

Publication

Differentiating needs of informal caregivers of individuals with ALS across the caregiving course: a systematic review

JournalArticle (Originalarbeit in einer wissenschaftlichen Zeitschrift)

ID 4604935

Author(s) Poppe, Christopher; Koné, Insa; Iseli, Luzia Margarete; Schweikert, Kathi; Elger, Bernice Simone; Wangmo, Tenzin

Author(s) at UniBasel [Wangmo, Tenzin](#) ; [Poppe, Christopher](#) ; [Elger, Bernice Simone](#) ; [Koné, Insa](#) ;

Year 2020

Title Differentiating needs of informal caregivers of individuals with ALS across the caregiving course: a systematic review

Journal Amyotrophic lateral sclerosis & frontotemporal degeneration

Volume 21

Number 7-8

Pages / Article-Number 519-541

Keywords Informal caregivers; caregiving stages; disease course; needs; support

Informal caregivers of people with amyotrophic lateral sclerosis (ALS) experience a range of needs across the course of the disease. For the provision of adequate support, an examination of the empirical evidence is necessary.; The purpose of the systematic review was to synthesize evidence of needs of informal caregivers of people with ALS at different stages of caregiving.; Systematic review of empirical research on needs of ALS informal caregivers in both English and German, from January 2000 to August 2018. We searched the databases EMBASE, MEDLINE (PubMed), PsycINFO, and CINAHL. Study selection, quality assessment, and data extraction was performed independently. Both quantitative and qualitative studies were included. Of the included studies, we additionally screened citing literature in Google Scholar (citation tracking). We linked the narrative synthesis to four stages of caregiving described by Williams and colleagues and used descriptive inductive thematic analysis to structure data within the stages.; From 3275 abstracts screened, 48 manuscripts met our inclusion criteria. Our data analysis shows that needs differ across the four caregiving stages. While the stage of bereavement (stage 4) includes too little data for separate themes, themes for needs after diagnosis (stage 1), and terminal stage (stage 3) could be specified. As the maintenance (stage 2) stage comprised of themes relevant across the caregiving course, it became an overall stage.; Healthcare professionals need to pay attention to current caregiving stages to provide support for informal caregivers. Further research is needed to tease out support needs for the bereavement phase.

Publisher Taylor & Francis

ISSN/ISBN 2167-9223

edoc-URL <https://edoc.unibas.ch/78818/>

Full Text on edoc No;

Digital Object Identifier DOI 10.1080/21678421.2020.1771735

PubMed ID <http://www.ncbi.nlm.nih.gov/pubmed/32657155>

ISI-Number WOS:000547661800001

Document type (ISI) Journal Article