

Navigating Towards a Self-determined Daily Life in Old Age

Experiences, Instrument Evaluation and Explanatory Factors

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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, unsatisfaction 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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SAMMANFATTNING PÅ SVENSKA

Självbestämmande är viktigt för äldre personers hälsa och välbefinnande. Trots att det är lagstadgat att personers självbestämmande ska respekteras är självbestämmande ingen självklarhet i hög ålder. Det övergripande syftet med avhandling var att undersöka självbestämmande i kontexten hemmaboende äldre personer med varierad nivå av beroende av hjälp i dagliga aktiviteter. För att undersöka de äldre personernas självbestämmande från olika perspektiv användes både kvalitativa och kvantitativa metoder. Resultatet visade att erfarenheter av självbestämmande var sammankopplat med ett ständigt skiftande av styrandet, från att styra på egen hand till att styras av den åldrande kroppen eller av andra personer. Möjligheten till att utöva självbestämmande var relationellt, relationen mellan den som erhöll vård och den som erbjöd vård hade en direkt inverkan på självbestämmandet. Att vara beroende av hjälp i dagliga aktiviteter var sammankopplat med upplevt reducerat självbestämmande, dock förelåg inget statistiskt signifikant samband. De faktorer som kunde förklara reducerat självbestämmande var hög utbildning, skörhet, dålig självskattad hälsa, otillfredsställelse med kroppsliga hälsan och att erhålla hjälp av hemtjänsten.

Det svenska frågeformuläret Inverkan på Delaktighet och Autonomi (IPA-S) bedömer delaktighet och beslutsmässig och utförandemässig autonomi. IPA-S har undersökts på personer i olika åldrar, men få av personerna har varit äldre. Med utgångspunkt i detta undersöktes IPA-S på personer 70 år och äldre. De äldre personerna uppfattade att frågorna var viktiga och relevanta. Antalet frågor var för omfattande och den beslutsmässiga delen var otydlig vilket gjorde att frågorna omformulerades till påståenden. IPA-S justerades och erhöll namnet IPA-Ä (-Äldre personer). Reliabilitetstestet visade att 15 av de totalt 22 påståendena hade god reliabilitet. Ett påstående av mera komplex karaktär hade låg reliabilitet och bör därmed tolkas med försiktighet.

För att hälso- och sjukvårdspersonal ska kunna möjliggöra för att navigera de äldre personerna mot ett självbestämmande liv kan ett första steg vara att införa en självbestämmandedialog. IPA-Ä kan ligga till grund för en dialog av detta slag. Genom att fokusera på äldre personers kapabilitet, och att utifrån ett personcentrerat perspektiv skapa goda relationer som baseras på ett partnerskap, kan de äldre personernas självbestämmande förbättras.

LIST OF PAPERS

This thesis is based on the following studies, referred to in the text by their Roman numerals I-IV. The published papers are reprinted with kind permission from the publishers.

- 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-welling older persons: explanatory factors. *In manuscript.*

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ABBREVIATIONS

ADL	Activities of Daily Living
CI	Confidence Interval
CIRS-G	Cumulative Illness Rating Scale for Geriatrics
I-ADL	Instrumental Activities of Daily Living
IPA	Impact on Participation and Autonomy
IPA-O	Impact on Participation and Autonomy – Older persons
IPA-S	Impact on Participation and Autonomy – Swedish version
OR	Odds Ratio
PA	Percentage Agreement
P-ADL	Personal Activities of Daily Living
RP	Relative Rank Position
RR	Relative Risk
RV	Relative Rank Variance
SDT	Self-Determination Theory

1 INTRODUCTION

This thesis, a collection of four studies, explores self-determination in the context of community-dwelling older people with different degrees of dependence in daily activities. Study I explores the concept of self-determination from the older person's point of view. Study II evaluates the Swedish version of the questionnaire Impact on Participation and Autonomy for the older population. Finally, self-determination is explored in relation to degree of dependence in daily activities (study III), and in relation to a set of explanatory factors (study IV).

Worldwide, the number of older persons is growing rapidly (1). In Sweden, about 500,000 people are older than 80 years, and by 2040 it is estimated that over one million people will be older than 80 years (2). A large proportion of this group will be community-dwelling older persons who will require help in their daily activities (3), but who will desire to be as self-determined as possible (4). Exercising self-determination is important for older person's subjective health and wellbeing (5, 6). In Sweden, several acts (7-9) support older people's right to exercise self-determination regarding their own health and home care. Although self-determination is a legal right, studies (10-13) from older people's perspectives have repeatedly shown that healthcare professionals do not always respect older people's self-determination.

Occupational therapy is built on the philosophical underpinning that human beings need to be active and need to participate in society in order to flourish. Self-determination has been described as one of the fundamental concepts within the occupational therapy practice (14-16). Therefore, occupational therapists ought to encourage persons to participate and exercise self-determination in daily life (16). External support is important for a person's self-determination (14, 17). Consequently, there is an urgent need to support older people to find ways to exercise self-determination in daily life even when they require help from others to perform their daily activities. Therefore, this thesis explores the concept of self-determination from different perspectives. To create a wider understanding of the older people's self-determination, related concepts are presented in the following sections.

2 BACKGROUND

2.1 The concept of Self-determination

From a medical perspective, the concept of self-determination refers to the ability to think, choose, decide, and act independently (18). A conceptual analysis (19) defined self-determination in the context of community-dwelling frail older persons as a process in which the persons has control/legal and ethical rights, as well as knowledge and ability to make decisions of own free choices. Self-determination includes the principles of privacy, liberty, free will, individual choices, and self-actualization (20). Historically, self-determination has been seen as the right of a person to be independent, free, and protected from coercion. Recently, this historical notion of self-determination has become a central part of healthcare and given credence through laws and bioethics. To combat oppression and often as a reaction to oppression, laws or rules are formulated that promote and protect people's possibility to exercise their self-determination (21).

Sandman (22) believes that healthcare professionals understand the concept of self-determination as people's ability to make decisions that reflect how they want to live their lives. Decreased self-determination often is the result of a lack of understanding, or that people have been forced to make decisions with incomplete knowledge (22). Exercising self-determination is a general desirable and indisputable requirement for persons with a Western point of view regardless of age, although self-determination is also important from an Eastern perspective (23). The meaning and the importance of exercising self-determination in daily life may vary widely between different countries and cultures (23-25). In healthcare, everyone is generally allowed to participate and exercise self-determination regarding one's own medical care, i.e., an individual-oriented principle on self-determination (23). On the contrary, self-determination is more influenced by a person's family from an Eastern perspective. The family is authorized to exercise the final self-determined choices in healthcare, i.e. an family-oriented principle on self-determination (23). This thesis explores self-determination from a Western perspective.

Researches often use self-determination and *autonomy* synonymously (26) or use self-determination as a central part of autonomy (22, 27-29). According to a conceptual analysis (29), the operational definition of autonomy is the

exercise of an independent judgement in order to effect a desired outcome. Attributes central for autonomy include independence, capacity for decision-making, judgement, knowledge, and self-determination (29). Sandman (22) concludes that healthcare professionals view the concept of autonomy as consisting of four aspects: *self-determination*, *freedom*, *desire to fulfilment*, and *independence*. For healthcare professionals, self-determination is the most important part of these central aspects (22). Collopy (27) and Cardol et al. (30) divide autonomy into *decisional autonomy* and *executorial autonomy* when the concept is situated in the context of persons with reduced ability to perform Activities of Daily Living (ADL) independently. Decisional autonomy is the capacity to make personal choices, irrespective of a person's ability to execute his or her desires. Executorial autonomy is the performance of choices made. It is particularly important to separate the two parts of autonomy when it concerns older persons (27, 30).

