

Publication

Supportive needs of informal caregivers of people with amyotrophic lateral sclerosis in Switzerland: a qualitative study.

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This study explores the supportive needs of informal caregivers of people with amyotrophic lateral sclerosis (ALS) in Switzerland.; We conducted semi-structured interviews with nine informal caregivers currently providing care to a person with ALS, 14 bereaved informal caregivers, and 13 healthcare professionals. Interviews were recorded on digital audio and analysed using an inductive thematic analysis within a realist framework.; Informal caregivers discussed five themes of support needs relating to being overburdened by administrative demand, in contact with healthcare providers, home support, especially during the terminal phase, and having or lacking social support. Healthcare professionals discussed three themes of support needs of informal caregivers which related to the general institutional support for informal caregivers, their own work as caring for informal caregivers, and the challenges in healthcare for families with ALS they encountered.; Informal caregiving for people with ALS can be demanding. This study provides evidence for improvements in supporting informal caregivers. It shows administrative needs of informal caregivers, stresses their needs regarding advance care planning early in the context of ALS, and underlines the importance of social support, be it in peer-groups or community care.

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