Utmaningar, utsatthet och stöd i palliativ vård utanför specialistenheter

av

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Akademisk avhandling

Avhandling för medicine doktorsexamen i medicinsk vetenskap med inriktning mot hälso- och vårdvetenskap, som enligt beslut av rektor kommer att förvaras offentligt fredagen den 16 mars 2012 kl. 13.00, Hörsal P2, Örebro universitet Örebro

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Abstract


The overall aim of this thesis was to study palliative end-of-life care outside specialist palliative care settings, from an organizational perspective and from professionals’ and relatives’ experiences. In Study I 174 individuals were identified retrospectively from nursing records and palliative care identification forms as being in a palliative phase. Data were analyzed with descriptive and analytic statistical methods. In Study II a total of nine nurses working in primary home care, community care, and hospitals were interviewed. Phenomenological methodology was used to analyze data. In Study III 17 enrolled nurses, who worked in community or primary care and in a sitting service organization, participated in four focus group interviews. Data were analyzed with qualitative content analysis. In Study IV seven relatives from four families were interviewed twice. They had each cared in the private home for a dying family member who had received sitting service. Direct interpretation and categorical aggregation were used to analyze data. The results highlight challenges in palliative care, vulnerable situations, and a need of support (I–IV). Individuals’ needs for both palliative care and sitting service were identified, including those of a smaller part of the population who actually received the sitting service. (I). Registered nurses’ responsibilities included care at the same time for individuals in both palliative and curative phases. This created vulnerable situations for the nurses, since their ambitions concerning the care did not correspond to available resources (II). The enrolled nurses’ task was to manage ongoing life and dying in different care settings, to meet individual needs and still provide equivalent care. Despite experiences of vulnerable situations, they felt safe (III). Relatives experienced care situations differently, related to differences in families, the illness trajectory, the need for support, and the support offered. Without sufficient support, vulnerable situations occurred, which made the relatives feel insecure (IV). Thus, care situations in palliative end-of-life care can be experienced in different ways, with different levels of vulnerability. One implication of the research might be to suggest that professional caregivers, to supplement the relatives’ own resources with support tailored to the individual’s and the family’s needs.

Keywords: vulnerability, support, challenges, palliative care, relatives, registered nurses, enrolled nurses, end-of-life care.

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