The literature defines self-determination in a similar way as *personal autonomy* (31). Personal autonomy refers to people's ability to govern their lives and to make choices based on actual information (31). Although the concepts of self-determination and autonomy are treated similarly in the literature, the essence of the concepts differs. The concept of self-determination involves a process (19), whereas the concept of autonomy implies an ethical perspective (32). Self-determination, on the contrary, does not involve freedom (19).

2.1.1 Operationalization of self-determination

No empirical referents to measure self-determination in the context of older people have earlier been found (19). However, a possible way to operationalize the concept could be to use the generic self-report questionnaire Impact on Participation and Autonomy (IPA) (33-36). IPA addresses a person's perceived participation and autonomy in diverse activities. The original IPA (33) was developed in the Netherlands and has been psychometrical tested for persons aged 23-79 years (mean age 48 years) with chronic conditions. The validity of the IPA has been compared between the countries of the Netherlands and England (37). Recently, the IPA was tested in Iran on people who had suffered from a stroke (aged 75 years or younger) (38). IPA has 31 items about perceived participation and autonomy, divided into five dimensions: autonomy indoors (seven items), family role (seven items), autonomy outdoors (five items), social relationship (six items), and work and education (six items). The participant answers the questions by

choosing one of five answer alternatives: very good, good, fair, poor, or very poor. After each domain, there is a question regarding perceived health problems to be answered using one of the following answer alternatives: no problems, minor problems, or severe problems. A lower score indicates minor problem (34).

The Swedish version (IPA-S) is similar to the original IPA version (39). The IPA-S (39) has been tested for validity and reliability for persons with spinal cord injury aged 17-84 years (mean age 52 years), with promising psychometric results. The IPA-S has also been used to capture perceptions of participation and autonomy among persons with polio aged 30-86 years. People with polio perceived restrictions in participation in activities related to autonomy outdoors, family role, and work and education (40). The original IPA has been tested on people 79 years or younger with different chronic conditions (33), and the IPA-S has been tested on people with spinal cord injury (39). Although the IPA and the IPA-S have been tested on diverse age groups, including older people, only a few of the tested participants were older ($70 \geq$). Because it is unclear whether the IPA is valid and reliable for the older population, there is a need to examine the IPA's psychometrical properties with respect to an older population.

2.1.2 Acts and charter supporting the right to self-determination

In the 1980s, the Swedish Medical and Health Service Act (1982:763) provided people with the legal right to self-determination, stating that healthcare should be built on respect for a person's self-determination and integrity (second paragraph, a) (7). To meet the requirements for good healthcare, good contacts between the care provider and patient should be promoted and the patient's need of continuity and safety should be satisfied (7). The importance of respecting the patient and cooperation between the parties is also emphasized in The Patient Safety Act (2010:659). Chapter 6; first paragraph, of this act stipulates that the care should be designed and carried out in cooperation with the patient and should be given in a respectful manner (41).

The Social Service Act (2001:453), chapter 1; first paragraph, stresses that a person's self-determination and integrity should be respected (8). Within this act (8) there is a special section that addresses the needs of the older

population. According to this section (chapter 5; fourth paragraph) social services should focus on enabling older people live a dignified life and experience wellbeing. This section also highlights the importance of enabling older people to choose how and when healthcare and aid services should be provided in their homes (chapter 5; fifth paragraph, act 2010:427).

Patients' right to self-determination in healthcare has recently been strengthened by a new act, the Patient Act (2014:821) (9). This act strengthens and clarifies a patient's position in healthcare and promotes patient integrity, participation, and self-determination. In chapter 4; first paragraph, the patient's self-determination is highlighted, and the following paragraph stresses that patient consent must be given before treatment is given. Patients' participation in healthcare is one of the core components of the Patient Act (2014:821) (9). Chapter 5; first and second paragraph, stresses that healthcare should be executed in collaboration with the patient and according to the patient's wishes (9).

In 2010, the European Charter of the right and responsibilities of older people in need of long-term care and assistance (42) was formulated to support human dignity and wellbeing in old age. Regardless of age, gender, and degree of dependence in daily activities, all people are entitled to human rights and freedom. One of the central parts within this Charter (42) is the right to freedom of choice. Even when being old and dependent on other persons, one has the right to make choices and this freedom must be respected.

2.2 Ageing

Ageing can be seen as a natural process that involves an interaction between a person's biological, psychological, physical, social, and spiritual factors. Some dimension within a person may decline, whereas other may develop (43). Ageing is not a single process, it consists of several of processes that occur during the course of an unavoidable deterioration of human functions during a progressive senescence (44).

Ageing can be classified according to different life course levels, so called *ages*. The third age begins when a person retire, with no or little functional decline and is able to choose how to spend his or her own time. The fourth age, marked by functional decline and illness, includes vulnerability and

unpredictability not found in the third age. During the fourth age, psychological mortality significantly accelerates and human dignity might be reduced (45). Although chronological age is commonly used to measure and describe ageing, it does not necessarily reflect a person's ability to perform activities. Often, *old age*, the next life course level, is defined as 65 years or older (43). This thesis focuses on subset of the old age level – people 70 years and older, with an emphasis on people 80 years and older.

Along with an increasing number of older persons, several theories have been developed that deal with the consequences of ageing. According to the theory of *Compression of morbidity* (46), a healthier prolonged life relates to improvements in interventions and preventive actions. The theory of *Dynamic equilibrium* (47), associates prolonged life with reduced disabilities and morbidity even though minor disabilities and morbidity are evident. In addition, another theory (48) stresses that prolonged fourth age necessarily implies poor health and disability.

Studies focusing on chronic diseases and functional decline have been complemented with studies focusing on aspects related to healthy and successful ageing (49, 50). The definition of *successful ageing* implies that there is only one way to age successfully, overlooking the fact that many older people may develop illnesses and disabilities (51). In contrast, Baltes (52) prefer the term *optimal ageing*, rather than successful ageing. Optimal ageing can be defined as the capacity to function across physical, functional, cognitive, emotional, social, and spiritual domains, to a person's own satisfaction, in spite of their medical conditions and limitations (53). Optimal ageing, a multidimensional construct, recognises different ways of ageing well, and takes into account a variety of vulnerabilities and resources that affect the ageing process. Optimal ageing entails the development of protective factors that may delay or reduce the processes of ageing and disease, resulting in good physical, mental, and cognitive health (54).

2.3 Frailty

Introduced in 1974, frailty was described to identify characteristics related to the ageing process (55). Frailty refers to vulnerabilities with unfavourable outcomes that older people experience (56). Recently, the use of frailty as a conceptual way to describe ageing has increased considerably (55). Often cited, Fried et al. (57) defines frailty as a physiologic state of increased

vulnerability to stressors as a result of a decline in physiologic reserves and dysregulation across multiple physiologic systems. Based on this definition (57), frailty can be illustrated as a complex geriatric syndrome where several factors related to disability and co-morbidity interact. Therefore, frailty can be regarded as a dynamic concept, ranging from not being frail to being frail (57). Gobbens et al. (58) define frailty as a dynamic state that affects people who experience decline in human functioning (physical, psychological, or social) as the result of many variables that increase the risk of negative outcomes. To date, there is no generally accepted definition of frailty (59). The debate has focused on whether frailty should be defined entirely in terms of biomedical factors or whether it should also include psychosocial factors (60).

