Tittel: Relatives’ participation in everyday care in special care units for persons with dementia

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Sammendrag: Background: Research concerning relatives’ participation in the everyday care related to persons living in special care units for persons with dementia is limited. Research questions: To examine relatives’ participation in their near one’s everyday care, the level of burden experienced and important factors for participation, in this special context. Design: The study had a cross-sectional design, and data collection was carried out by means of a study-specific questionnaire. Participants and context: A total of 233 relatives from 23 different special care units participated. Ethical consideration: The study was approved by the Norwegian Social Science Data Services. Results: A great majority of relatives reported that they visited weekly and were the resident’s spokesperson, but seldom really participated in decisions concerning their everyday care. Participation was seldom reported as a burden. Discussion: This study indicated that relatives were able to make a difference to their near one’s everyday life and ensure quality of care based on their biographical expertise, intimate knowledge about and emotional bond with the resident. Since knowing the resident is a prerequisite for providing individualised care that is in line with the resident’s preferences, information concerning these issues is of utmost importance. Conclusion: This study prompts reflection about what it is to be a spokesperson and whether everyday care is neglected in this role. Even though relatives were satisfied with the care provided, half of them perceived their participation as crucial for the resident’s well-being. This indicated that relatives were able to offer important extras due to their biographical expertise, intimate knowledge about and emotional bond with the resident. Good routines securing that written information about the residents’ life history and preferences is available and used should be implemented in practice.
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