

Navigating towards a self-determined daily life in old age

Experiences, instrument evaluation and explanatory factors

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- I. Ottenvall Hammar I, Dahlin-Ivanoff S, Wilhelmson K, Eklund K. Shifting between self-governing and being governed: a qualitative study of older persons' self-determination. *BMC Geriatrics* 2014;14:126.
- II. Ottenvall Hammar I, Ekelund C, Wilhelmson K, Eklund K. Impact on Participation and Autonomy – test of validity and reliability for older persons. *Health Psychology Research* 2014;2:68-73.
- III. Ottenvall Hammar I, Dahlin-Ivanoff S, Wilhelmson K, Eklund K. Dependence in personal daily activities limits self-determination – a cross-sectional study with community-dwelling older persons. *Submitted for publication*.
- IV. Ottenvall Hammar I, Dahlin-Ivanoff S, Wilhelmson K, Eklund K. Self-determination among community-dwelling older persons: explanatory factors. *In manuscript*.



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ABSTRACT

Aim: The overall aim of this thesis was to explore self-determination in the context of community-dwelling older persons with different degrees of dependence in daily activities. **Methods:** Using a qualitative, grounded design, study I explored how people 80 years and older experienced their self-determination when developing dependence in daily activities. Study II employed a qualitative and quantitative design where the validity of the questionnaire Impact on Participation and Autonomy (IPA-S) was tested using focus group discussions and individual interviews. The participants were aged 70 years and older. The focus groups were followed by a reliability test-retest of the adjusted version (IPA-O) on persons in the same age. Study III and IV applied an exploratory, cross-sectional design where two sets of data were combined, resulting in a sample of persons aged 80 years and older. Perceived self-determination in daily life was explored in relation to degree of dependence in daily activities (study III) and in relation to a set of explanatory factors (study IV). **Results:** The results showed that self-determination was experienced as constantly shifting between self-governing and being governed by the ageing body or by other persons. This shift gave rise to a struggle against the ageing body and a need to constantly guard one's own independence. The relationship had an impact on the person's possibilities to make decisions; that is, decision-making was relational (study I). The validity test showed that the items within the IPA-S were important and relevant, but the questionnaire was too extensive and focused on the executional part of the activities. The IPA-S was adjusted to a version entitled IPA-O (-Older persons) consisting of fewer items with emphasises on the decisional part. The reliability test-retest step showed that 15 of the 22 items within the IPA-O had high agreement and six items had moderate agreement. One item showed low agreement between the test and retest (study II). People dependent in activities of daily living (ADL) showed a general pattern of perceiving reduced self-determination in daily life. Perceptions of reduced self-determination were most pronounced among people dependent in personal activities of daily living (P-ADL) (study III). However, the association between dependence in ADL and reduced self-determination was not statistically significant. The final regression model showed that the explanatory factors of high education, frailty, poor self-rated health, dissatisfaction with physical health, and receiving help from public home care service were significantly associated with perceiving reduced self-determination (study IV). **Conclusions:** Being dependent in daily activities occasionally meant being governed by the ageing body or by others. Reduced perceptions of self-determination in daily life were associated with both internal and external factors. Exercising self-determination in old age was directly related to the relationship between the persons receiving help and the persons providing help. Therefore, healthcare professionals should enable trough navigate towards a more self-determined daily life in old age. A first step in this direction could be to conduct a conversation about self-determination based on the IPA-O, a psychometrically tested and adjusted instrument designed specifically for older people. Acknowledging human capabilities and creating relationships based on partnership could enhance the older person's self-determination.

Keywords: Activities of daily living (ADL), aged 80 and over, dependence, frailty, self-determination, IPA-O, person-centredness

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