Frail older people generally experience changes in both physical function and mental health (61, 62), and these changes often lead to dependence on another person in daily activities (63-66). For the oldest as well as for the younger older people, frailty can be a concern; however, frailty is more common among people with multi-morbidity (67). The development of frailty has been proposed as a result of either physiological changes of ageing, not based on diseases, or a result of a single or comorbid disease (68).

Several theories deal with the consequences of ageing. The *Phenotype model* measures presence of signs or symptoms (68), whereas the *Cumulative deficit model* constitute of a checklist of clinical conditions and diseases (59). A consensus group consisting of gerontology researchers define frailty as a clinical state where a person's vulnerability for developing mortality and/or dependency increases when exposed to stressors (69). This consensus group (69) recommended that measures of physical frailty should be performed in accordance with the Phenotype model developed by Fried and colleagues (57). The Phenotype model takes into account the presence of three or more of the criteria: unintentional weight loss, self-reported exhaustion, low energy expenditure, slow gait speed, and weak grip strength (57, 68). Ferrucci et al. (63) characterizes frailty as a continuum from robustness to pre-frail to the extended full frailty phase, a condition that can be mild to severe (63). Among the community-dwelling older persons, the pre-frail phase is common (3). Frail people may transition between frailty stages, but the transition to a later stage is more common than a transition to an earlier stage (3).

2.4 Human occupation

Human beings need to engage in occupations related to their own needs and choices, to grow through the performance, and to experience independence, participation, health, and wellbeing (70). The concept of occupation can be defined as everything people do to occupy themselves, from looking after oneself, to contributing to one's social community, to enjoying life (15). Occupations are both complex and multidimensional (71) and define the core characteristic of human experience, providing tools for social interaction as well as social development and growth. Although social-cultural values and beliefs motivate how people occupy their time, the need to engage in meaningful occupations is inherent and relates to health and wellbeing (72). The meaning of engaging in an occupation can only be truly known by the person performing the occupation (73, 74), and this performance takes place in a specific environment (75).

Because human beings are occupational beings, participation in occupations is essential for health and wellbeing. Defining people as occupational beings recognises that people need to engage in occupations in order to flourish. By engaging in occupations, people can express their hopes and desires, revealing who they are to themselves and others (72, 76). However, the power to participate in an occupation may be governed by physical limitations or by regulations, and sociocultural expectations (70). The ageing process may also influence a person's ability to perform occupations (77). Thus, the human need to engage in occupation may be governed by several factors and cannot be taken for granted (70).

2.4.1 Activities of Daily Living (ADL)

The broad concept of occupation can be understood in light of the term Activities of Daily Living (ADL): rest and sleep, education, work, play, leisure, and social participation. ADL consist of both Personal Activities of Daily Living (P-ADL) and Instrumental Activities of Daily Living (I-ADL). P-ADL concerns activities related to a person's own body, such as bathing, eating, dressing, and toileting. I-ADL refers to activities in daily life within one's home and community, such as financial management, cleaning, cooking, and shopping. I-ADL often requires more complex interactions than P-ADL (71).

A common way to measure a person's independence or degree of dependence on help in ADL is by using the ADL Staircase (78, 79). The ADL Staircase (78, 79), which is a cumulative scale, assesses whether a person is independent, partly dependent, or dependent on help in P-ADL and I-ADL. The ADL Staircase assesses people's dependence in six P-ADL items (bathing, dressing, going to the toilet, transfer, feeding, and continence) and in four I-ADL items (cleaning, shopping, transportation, and cooking) (78, 79).

2.4.2 Dependence in Activities of Daily Living

Dependence can be defined as an inability to perform certain tasks, a functional incapacity, a state of need, and low access to resources (80, 81). Dependence, when it refers to physical dependence, often is defined as a functional incapacity, or a person's incapacity to carry out essential activities in daily living (82). Some definitions focus on the social nature of dependence (82-85), reflecting dependence as a state where a person receives help from other people (83, 84). According to the latter definition, dependence is a social construction, a result of the interaction between the people receiving care and their environment (82, 85). In this thesis, dependence refers to another person being involved in an activity by providing personal or directive assistance (78, 79).

In modern society, advanced age often is associated with dependence in ADL (86). Dependence in ADL may influence older people's health and wellbeing, and it is strongly connected to mortality (87). Lack of everyday life satisfaction can also be associated with increased dependence and use of home care services (88). The connotation attached to the concept is rather negative (86, 89) and usually reflects the absence of independence (89), whereas independence has a more positive character, usually linked to freedom of choices (86). Secker et al. (90) separate independence from dependence by proposing a two-dimensional model, taking into account older people's concerns of choice and social roles. In this model (90), people may experience high levels of independence even when being dependent on others, as their sense of independence is a subjective experience of autonomy, self-actualisation, and self-reliance. From this point of view, dependence could be defined as the extent of a person's reliance on others or the resources that other people contribute (90).

Older people highly desire to continue to perform ADL independently (91). This desire to maintain one's independence as long as possible, however, reflects a more Western perspective (23, 24). Thus, the meaning of independence and dependence may differ (92). That is, variation in social, economic, and political contexts may influence a person's view of independence and dependence (86). From an Eastern perspective, independence is not always the ultimate goal, as being helped by one's family is a positive sign of love and respect (23).

2.4.3 Human capability

Human capability concerns what a person is effectively able to do and to be – a person's capability (93-95). Capability encompasses the real opportunities a person has regarding the life that one leads (93). Capability is closely related, but not the same as *functionings*. Capability is the ability to achieve, while *functionings* is the achievement. *Functionings* comprise *beings* and *doings* (94), the variation of things a person value doing or being. *Functionings* may differ from more elementary activities, to activities of more advanced nature (95), and are more related to aspects of living (93). Within the variation of *functioning*, a person may value participation in community life, being respected, happiness, good health, and resting (94, 96).

In the early 1980s, the economist Amartya Sen (93-95) shed light on human capability by proposing the Capability approach as a response to the conventional approach to welfare economics. The Capability approach is a normative framework that emphasises the importance of personal freedom and the achievement of health and wellbeing. According to Sen (97), a person's capability depends on several factors that determine a person's ability to do the things the person chooses to do. It is of great importance that people develop and maintain their capabilities; freedom or valuable opportunities, as these capabilities influence to what degree they can be who they want to be, do what they want to do, and lead the life they want to lead. If people's capabilities are neither recognized nor enabled, they might become excluded from opportunities to make their own decisions or to participate in society (98). When people have substantive opportunities to participate in decision making as well as in society at large, they can choose the options they value (99). Therefore, evaluations and policies should pay attention to a person's capabilities – what the person is able to do and to be – and reduce barriers to personal freedom (93-95).

Recognizing human capability could be important for the understanding of human rights and freedom (93-95). Shedding light on a person's freedom is important for several reasons. Greater freedom to do things that a person values is significant in itself, and greater freedom enriches the ability of a person to influence his or her world (95). Along with the focus on personal freedom, the capability approach emphasises all dimensions of human wellbeing. Sen (93-95) makes a clear distinction between the means and ends of wellbeing: the ends are essential, whereas the means only contribute to reaching goals related to enhanced wellbeing.

