

Research Project

Palliative care at home: A multi perspective study on the complex needs of ALS family caregivers

Third-party funded project

Project title Palliative care at home: A multi perspective study on the complex needs of ALS family caregivers

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In palliative care family members are vital, not only as primary caregivers for their loved ones, but also because they are key informants in health services research and quality improvement studies aimed at improving the care of future patients. Unfortunately, most research with family caregivers concentrates on quality of life, providing concrete knowledge and information, training home care and management skills. Focus upon boosting resilience in caregivers is nowadays enhanced as compared to research interest over the last few years. For the support made available to the family caregivers to be effective and efficient, all of their support needs (informational, practical, ethical, emotional) should be known, which will be crucial in reducing the caregiving burden felt by many family caregivers. Besides ongoing research in Ireland and the Netherlands on needs of informal caregivers of patients with Amyotrophic Lateral Sclerosis (ALS), there are hardly any studies or systematic data on the perception of family caregivers of ALS patients regarding their palliative care situation at home. Suggestions for improvement from their perspectives is much needed so that both the ALS patient and the family caregivers are supported during the care process in the best possible way. Doing so is productive not only for the affected family members but also for the overall care system.

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Research on the needs of ALS family caregivers have received very little attention in Switzerland. This is saddening in light of the national initiatives to learn about end-of-life care and palliative care. Despite promising genetic discoveries, this chronic neuromuscular disorder is terminal. ALS is progressive and may be rather rare, whereas for palliative care it possesses model qualities. That is, ALS palliative patients highlight a rich pattern of basic questions raised by different patient groups that need palliative care, such as breaking the (unexpected) news, how to support a terminally ill person, the need to always stay a step ahead of the illness, advance care planning, and including family members in shared decision-making. But they are unique because of the speed of the illness that results in a rapid sequence of essential bodily functions such as mobility, speaking, swallowing and breathing, which asks for adaptation to the changes in a very short time.

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Using the example of the disease course in ALS, this project aims at improving the palliative care situation of patients by exploring the complex needs of family caregivers und how they can be best supported, so that the person with ALS can determine his or her end-of-life circumstances. In terms of possible pal-

liative support in home care situations, the needs, benefits, and conditions of ethics consultation by a mobile palliative care team will be assessed from the perspective of the different professional and informal actors that enable palliative care at home. The project will use qualitative methodology. Semi-structured interviews will be carried out with two types of ALS family members (total n=40): those who have provided care to an ALS patient in the past and those who are currently providing care to an ALS patient. Family members could be spouse, partner or adult children. Focus group interviews (n = 8; in each focus group there will be at least 4 participants) will be carried out with nurses providing home care (Spitex); and GPs and palliative care physicians. All participants will be recruited from St. Gallen and the Basel regions because we already have good collaborations with teams in these two regions. The results of this study will be analysed using qualitative analysis followed by data triangulation between the two data sources (family caregivers and professional carers) and in-depth discussions of our findings with professionals working in the field using planned analysis workshops.

As an exploratory study of its nature, we will unfortunately not be able to gather data from the French speaking region of the country, but the results should be useful to all families in similar situation nationwide. Finally, even though ALS is chosen as the key palliative situation of interest, findings can relate to family caregivers experiencing similar situations with other conditions such as Parkinsons, Alzheimer's, and other conditions that require continued and round the clock family support.

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Foundations and Associations

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Published results

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