C49 MEANING IN LIFE AND PERSONAL VALUES IN ALS: EMPIRICAL DATA AND CLINICAL RELEVANCE

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Loss of meaning in life (MiL) is known to be one of the main determinants of requests for hastened death. Empirical data with respect to personal values and MiL in ALS patients and their clinical relevance will be discussed.

In a first study, the relationship between personal values and individual quality of life was evaluated in 28 ALS patients and 36 patients suffering from advanced cancer (1). The most important values were benevolence, self-direction and universalism, whereas power, achievement and stimulation were the least important. Self-transcendence values were higher than self-enhancement values in all patients. Compared with healthy adults, palliative care patients scored significantly higher in benevolence and lower in self-enhancement values. There were no significant differences between ALS and cancer patients. The observed shift towards self-transcendence values may be related to coping processes of terminally ill patients.

In another study (2), MiL was assessed with a newly developed instrument for the evaluation of individual MiL. In the Schedule for Meaning in Life Evaluation (SMiLE), the respondents list 3 to 7 areas which provide meaning to their life before rating the current level of satisfaction and importance of each area. Indices of total satisfaction (IoS), total weighting (IoW), and total weighted satisfaction (IoWS, range 0–100) are calculated. Forty-nine ALS-patients were interviewed at the Interdisciplinary Center for Palliative Medicine, Munich University Hospital-Grosshadern. All open answers were assigned to 13 categories found in the representative survey (3). The results were compared to those of the representative sample (n = 1,004).

MiL was slightly lower in ALS-patients (SMiLE-Index = 76.6 ± 20.2) compared to the representative sample (83.3 ± 14.8 ; $p = 0.03$; $d = 0.4$). The areas of MiL mentioned most often were family (82%), partnership (61%), leisure activities (53%) and friends (39%). Partnership and leisure activities were listed significantly more often by ALS-patients compared to the representative sample, while work and health were mentioned significantly less often ($p < 0.001$ for each). This was shown by logistic regression analyses; age, marital status and education were included as additional predictor variables. Overall MiL (SMiLE-Index) was slightly lower in ALS-patients compared to the representative sample. Health and work were less important for ALS-patients, relations to significant others, especially partnership and leisure time were listed more often. This could be due to “response shift” in the progress of the disease, i.e. a change of internal standards (4). Identifying ALS-patients who are at risk of losing their MiL and helping them to find alternative sources of MiL may be an important step towards preventing requests for hastened death.

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C50 EVIDENCE BASED SPIRITUAL CARE IN ALS: FACT OR FICTION?

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Keywords: measuring spirituality, spiritual care training, pastoral care

Spiritual care is an essential part of holistic medicine, yet the methods of intervention in professional spiritual care seem to be somewhat obscure. What exactly does a spiritual care provider do in existential interventions for people facing a life threatening illness? Is there any evidence spiritual care is based on?

The talk starts with a wide and open understanding of spirituality where religion may or may not be part of a patient’s spirituality. The realm of spirituality includes issues of meaning, transcending, becoming, and relating, depending on the individual. The spiritual relates to essential issues in palliative care, e.g. quality of life, hope, coping, anxiety, and awareness of dying. Tools measuring spirituality work with varying constructs of spirituality, depending on the expected outcome. Especially with ALS patients, constructs include an understanding of spirituality as a resource to the patient, as an area of conflict or suffering, as a search for meaning while nearing the end of life. These constructs affect the way a multiprofessional team includes spiritual issues in care. Some studies show the importance of a patient’s spirituality for treatment decisions at the end of life.

Spiritual Care, however, not only focuses on the spirituality of the patient, but also the needs and resources of relatives, and of care providers. Studies point out the importance of spirituality for care providers, raising the question whether training in spiritual care makes sense.

Since spiritual issues are an integral part of a whole person/whole care approach to medicine, the question remains to be answered, who (i.e. which profession) should provide spiritual care? Is spiritual care – performed by doctors – another tool that helps physicians to better connect with patients, to better understand them as people? Or should the provision of spiritual care be reserved to chaplains? In order to answer these questions, the talk will present findings from studies on pastoral care in palliative care settings in Germany, giving facts on actual spiritual care, and their inclusion in a multiprofessional approach to whole person care. Some cases with ALS patients will be discussed that put spiritual care into the frame of evidence based reality instead of fiction.