With respect to wellbeing and justice, people should be given the opportunity to decide what activities they want to engage in, and who they want to be (99). People's motivation is directly related to attaining goals; different types of motivation can result in diverse outcomes. According to the Self-Determination Theory (SDT), constructed by Deci and Ryan (17, 100-102), there are two types of motivation that reflect a person's intention to act – *autonomous* and *controlled*. Autonomous motivation is associated with positive human experiences, while controlled motivation means that a person is coerced or forced to do things by others (17). If a person's goal-directed behaviour is more autonomous rather than controlled, both the consequences and connection of the quality of a person's behaviour, including one's health and wellbeing, will be positive and the outcomes they experience will be positive (17, 100, 101). The quality of these positive outcomes is related to the extent the person is successful in reaching the opportunities and accomplishing goals (100).

From an SDT perspective, people are seen as self-motivated and active creatures, interested in accomplishing things (100). Self-determination is a motivational factor for human beings (17, 100). Human beings have three universal, psychological, and natural needs; *self-determination/autonomy*, *competence* and *relatedness*. Self-determination/autonomy refers to the universal need to be an agent in one's own life, and includes acting in harmony with one's integrated self. This does not necessarily mean that the person must be completely independent (103). To experience this, people need support from others (17). Competence is the need to control outcomes and to master experiences, and relatedness refers to the universal need to interact with others, to experience care, and to be connected with others (103).

2.5 Approaches based on creating a partnership

During the last decades, the client-centred approach has been central for the occupational therapy profession (15, 75, 104). The key characteristic is the collaborative partnership between the client and the occupational therapist, a relationship that focuses on a client's needs and experiences and encourages a client to actively partake in decisions that affect his or her life (15). Yet, the client's perspective has not always been taken into account in practice (105). To ensure that the core values of the client-centred approach are met, a client's abilities, experiences, knowledge, and choices should be embraced (106).

Similarly, the person-centred approach emphasises creating partnerships. This approach entails shared decision-making throughout the whole care process, which means that all decisions that affect a person's care should be executed from the basis of a partnership (107). The person-centred approach has been widely used in healthcare, although it still lacks a consensus definition (108). The person-centred approach focuses on interaction between people and how people relate to one another. When adopting this approach, the essence of a *person* must be clarified. Ricoeur (109) highlights two essential notions of personhood, the *selfhood* and the *sameness*. The *selfhood* concerns the identity that belongs to an individual self, the constantly identification of a *genuine self*, an independent and unique identity. It relates to properties that answers *who* a person is. The *sameness* is a state of being the same as someone or something, and aims to answer *what* a person is. Together, these two central notions create a person's narrative identity. The narrative identity is the personal identity that remains over time (109).

Human beings are capable not only of having feelings, desires, and beliefs but also of possessing the capacity to make moral evaluations (110). Smith (110) describes a person as a conscious, embodied, reflexive, and transcendent centre of subjective experiences. The centre is linked with a resilient identity, social communication, and moral commitments caused by people's own actions and interactions. People are interactive, communicative, and inescapably social. Because communication is used to create an identity of oneself and for mutual understanding, it signifies what it means to be a person (110).

Professionals following the person-centred approach should treat people as unique and address areas of difficulties in a person's real life. People should be treated as experts, be as active as desired, and be involved in developing their own interventions, including implementation and evaluation. Finally, treating people with respect and dignity is fundamental. Focus should be on a person's capabilities and their strengths rather than their disabilities and weaknesses (111).

2.6 Rationale

One of the key concepts in medical ethics is the right to self-determination (18). Exercising self-determination in daily life is highly valued by dependent older persons (4), and it is essential for the older person's subjective health and wellbeing (5, 6). Several acts (7-9) support older people's right to self-determination regarding their own health and home care. However, being in the hands of other people may challenge one's possibilities to exercise self-determination in daily life (4, 10-13), and further knowledge is needed to ensure that self-determination is maintained throughout old age (4).

To successfully navigate towards a self-determined daily life in old age, the phenomenon of self-determination must be addressed from different areas. One way to increase knowledge is to explore the older person's own experiences of their self-determination when they are developing dependence in daily activities. Furthermore, there is a need of a questionnaire that addresses perceptions of self-determination in old age that is validity and reliability tested for the age group. To fully understand self-determination in the context of people with different degrees of dependence, it is important to explore self-determination in relation to different degrees of dependence in daily activities in a larger context. Finally, it is relevant to explore a number of explanatory factors for perceiving reduced self-determination in daily life. A growing body of knowledge could navigate healthcare professionals to enable older people to achieve a continued self-determination in their daily life. Therefore, this thesis aims at increasing the knowledge of older people's own experiences of their self-determination, whether self-determination in old age can be assessed with the IPA-S questionnaire, and to what extent dependence in daily activities and a number of explanatory factors are related to community-dwelling older people's perceptions of self-determination.

3 AIMS

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. The specific aims were:

- To explore experiences of self-determination when developing dependence in daily activities among community-dwelling persons 80 years and older (study I).
- To examine the validity and reliability of the IPA-S questionnaire for persons aged 70 years and older (study II).
- To explore the relationship of self-determination with degree of dependence in daily activities among community-dwelling older persons (study III).
- To explore explanatory factors for self-determination in the context of community-dwelling older persons (study IV).

4 METHODS

4.1 Design

In this thesis, several methodological approaches were used to explore older people's self-determination (Table I). Study I, was a qualitative, grounded theory study inspired by the developments by Charmaz (112). Study II, consisting of both a qualitative and quantitative design, was performed in two steps: a validity test of the IPA-S questionnaire with focus group discussions and individual interviews and a reliability test-retest of the adjusted version. The design used in study III and IV were cross-sectional, and the sample consisted of two sets of data *Elderly persons in the risk zone* (113), and *Continuum of care for frail elderly people* (114). An overview of the samples and methodological approaches is presented in Table I.

Table I. Overview of the samples and methodological approaches

	Sample	Study design	Data collection	Analysis
Study I	Persons (84-95 years) in the beginning to develop dependence in daily activities ($n=11$)	Grounded Theory	Individual interviews	Grounded Theory inspired by Charmaz
Study II	Persons (70-88 years) at a community based service centre ($n=13$)	Validity test	Focus groups discussions/ Individual interviews with IPA-S	Krueger's method and Content analysis
	Persons (70-99 years) finalized geriatric rehabilitation ($n=16$), or a continuum of care intervention ($n=23$)	Reliability test-retest	IPA-O	Svensson's method
Study III	Persons (84-103 years) with different degrees of dependence in daily activities, recruited from two sets of data ($n=456$)	Cross-sectional Explorative	Face-to-face interviews with IPA-O and ADL staircase	Fisher's exact test and the Relative Risk
Study IV	Persons (84-103 years) with different degrees of dependence in daily activities, recruited from two sets of data ($n=456$)	Cross-sectional Explorative	Face-to-face interviews with IPA-O and questionnaires measuring a set of relevant explanatory factors*	Bivariate Logistic Regression

* Explanatory factors: gender, education, age, morbidity/disability, frailty, self-rated health, satisfaction with physical health, dependence in ADL, living conditions, and persons offering help in terms of receiving help from public home care service and receiving help from husband/wife/children.

4.2 Study I

To explore the older person's self-determination when developing dependence in daily activities, a qualitative, grounded theory method, inspired by the developments by Charmaz (112), was used.

