Life Situation as Next of Kin to Persons in Need of Care: 
Chronic Sorrow, Burden and Quality of Life 

av 

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Abstract

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Nursing research has been performed during the last 20-30 years, about the next of kin’s vulnerability. Despite this, the health care system has had difficulties to integrate the next of kin in a way that gives support. The overall aim of the thesis was to describe and further explore the life situation of the next of kin to persons who are long-term ill, disabled, and/or older, and in need of care. Method: Multiple methods were used. Study I had a descriptive design, 44 next of kin of patients with multiple sclerosis were interviewed, latent content analysis was used for the analysis. Study II had a mixed method approach; the descriptive core study was analyzed with directed content analysis. The supplementary study with descriptive, correlative design was analyzed with descriptive and correlative statistics. Forty-four next of kin of patients with multiple sclerosis were interviewed; thereafter 37 of them answered a questionnaire about Quality of Life. Study III had a descriptive, explorative design. Twelve next of kin of older persons were interviewed with repeated informal conversational interviews, analyzed with latent content analysis. Study IV was cross-sectional with a descriptive, correlative design. Eighty-four next of kin of persons who were long-term ill, disabled, and/or older answered two questionnaires about Burden and Quality of Life that were analyzed with descriptive and correlative statistics. Results and Conclusions: Next of kin described a balance/imbalance in their relations to others and a high burden, but in general a good Quality of Life. Some next of kin also experienced chronic sorrow. Significant correlations were found between interpersonal relations and Quality of Life as a whole. Love and obligations were two anchor points on a continuum, describing the next of kin’s relationship to the ill/disabled person. The relationship with the health care personnel was described through cooperation and obligations. Good communication was seen as the key to balance the relationship with others. One possibility to achieve symmetrical communications is to adapt the Partnership Model, as a tool for creating good relationships. Honest and specific communication between the health care personnel, the next of kin, and the care receiver are necessary.

Keywords: life situation, next of kin, informal caregiving, chronic sorrow, burden, quality of life, Partnership model

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