C51 SPIRITUALITY AND FAITH: MEANS FOR COPING WITH THE EFFECTS OF ALS/MND

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Keywords: spirituality, faith, coping

Background: Spirituality and personal faith are recognised as important factors contributing to quality of life amongst those diagnosed with ALS/MND, assisting individuals to develop perspective and influencing their decisions as they adapt to living with the disease (1).

Objectives: To explore the personal experience of living with ALS/MND as documented in personal illness narratives, written by people diagnosed with the illness and examine the role of spirituality and faith as a means of coping with ALS/MND.

Methods: We previously reported the processes used for locating published and unpublished personal illness narratives about life with ALS/MND (2). The 161 narratives identified were subject to content and thematic analysis. Data management was aided by Nvivo 7 software.

Results: There is frequent reference throughout the narratives to the power of spirituality to impact positively on the illness experience. Authors refer to the strength acquired from seeking a spiritual understanding of their circumstances. There is a sense of being used for a 'higher purpose', being seen as a spiritual example to others. Religious convictions are frequently strengthened following the diagnosis, bound up in a feeling of not being burdened beyond their ability to cope. Faith is regarded by some as a cornerstone of the ability to cope. Belief in an afterlife sustains many authors as they recognise the present time as a small part of a much longer time span.

Conclusions: It is evident within the narratives that people with ALS/MND tolerate distress through maintaining hope by belief in a divine entity and through connection with a higher being (3). Spirituality should be regarded as an important resource for coping with ALS/MND.

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C52 MANAGING DEATH IN ALS/MND: IDENTIFYING CAREGIVERS' PERSPECTIVES OF THE FINAL DAYS OF LIFE

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Keywords: caregivers, dying, advanced planning

Background: Family caregivers usually remain central to the provision of care throughout the illness trajectory. Yet, little is

known about how they manage or cope with the dying process and the death of their relative with ALS/MND.

Objective: This study sought to understand the experiences and support needs of family caregivers, during their relatives' final days of life.

Methods: Longitudinal studies of family caregiving in ALS/MND were undertaken in Australia and United Kingdom. Primary caregivers participated in in-depth interviews at four month intervals throughout the illness trajectory, including the bereavement phase. Five cases from each country were purposively sampled for analysis. A process of open and axial coding was used to categorise the data and identify themes as they emerged from each caregiver's story.

Results: In the broadly similar socio-cultural structure of Australia and the United Kingdom, family caregivers in both countries expressed similar experiences of their relative dying. However, their construction of the dying process varied, exhibiting delicately nuanced differences in their experiences and their responses. In eight out of ten cases, patients were cared for at home until their last days of life. All the United Kingdom cases died in hospital/hospice. Three of the Australian cases died at home and two died in hospital/hospice. Conversations between the caregiver and the dying person, about end of life, were only evident in six out of ten cases.

The most prominent themes across all cases were dignity, emotional labour, advanced care planning, spiritual sustenance, reflective guilt, and redefinition. Caregivers were often unprepared for the rapid deterioration and sudden death of their relative, prolonging their sense of loss and disconnection.

Discussion and Conclusion: The increasing trend towards dying at home is both challenging and rewarding for family caregivers. The quality of life focus, prominent during the earlier phases of living with ALS/MND, can be easily overlooked in the medicalised processes of dying. When caregivers reflected on the dying experience and said "we got it right", they lived with the positive affirmations of caregiving. However, if the dying experience was characterised by conflict about decision making, then negative memories are perpetuated.

This study demonstrated the need for an inclusive process of effective communication between the patient, the family and health and social care professionals, to prepare for dying. There is a need to develop communication skills to facilitate conversations that will support patient and family caregiver decision making and enhance their coping skills. While it is recognised that patients and caregivers have to be emotionally ready to have these conversations, the often unpredictable, degenerative nature of ALS/MND increases the need to facilitate preparation for dying in a timely manner.