4.2.1 Recruitment and sample

The participants were recruited by using a target selection with persons from the larger study *Elderly persons in the risk zone* (113). The sample included community-dwelling people 80 years and older ($n = 459$), who were at risk of developing dependence in daily activities. These participants were drawn from two urban districts in Gothenburg, Sweden. To achieve a variation of experiences among the participants, and in accordance with the grounded theory method (112), a heterogeneous sample in terms of gender, ages, marital status, degree of dependence, persons helping, and degree of frailty was selected. A person's degree of dependence in daily activities and degree of frailty were assessed at the two year follow-up in the larger study (113). The ADL staircase (78, 79) was used to assess degree of dependence in five P-ADL items (bathing, dressing, going to the toilet, transfer, and feeding), and in four I-ADL items (cleaning, shopping, transportation, and cooking). A person's need for help with laundry was also included. Frailty was assessed using eight frailty indicators: weakness, fatigue, weight loss, physical activity, poor balance, slow gait speed, visual impairment, and cognition, categorized into non-frail (0 indicators), pre-frail (1-2 indicators) and frail (3 or more indicators).

4.2.2 Data collection and analysis procedure

The data were collected through face-to-face interviews in the participants' homes over eleven months. All interviews followed an interview guide that addressed the older people's experiences of their self-determination when developing dependence in daily activities. The interview guide was revised throughout the study, as recommended in grounded theory (112). The two opening questions, focusing on the older person's meaning of self-determination, and their experiences of exercising self-determination when developing dependence, were asked during each interview.

Data were analysed in accordance with grounded theory inspired by the developments by Charmaz (112), consisting of initial coding, focused coding, and constant comparison. Detailed memos were written after each interview

and during analysis of the data. Free writing, a form of pre-writing (112), was used to get closer to the essence of the data. The analysis process continued until saturation was achieved, i.e. no new codes were found, resulting in a total of 11 interviews. The interviews lasted from 31 to 66 minutes. The participants had been dependent in daily activities from a few months, up to 18 months. Characteristics of the participants are presented in Table II.

Table II. Characteristics of participants in study I

Participant	Gender	Age	Marital status	Dependent in ¹	Help offered by	Degree of frailty ²
1	Male	87	Married	P-ADL/ I-ADL	Relatives/ Privately	4 (Frail)
2	Male	90	Widower	I-ADL	Home care service	2 (Pre-frail)
3	Female	89	Single	P-ADL/ I-ADL	Home care service	4 (Frail)
4	Female	95	Widow	I-ADL	Privately	4 (Frail)
5	Female	84	Married	I-ADL	Relatives/ Privately	1 (Pre-frail)
6	Female	90	Single	I-ADL	Privately	3 (Frail)
7	Male	92	Widower	I-ADL	Relatives/ home care service	1 (Pre-frail)
8	Male	91	Widower	I-ADL	Home care service	0 (non-frail)
9	Female	89	Single	P-ADL/ I-ADL	Home care service	2 (Pre-frail)
10	Female	86	Widow	I-ADL	Privately	2 (Pre-frail)
11	Male	87	Married	I-ADL	Home care service	1 (Pre-frail)

¹P-ADL = Personal Activities of Daily Living, I-ADL = Instrumental Activities of Daily Living.

²Frailty measured with the following frailty indicators: weakness, fatigue, weight loss, physical activity, poor balance, slow gait speed, visual impairments, and cognition categorized into non-frail (0 indicators), pre-frail (1-2 indicators) and frail (3 or more indicators).

4.3 Study II

The second study was performed in two steps: a validity test of the IPA-S questionnaire followed by a reliability test-retest of the adjusted version (Figure I). In the first step, the face and content validity of the IPA-S was tested using focus group discussions and individual interviews. The results were analysed and discussed by an expert panel ($n=4$) with knowledge in geriatrics ($n=1$), occupational therapy ($n=3$), instrument development ($n=2$), interviewing older people ($n=4$), and focus group methodology ($n=3$). The expert panel discussions resulted in an adjusted version, IPA-O (-Older persons). Finally, the IPA-O was reliability test-retested using Svensson's method (115, 116). Both steps were performed with persons aged 70 years and older.

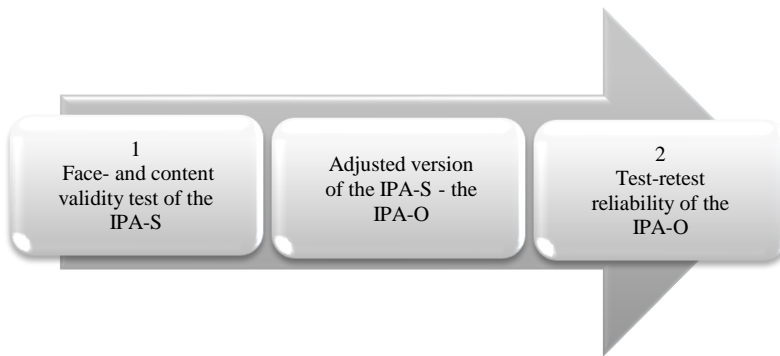


Figure I. Research design with the diverse steps

4.3.1 Questionnaire

The IPA-S questionnaire (39) was used in the validity step. IPA-S is similar to the original version and has been tested for younger age groups (≤ 84 years) with spinal cord injury, proving good psychometrical properties (39). The original IPA (33) consists of 31 items divided into five dimensions: autonomy indoors (seven items), family role (seven items), autonomy outdoors (five items), social relationship (six items), and work and education (six items). Five answer alternatives are provided: very good, good, fair, poor, or very poor. The respondents score all items by themselves. At the end of each dimension, the participants answered general questions regarding their perceived health problems with the answer alternatives: no problems, minor problems, or severe problems. A higher score on the scale signifies severe problems (34).

4.3.2 Recruitment and sample

Overall inclusion criteria for the validity step and reliability test-retest step were community-dwelling persons 70 years and older who were dependent in at least one activity of daily living.

Validity step

The sample consisted of people visiting a community-based service centre and who had been cognitively assessed and recruited by healthcare professionals. Nine persons agreed to participate in focus group discussions, forming two groups (one group of four people and one group of five people), and four people participated in individual interviews. The people had varied degrees of dependence in daily activities and had at least one chronic condition. The characteristics of the participants in the validity step are presented in Table III.

Table III. Characteristics of participants in the validity step (n=13)

	%	n
Age, range (70-88 years)		
Gender, male/female	23/77	3/10
Marital status		
Living alone	100	13
Housing		
Ordinary housing	100	13
Dependence		
I-ADL ¹	100	13
I-ADL and P-ADL ²	46	6

¹I-ADL=Instrumental Activities of Daily Living

²P-ADL=Personal Activities of Daily Living

Reliability test-retest step

People who finalized a geriatric rehabilitation or a continuum of care intervention (114) were asked to participate. Of the 45 invited people, 39 participated; 16 had finalized a geriatric rehabilitation and 23 had finalized a continuum of care intervention (114). Characteristic of the participants in the reliability test-retest step are presented in Table IV.

Table IV. Characteristics of participants in the test-retest step ($n=39$)

	%	<i>n</i>
Age, range (70-99 years)		
Gender, male/female	33/67	13/26
Marital status		
Married/Cohabiting	23	9
Living alone	77	30
Housing		
Ordinary housing	90	35
Nursing home	10	4
Dependence		
I-ADL ¹	100	39
I-ADL and P-ADL ²	49	19

¹I-ADL=Instrumental Activities of Daily Living

²P-ADL=Personal Activities of Daily Living

4.3.3 Data collection and analysis procedure

Validity step

The validity test of the IPA-S started with the focus group discussions, followed by the individual interviews. In the focus group discussions and in the individual interviews, all the questions in the IPA-S were read out loud. No definition of the concept of self-determination was given before starting an interview. Both the focus group discussions, and in the individual interviews, the comprehensiveness of the questionnaire, and relevance of each single question were discussed. The participants were also asked about their overall impression of the IPA-S. All discussions and interviews were recorded and transcribed verbatim.

