

Maintaining self-determination in palliative phase in residential care

A model to facilitate person-centred care for older persons

Akademisk avhandling

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Avhandlingen baseras på följande delarbeten

- I. Schenell, R., Henoch, I., Strang, S., & Ozanne, A. (2020). Struggling for a dignified life: The meaning of self-determination in palliative phase in residential care. *International Journal for Human Caring*, 24(2), 147–157. doi:10.20467/HumanCaring-D-19-00029
- II. Schenell, R., Ozanne, A., Strang, S., & Henoch, I. (2019). Residents' and family members' perception of care quality and self-determination in palliative phase in residential care. *Palliative and Supportive Care*, 18(1), 69–81. doi:10.1017/s1478951519000178
- III. Schenell, R., Ozanne, A., Strang, S., & Henoch, I. (2019). Balancing between maintaining and overriding the self: Staff experiences of residents' self-determination in the palliative phases. *International Journal of Older People Nursing*, 14(4), e12255. doi:org.ezproxy.ub.gu.se/101111/opn.12255
- IV. Schenell, R., Ozanne, A., Strang, S., & Henoch, I. (2020). To make and execute decisions throughout life: A person-centred model that facilitates self-determination in residential care, developed through participatory research. *Applied Nursing Research*, 55(October). <https://doi.org/10.1016/j.apnr.2020.151318>

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Abstract

The overall aim of the thesis was to develop a model that facilitates self-determination in palliative phase in residential care. The three first studies constituted the ground for the model which was developed in the fourth study.

Study I Persons residing in residential care were interviewed about self-determination in this hermeneutic study. The findings show that the residents are forced to adapt to new circumstances and that they are trying to navigate in this forced situation. This is interpreted as a struggle for a dignified life.

Study II Quality of care and self-determination was evaluated and compared between residents and their family members. The findings show a high consistency in their experiences and an extensive need for improvements, especially in the psychosocial aspects of care.

Study III The findings in this interview study with staff, analyzed using qualitative content analysis, revealed that the residents' self-determination is connected to the maintenance of their self's and that their own abilities and others' efforts strengthens their self-determination while their vulnerability and others' dominance undermine it.

Study IV A model to facilitate self-determination was developed through participatory research involving different stakeholders. The core message *In my way, at my pace, with the help of you* emphasize the right to self-determination and the need for assistance to make it possible. The core message is supported by seven categories with strategies to facilitate self-determination.

The conclusion of this thesis is that age and illness make the residents dependent and reduce their self-determination. This is a threat against their dignity of identity. The model presents a person-centred approach that facilitates self-determination despite the many obstacles described in the studies.

Keywords: autonomy, content analysis, hermeneutics, palliative, participatory research, person-centredness, relational autonomy, residential care, self-determination