

Publication

Feelings of Burden in Palliative Care: A Qualitative Analysis of Medical Records

JournalArticle (Originalarbeit in einer wissenschaftlichen Zeitschrift)**ID** 4169638**Author(s)** Rakic, Milenko; Escher, Monica; Elger, Bernice Simone; Eckstein, Sandra; Pacurari, Nadia; Zwahlen, Susanne; Wienand, Isabelle**Author(s) at UniBasel** [Rakic, Milenko](#) ; [Wienand Madelon, Isabelle Marie-Odile](#) ; [Elger, Bernice Simone](#) ; [Pacurari, Nadia](#) ;**Year** 2018**Title** Feelings of Burden in Palliative Care: A Qualitative Analysis of Medical Records**Journal** Journal of palliative care**Volume** 33**Number** 1**Pages / Article-Number** 32-38**Keywords** palliative care; burden; qualitative research; caregivers**Mesh terms** Adult; Aged; Aged, 80 and over; Caregivers, psychology; Family, psychology; Female; Humans; Male; Medical Records, standards; Middle Aged; Palliative Care, psychology; Qualitative Research; Research Design, trends; Stress, Psychological; Young Adult

Background: Care for palliative care patients is often provided by unpaid caregivers (e.g. family members) who take care of the patient's daily needs (e.g. bathing, dressing). Family members of palliative care patients are involved in numerous ways. These tasks and responsibilities can make them feel burdened and even overburdened. Aim: We specifically looked at patients' medical records to determine what is being reported about burden and overburden and who seems to be mostly affected. Burden was understood as a weight or task that is difficult to accept or carry, whereas overburden indicates that this weight or task cannot be carried anymore. Methods: We looked at 300 medical records of palliative care patients written by healthcare professionals. Written notes were analysed using latent content analysis as it helps to analyse large amounts of textual data qualitatively and to understand the underlying concepts of what was said. Results: Most patients (73.5%) had a cancer diagnosis. Mean age was 67.6 years (range 22 to 98 years). Burden and overburden were identified as main categories and further divided into the following sub-categories: for patients and families. According to the written notes, patients often felt burdened by their disease, financial problems, situation at home and families' reactions to their disease. By and large, patients felt overburdened by their own disease. Families often felt burdened because of issues related to patients' medical condition, providing home care or financial and social aspects. Families mentioned homecare and the decision-making process as being overburdening. Conclusion: Findings in the palliative care patients' medical records are inasmuch important, as they point at the healthcare staff's awareness of possible weights and tasks that might be burdensome for patients and their families. Attention should be drawn to the documentation of medical records in order to identify recurrent difficulties and to help discuss these.

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