The analysis of the focus group discussions was performed using Krueger's method (117), and the individual interviews were performed using Graneheim and Lundmans content analysis (118). First, the analysis of the focus group discussions was performed. At this stage, central sections within the empirical data were identified and sorted in accordance with the purpose. Then, data from the individual interviews were identified as meaning units using manifest content analysis. Finally, the expert panel analysed and sorted all meaning units from the focus group discussions and the individual interviews, which resulted in an adjusted version, the IPA-O.

Reliability test-retest step

For the reliability test-retest, participants were contacted by phone. The first interview, conducted in the participant's home, consisted of a face-to-face interview that followed the 22 items in the IPA-O. The second interview was conducted by phone. In two cases, both interviews were carried out in the participants' homes because of a hearing impairment. During both the first and the second interview, the participants had an enlarged copy of the answer alternatives, and the IPA-O statements were given in the same order at both interviews. To ensure that the participants' health status had not changed between the first and the second test, which could affect their self-determination, the interviewer asked the participants about their health status before conducting the second interview. The timeframe between the first and second interview was approximately 14 days.

The reliability test-retest was analysed using Svensson's method (115, 116), a method developed for treatment of paired assessments of ordinal data. Svensson's method (115, 116) identifies and separately assesses both systematic and occasional disagreement. The following measures were taken into account during the analysis process:

- The Percentage Agreement (PA) for categorical pairs of data between the two assessments (119). A PA of $\leq 59\%$ was defined as low percentage agreement, PA of 60-69% as moderate, and PA of $\geq 70\%$ as high percentage agreement.
- The Relative Rank Position (RP), a measurement of systematic shift in categorical levels (ranging from -1 to 1). Higher values on RP indicate higher systematic group change (115, 116).
- The Relative Rank Variance (RV), a measurement of the observed individual variability (ranging from 0 to 1). Higher values on RV indicate a presence of individual variability (116). An $RV \geq 0.1$ was considered as evidence of systematic disagreement.
- The 95% CI was calculated for the RP and RV.

4.4 Study III-IV

Study III and IV applied a cross-section design, and combined the two sets of data *Elderly persons in the risk zone* (113) and *Continuum of care for frail elderly people* (114). The studies took on an exploratory design where the older person's self-determination was explored in relation to degree of dependence in daily activities (study III), followed by an exploration of a set of relevant explanatory factors (study IV).

4.4.1 Recruitment and sample

Overall inclusion criteria were community-dwelling persons aged 80 years and older. The two sets of data *Elderly persons in the risk zone* (113) and *Continuum of care for frail elderly people* (114) were combined. The data set *Elderly persons in the Risk zone* (113), at the inclusion, constituted people aged 80 years and older, living in ordinary housing with no home help or service, independent in daily activities, and cognitive intact ($25 \geq$ on the Mini Mental State Examination). This group was drawn from the official register of persons 80 years and older living in two municipalities in Gothenburg, Sweden ($n=459$). The data set *Continuum of care for frail elderly people* (114), at the inclusion, consisted of people aged 80 years and older, and people 65 to 79 years that had at least one chronic disease and who were dependent in at least one activity of daily living, which had sought care at the Emergency Department of Mölndal Hospital, Sweden ($n=161$). People under the age of 80 from the *Continuum of care for frail elderly people* (114) were excluded. The studies *Elderly persons in the Risk zone* (113) and the *Continuum of care for frail elderly people* (114) have been described in detail elsewhere.

To achieve a heterogeneous sample regarding degree of dependence, the two year follow-up data from the *Elderly persons in the risk zone* (113) were combined with baseline data from the *Continuum of care for frail elderly people* (114), which resulted in a total of 456 participants (Figure II). Characteristic of participants in study III and study IV are presented in Table V.

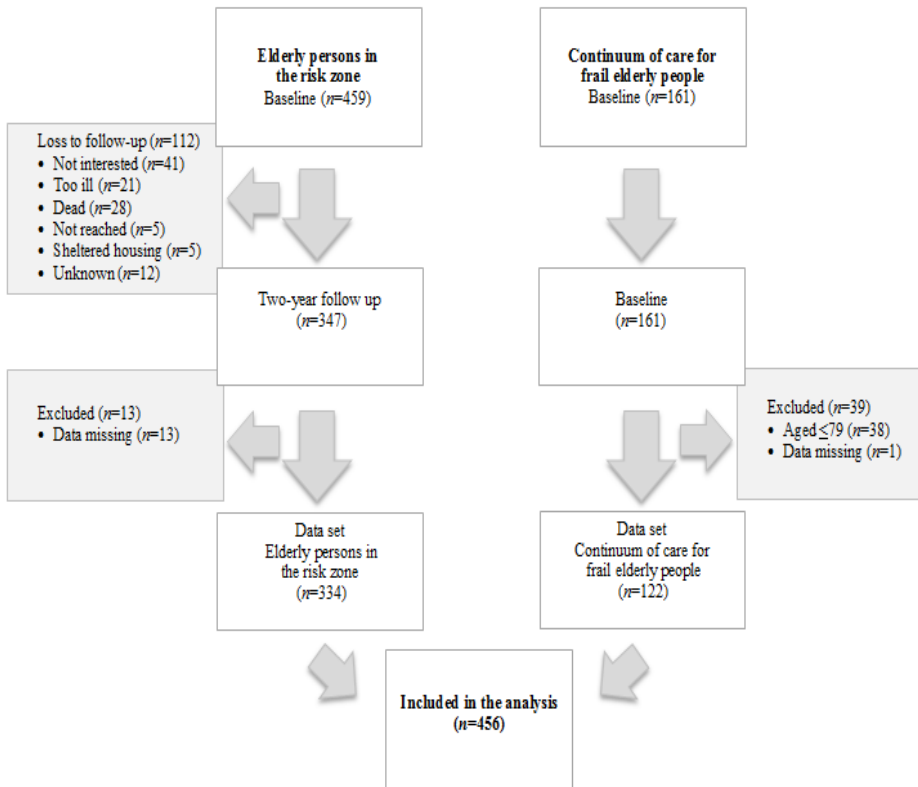


Figure II. The flow of participants in the two sets of data *Elderly persons in the risk zone* and *Continuum of care for frail elderly people*

Table V. Characteristics of participants in study III and IV (n=456)

	%	n
Female	63	287
Living alone	55	252
Non-frail ¹	54	245
Frail ¹	46	211
Tertiary education ²	18	80
Self-rated health ³	61	279
Independent	47	213
Dependent in I-ADL ⁴	46	209
Dependent in P-ADL ⁵	7	34

¹Frailty measured with the following frailty indicators: weakness, fatigue, weight loss, physical activity, poor balance, slow gait speed, visual impairments, and cognition categorized into non-frail (0-2 indicators) or frail (≥ 3 indicators)

²Tertiary education (university or college)

³Excellent/very good/good

⁴I-ADL=Instrumental Activities of Daily Living

⁵P-ADL=Personal Activities of Daily Living (refer to those persons who reported dependence in at least one P-ADL activity and in at least one I-ADL activity)

4.4.2 Data collection and measurements

The data were collected during structured face-to-face interviews and by using assessment conducted in the participants' homes between October 2008 and the end of June 2011 (113, 114). In all the interviews, specific study questionnaires were used, in accordance with the guidelines for the assessments included in each data set (113, 114). The study questionnaires contained several questions regarding demographic data, depression, morbidity/disability, and quality of care. It also contained assessments concerning cognition, functional ability, self-determination, and visual impairment (113, 114). The interviews in both the data sets were performed by research assistants with different backgrounds (occupational therapy, physiotherapy or registered nurse). All interviewers were trained in assessing, interviewing, and observing. In addition, study protocol meetings were held regularly to ensure standardization.

