

There is no escape from getting old
Older persons' experiences of environmental change
in residential care

Akademisk avhandling

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av

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The thesis is based on the following papers:

- I. Falk, H., Persson, L.O. & Wijk, H. (2007). A Psychometric evaluation of a Swedish version of the Quality of life in Late-Stage Dementia (QUALID) scale. *International Psychogeriatrics*, 19(6), 1040-1050.
- II. Falk, H., Wijk, H. & Persson, L.O. (2008). Effects of refurbishment on residents' QoL, wellbeing, and perceived person-centeredness. *Health & Place*, 15, 717-724.
- III. Falk, H., Wijk, H. & Persson, L.O (2009). Older persons' experiences of an inter- institutional relocation and its effects on QoL, wellbeing, and perceived person centeredness. *Submitted*.
- IV. Falk, H., Wijk, H., Persson, L.O. & Falk, K (2010). Wherever I lay my hat is home – Processes and strategies in creating attachment in residential care. *In manuscript*.



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ABSTRACT

A life of quality in residential care has to be finely balanced against the characteristics of institutionalization. Highly desirable aspects of person-hood, such as dignity, privacy, and eligibility, are bound up with satisfying and supportive living arrangements. The overall aim of this thesis was to achieve a comprehensive understanding of how environmental changes affect frail older persons' perceptions of quality of life, wellbeing, and care atmosphere, and how people create attachment and self-identity in residential care facilities. A secondary aim was to psychometrically evaluate a Swedish translation of a quality of life instrument, specifically for dementia. This thesis combines quantitative (I), qualitative (IV), and mixed method designs (II and III) to explore meaning, gain understanding, examine relationship between variables, as well as outcome effects. Paper I (n=169), used a cross-sectional design to psychometrically evaluate a Swedish translation of the Quality of Life in Late-Stage Dementia (QUALID) Scale. Paper II (n=131), used a sequential mixed method design to follow a refurbishment aimed at enhancing the supportiveness of the physical environment. Paper III (n=155), used a concurrent mixed method design to follow an inter-institutional relocation. Paper IV (n=25), used a grounded theory method to gain an understanding of the various ways in which older persons create attachment in residential care, and to discover a plausible variety of real-life contingencies that affect this creation process. The findings suggest that the Swedish translation of the QUALID provide reliable and valid information about quality of life in older persons with late-stage dementia. That interior design features alone may have little importance to the care climate, and that the disruption caused by the refurbishment had negative effects on the wellbeing and quality of life of frail older persons. That inter-institutional relocation has adverse effects for those able to self-report and describe their experiences and that there is a lack of preparatory programs aimed at minimizing the adverse effects of relocation. The findings also show that frail older persons who are able to create a sense of home in the residential care facility, and thereby improve their sense of wellbeing and belonging, are those who create an attachment to the place, the space, or to someplace beyond the institution. The results provide added insight on the complex and transactional relationship between frail older persons and their living environment in residential care facilities. There is a need for further research into how a homely atmosphere can be created in institutional contexts in order to avoid oversimplification in which a physical environment with an aesthetic appearance of a home becomes the general standard for good residential care. This work also expands existing knowledge regarding quality of life in late-stage dementia, and the methodological difficulties that surrounds measurement. Altogether, the results in this thesis might improve the lives of frail older persons in residential care by acknowledging the fundamental human need for a home. A home is more than a physical environment, and the present thesis challenge us to learn from the inside about life in residential care, which is a prerequisite for wise and supportive interventions aimed to improve the wellbeing and quality of life in old age.

Key words; frailty, person-centeredness, elderly, dementia, residential care facility, quality of life, wellbeing, attachment