

## Publication

## Bereavement and Support Experiences of Informal Caregivers of Persons with Amyotrophic Lateral Sclerosis: A Qualitative Study.

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**Author(s)** Poppe, Christopher; Iseli, Luzia M; Verwey, Martine; Wangmo, Tenzin**Author(s) at UniBasel** [Wangmo, Tenzin](#) ; [Poppe, Christopher](#) ; [Iseli, Luzia Margarete](#) ;**Year** 2021**Title** Bereavement and Support Experiences of Informal Caregivers of Persons with Amyotrophic Lateral Sclerosis: A Qualitative Study.**Journal** Journal of social work in end-of-life & palliative care**Pages / Article-Number** 1-17**Keywords** Amyotrophic lateral sclerosis; bereavement; family; informal caregiving; needs; qualitative study

Informal caregivers provide the major part of care for persons with amyotrophic lateral sclerosis (ALS), a terminal neurodegenerative disease. Apart from providing care, informal caregivers are themselves in need of support to fulfill the task of daily caregiving and to reduce their burden of caregiving. This need for support does not end with the death of the person cared for. In this study, we explore the themes of bereavement and support experience of informal caregivers of persons with ALS from interviews conducted with bereaved informal caregivers (; n; = 14) in Switzerland. Three key themes were salient in our data:; Reacting to bereavement, finding support; , and; adjusting to life without the person with ALS.; These themes are contrasted with themes from interviews (; n; = 11) with healthcare professionals (nurses, therapists, physicians) who care for patients and families with ALS. The themes described were; offering support; and; identifying gaps in the support; . We discuss support after bereavement for informal caregivers of persons with ALS in the established public health model of bereavement support. Bereavement support needs to be proactive from healthcare professionals; however, it requires the goodness of fit to address those in need and not those who are adequately supported by informal sources of support.

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