In study III and IV, the participants' self-determination was assessed with the Impact on Participation and Autonomy-Older persons (IPA-O) that had been psychometrically tested in a previous study. Before the analysis process, the response options of *totally agree* was dichotomised to *perceiving self-determination* and the remaining four response options (partly agree, neither agree nor disagree, disagree, and totally disagree) were dichotomised to *not perceiving self-determination*. The same pattern was followed when dichotomizing on dimension level, where the participants were treated as *perceiving self-determination* when they assessed *totally agree* in all items within the dimension.

In study III, the participants' self-determination was explored in relation to degree of dependence on another person in ADL with the ADL staircase (78, 79). The ADL staircase is a cumulative scale that indicates a person's independence or degree of dependence on another person in six P-ADL items (bathing, dressing, going to the toilet, transfer, feeding, and continence) and in the four I-ADL items (cleaning, shopping, transportation and, cooking). Continence was omitted since it was not considered to be an activity. Participants living with another person were assessed as independent if they performed the activity by themselves while alone. Degree of dependence in ADL was dichotomised to either *independent* or *dependent* in accordance with the ADL staircase (79). A second dichotomisation was performed where participants' independence or degree of dependence was divided in the

following parts: independent, dependent in I-ADL, and dependent in P-ADL. In study IV, degree of dependence in ADL was included as one of the central explanatory factors and assessed in the same way as described above.

Explanatory factors

In study IV, the response variable self-determination was explored in relation to a set of explanatory factors inspired from a previous qualitative study. The following explanatory factors were explored: gender, education, age, morbidity/disability, frailty, self-rated health, satisfaction with physical health, degree of dependence in ADL, living conditions, receiving help from public home care service, and receiving help from husband/wife/children. Each of these factors is discussed in more detail below.

Education was dichotomized into *low education* (incomplete education/college or lower degree) and *high education* (university or college).

Age was dichotomized into *age* ≤ 89 and *age* $90 \geq$, resulting in the age groups of 84-89 years and 90-103 years.

Morbidity/disability was measured with the Cumulative Illness Rating Scale for Geriatrics (CIRS-G) (120), a quantitative rating instrument of the chronic medical illness burden modified for geriatric assessments. The CIRS-G (120) comprises 14 categories: heart, vascular, hematopoietic, respiratory, eyes-ears-nose throat and larynx, upper gastrointestinal, lower gastrointestinal, liver, renal, genitourinary, musculoskeletal, neurological, endocrine, and psychiatric illness. The 14 categories are rated as follows: 0 = no problem, 1 = current mild problem, 2 = moderate disability or morbidity/require “first line” therapy, 3 = severe/constant morbidity/disability, and 4 = extremely severe morbidity/disability with immediate treatment required. The interviewer rated the participants’ level of morbidity (0-4) after the participants had reported their problems. In study IV, morbidity/disability was defined as having a number 3 or more (severe/constant morbidity/disability), i.e. “uncontrollable” chronic problems.

Frailty was measured using eight frailty indicators: weakness, fatigue, weight loss, physical activity, poor balance, slow gait speed, visual impairments, and cognition. Weakness (grip strength) was measured with the North Coast dynamometer (121). Frailty was defined as a grip strength of less than 13 kg

(dominant hand), and 10 kg (non-dominant hand) for women and less than 21 kg (dominate hand) and 18 kg (non-dominant hand) for men. Fatigue and weight loss was measured using the Göteborg Quality of Life instrument (GQL) (122), where the answer of “yes” to the two questions: *Have you suffered any general fatigue/tiredness over the last three months?* and *Have you suffered from any weight loss over the last three months?* indicated frailty. Frailty was also indicated by low physical activity (outdoor walking two times or less each week) measured with a six-point scale. Poor balance, indicated as a score of 47 or lower (maximum is 56 points), was measured with the Bergs Balance Scale (BBS) (123). Gait speed of 6.7 seconds or slower over four metres (124) was considered an indicator of frailty. Visual acuity of ≤ 0.5 (both eyes) measured with the KM chart (125, 126), and reduced cognition below 25 points measured with the Mini Mental State Examination (MMSE) (127) indicated frailty. The sum of the frailty indicators was categorized into non-frail (0-2 indicators) and frail (≥ 3 indicators).

Self-rated health (SRH) was derived from the first question in the SF-36 Short-Form Health Survey: *In general, would you say your health is excellent, very good, good, fair or poor?* (128). The response alternatives were dichotomized into *good* (excellent, very good, or good) and *poor* (fair or poor).

Satisfaction with physical health was measured with one of the questions in the six-grade scale Fugel-Meyer Satisfaction Assessment (Lisat-11): *How satisfied are you with your physical health?* (129). The response alternatives were dichotomized into *satisfied* (very satisfied, satisfied or rather satisfied) and *unsatisfied* (rather unsatisfied, unsatisfied, or very unsatisfied).

Degree of dependence in ADL was dichotomized to *independent* or *dependent* following the guidelines for the ADL staircase (79). Thereafter, people who were dependent in at least one activity were dichotomised into *dependent in ADL*.

Living conditions were dichotomised into *living together* (living with husband/wife/children) and *living alone*.

Receiving help from public home care service referred to people who received help from public home care service at least once a month, less frequently, or more frequently.

Receiving help from husband/wife/children referred to people who received help from husband/wife/children at least once a month, less frequently, or more frequently.

4.4.3 Statistical analysis

The analysis included the two year follow-up data from the *Elderly persons in the risk zone* (113) ($n=334$) and the baseline data from the *Continuum of care for frail elderly people* (114) ($n=122$). Statistical analysis was performed per protocol by using PASW Statistics, version 22.0 (IBM SPSS Inc., Chicago, IL, 2009).

In study III, Fisher's exact test was used to test the differences in proportions of perceiving self-determination between independent people and people dependent on others in daily activities. A p -value of ≤ 0.05 was considered significant. To analyse the risk of perceiving reduced self-determination among the dependent persons in relation to the independent persons, the Relative Risk (RR) with a 95 % Confidence Interval (CI) was determined.

In study IV, initial analysis was carried out with Chi-Square in order to explore the significance of the association between the response variable and the 11 explanatory factors. A p -value of ≤ 0.05 was considered significant. A bivariate Forced Entry Method logistic regression was performed to analyse the association of self-determination and the 11 explanatory factors. All the explanatory factors used in the initial analysis were included in the final regression model. Nagelkerke R Square was performed to test the power of explanation of the model, and the Hosmer and Lemeshow test was performed to test goodness of fit in the model (130).

5 ETHICAL CONSIDERATIONS

The studies were guided by the World Medical Association (VMA) Declaration of Helsinki's ethical principles for medical research involving human subjects (131). In study I, the participants were recruited from the *Elderly persons in the risk zone* (113), a study that has been approved by the Regional Ethical Review Board Gothenburg, Sweden (ref.nr: 650-07). An additional application for the individual interviews was performed for study I (ref.nr: 401-12). Study II, followed the recommendations given by the VMA's ethical principles (131). The participants in the validity test and the reliability test-retest gave written and verbal consent, and they were informed of their right to withdraw from the study at any time. The participants were also informed that their identity would remain anonymous. The two sets of data used in study III and study IV - *Elderly persons in the risk zone* (113), and *Continuum of care for frail elderly people* (114) - were approved by the Regional Ethical Review Board in Gothenburg, Sweden (ref.nr: 650-07 and ref.nr: 413-08).

