

Publication

"Walking a tightrope": A grounded theory approach to informal caregiving for amyotrophic lateral sclerosis.

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Informal caregivers, mainly family members and friends, provide supportive and palliative care for people with amyotrophic lateral sclerosis (ALS) during their terminal disease course. Informal caregiving for people with ALS continues towards palliative care and end-of-life care with the progression of the disease. In this study, we provide a theoretical understanding of informal caregiving in ALS utilising 23 semi-structured interviews conducted with informal caregivers of people with ALS (pwALS) in Switzerland. Due to the expected death of the care recipient, our grounded theory approach outlines informal caregivers' caregiving work as an effort to secure a balance amongst different caregiving activities, which feed into the final stage of providing palliative care. Overall, our theoretical understanding of ALS informal caregiving work encompasses the core category 'holding the balance' and four secondary categories: 'Organising support', 'being present', 'managing everyday life' and 'keeping up with ALS'. The core category of holding the balance underlines the significance of ensuring care and normalcy even as disease progresses and until the end of life. For the informal caregivers, this balancing act is the key element of care provision to pwALS and therefore guides decisions surrounding caregiving. On this understanding, those caregivers that succeed in holding the balance can provide care at home until death. The balance is heavily influenced by contextual factors of caregiving, for example relating to personal characteristics of the caregiver, or activities of caregiving where the goal is to ensure the quality of life of the pwALS. As there is a heterogeneity of speed and subtype of progression of ALS, our work accounts for multiple caregiving trajectories.

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