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Vård i livets slutskede på särskilt
boende för äldre personer
Närstående och vårdpersonals skattade och
berättade erfarenheter

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Title
End-of-life care in residential care homes for older persons; family members and care professionals reported and narrated experiences

Abstract

Aim The overall aim of this thesis was to describe family members' and care professionals' perspectives on end-of-life care in residential care homes for older people. **Methods** This thesis consists of four studies, two quantitative and two qualitative. The data in *Study I* were based on the questionnaire, "Views of Informal Carers – Evaluation of Services" (VOICES), filled in by family members (n=189) of older persons who had died in RCHs. Descriptive statistics were used to analyse the data. *Study II* was based on registered expected deaths in RCHs (n=22 855) reported to the Swedish Register of Palliative Care (SRPC) by care professionals. The data were explored with univariate and multivariate logistic regression analysis. In *Study III and IV*, a descriptive qualitative design was used. Data in *study III* were collected through focus groups and individual interviews with care professionals (n=24). The data in *Study IV* were collected through individual interviews with family members of residents who had died in RCHs (n=15). The data in Studies III and IV were analysed with qualitative content analysis. **Results** The family members in *Study I* reported that they had been given enough help with nursing such as getting dressings change and with medication, and personal care such as bathing, dressing, help with eating and going to the bathroom, in the last three days of life. They also reported that they were told (86.2%) that the resident was likely to die shortly, and most of them (94.1%) reported that they felt that the resident had died in their preferred place. Just under half of the residents (46.5%) had experienced pain, with the majority (86.4%) receiving treatment for this symptom, and slightly more than half (55.9%) had experienced shortness of breath, with around a third of them (39.7%) receiving treatment for this. Shortness of breath was significantly more common in the younger age group (<85 years; p=0.01) and they were significantly more likely to have received treatment (p=0.006). In *Study II*, the SRPC data revealed high prevalence of pain (68.8%) and anxiety (44.0%). Shortness of breath (14.1%) and nausea (10.2%) were less common. In the multivariate regression analyses, two explanatory factors were significantly associated with symptom relief, of pain, nausea, anxiety and shortness of breath: use of validated pain assessment scales, and assessment of oral health. In both the univariate and multivariate logistic regression analysis, individual prescriptions of injections to be administered when required (PRN, pro re nata) for pain, nausea, and anxiety were significantly associated with relief of symptom. The care professionals in *Study III* described several aspects of their experiences of EOL care after implementation of the LCP: they became more confident through a shared approach, they were supported in tailoring the care to the residents' individual needs, they were supported in involving the family members in decision-making and care, and they had become more aware of the care environment. The family members in *Study IV* also described several aspects of their experiences of care of the dying in RCHs where an EOL care pathway was used: they felt confident in a familiar and warm atmosphere, they were involved or not in the EOL care, and they were consoled by witnessing the care professionals' endeavours to relieve suffering. **Conclusion** The results described in this thesis indicate a high quality of nursing care and personal care, but also inadequate management of symptom relief in the last days of life for residents in RCHs. Still, despite a high prevalence of symptoms such as pain, shortness of breath, and anxiety, RCHs were described as a natural and appropriate place of death. The results confirm that use of a validated pain assessment scale and medication PRN prescribed could be a way to increase the quality of EOL care. The results also indicate that a standardized care pathway can offer one way to improve the quality of care. The care professionals felt supported in involving the family members in care and decision making, and both family members and care professionals felt supported in the care by the use of the LCP.

Keywords

care pathway, care professionals, end-of-life care, family members, older people, palliative care, residential care homes, residents

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