General rules followed in the four studies consisted of information regarding the participants' right to withdraw from the separate studies at any time. Before the interviews started, the participants signed an informed consent form, and received written and verbal information about the specific study. The participants were informed about the confidentiality policy and that participation in interviews was voluntary. In addition, the participants were advised to stop the interview if they felt exhausted. The questionnaires used in the *Elderly persons in the risk zone* (113) and in the *Continuum of care for frail elderly people* (114) were comprehensive and therefore potentially exhausting for the participants. With this in mind, all participants were advised to stop if necessary. Moreover, when needed, the interview was performed on two occasions to lessen the burden of answering the questionnaires.

6 RESULTS

The results from the four studies are presented under the following three headings: *Experiences of self-determination* (study I), *Instrument evaluation* (study II), and *Self-determination and related variables* (study III and study IV). The sections represent a summary of the main results; detailed results are presented in the separate papers.

6.1 Experiences of self-determination

Self-determination was experienced as a shifting process during the development of dependence in daily activities. The shifting was two-fold and constantly moved between *self-governing* and *being governed* by the ageing body or by other persons, depending on *which activity was being performed*, *who was helping*, and *how extensive the help was*. The shifting process was expressed through the categories *Struggling against the ageing body*, *Decision-making is relational*, and *Guarding one's own independence* (Figure III).

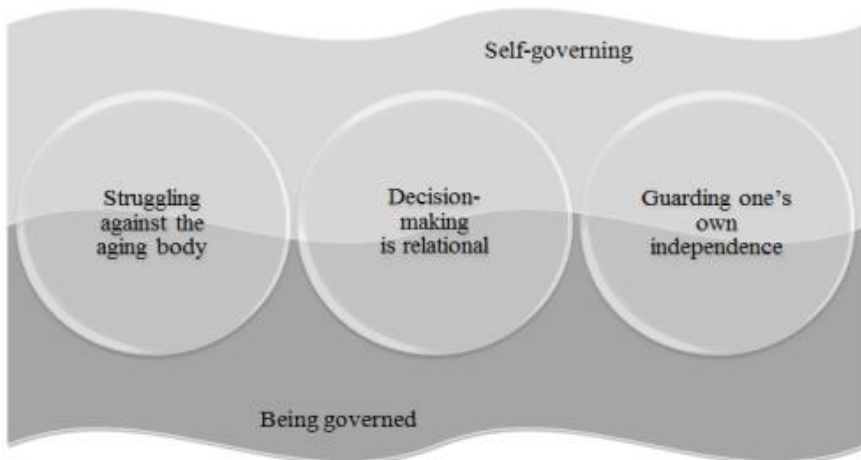


Figure III. A model illustrating self-determination as shifting between self-governing and being governed

Struggling against the ageing body referred to the constant struggle to carry on with daily activities in the face of the ageing body. The struggle was based on the primary purpose to maintain one's self-determination, resulting in

feelings of being able to govern in daily life. The possibilities of exercising self-determination in daily life were reduced when the ageing body, rather than one's own will, governed. This limitation could result in frustration due to decreased ability to exercise self-determination in daily life.

Decision-making is relational means that the relationship between the person receiving and the person offering help had a direct impact on the older person's possibilities to exercise self-determination. The shift of governing varied depending on whether help was provided by relatives, privately financed helpers, or public home care service personnel. Irrespective of the person who provided the help, the idea of being respected was considered important. Personal attitudes and cooperation between the parties involved in the activity facilitated versus hindered participation in decision-making.

Guarding one's own independence referred to the constant need to guard one's independence in daily activities by only accepting help when needed. By constantly guarding one's independence, a sense of control, and that it was possible to continue to govern one's daily life even when being dependent on others in daily activities. A way to guard one's independence was by consulting family and friends. Increased knowledge generated a sense of security, an attitude that encouraged a sense of control over decisions regarding one's daily life.

6.2 Instrument evaluation

The IPA-S questionnaire was evaluated for validity, followed by a reliability test-retest of the adjusted version (IPA-O). The main finding was that the IPA-O was valid and reliable for assessing older persons' perceived self-determination in daily life.

The validity step revealed that the IPA-S was an important and relevant questionnaire for the older persons, but adjustments were needed since it was too extensive and some items needed to be clarified. In addition, the older persons *Valued that their voice could be heard* regarding the opportunity to decide for themselves. Several of their friends and acquaintances had been questioned or opposed by relatives or by public home care service. Individual habits were especially hampered when being assisted by others.

The older persons expressed that *The questionnaire was extensive*. The dimension about family and the dimension about social relationship had too many items and some items were irrelevant, such as the whole dimension of work and education. The item *my chances of helping or supporting people in any way* was considered very important. The older persons *Focused on the execution* and not on the decision part when answering the items. During all interviews, the interviewer repeatedly reminded the participants that the chances of having the items done the way they wanted or when they wanted was assessed, and not their ability to perform the items.

In the adjustment phase, the items in IPA-S were adjusted from questions to statements that could be answered with the following response options: totally agree, partly agree, neither agree nor disagree, disagree, and totally disagree. The amount of questions was reduced to seven dimensions with 22 items (Table VI). Since the items about perceived health problems were relevant and important, no adjustments were made within this part of the questionnaire. The adjustments resulted in the IPA-O (-Older persons).

In the reliability step, 15 of the 22 items had high agreement ($PA \geq 70\%$), and six items had moderate agreement ($PA \geq 60\%$ to 69%) (Table VI). Only the item 4 showed low agreement between the test and retest ($PA \leq 59\%$). The RP in this item indicated increased self-determination after the first test, and the RV was on the cut-off limit ($RV \geq 0.10$) with a 95% CI 0.07 to 0.12, indicating a significant presence of individual variability (Table VI).

Table VI. The Percentage Agreement (PA), Relative Position (RP) and Relative Variance (RV) in the IPA-O. 95% Confidence Interval (CI) in brackets

Self-determination/Dimensions and items	n	PA (%)	RP	RP 95 % CI	RV	RV 95 % CI
Mobility (4 items)	39	97	-0.03	(-0.08 to 0.03)	0.00	(0.00 to 0.03)
1. My chances to decide where to get around in my house are good						
2. My chances to decide when I want to get around in my house are good	39	90	0.03	(-0.02 to 0.08)	0.00	(0.00 to 0.03)
3. My chances to decide when to visit relatives and friends are good	38	71	0.07	(0.02 to 0.12)	0.03	(0.00 to 0.06)
4. My chances to decide to go on the sort of trips and holidays I want to are good	37	54	-0.08	(-0.13 to -0.03)	0.10	(0.07 to 0.12)
Self care (5 items)						
5. My chances to decide to get washed and dressed the way I want are good	38	92	0.03	(-0.03 to 0.08)	0.00	(0.00 to 0.03)
6. My chances to decide when I get washed and dressed are good	39	79	-0.02	(-0.08 to 0.02)	0.01	(0.00 to 0.04)
7. My chances to decide when I want to go to bed or get up are good	39	95	-0.05	(-0.10 to 0.00)	0.00	(0.00 to 0.03)
8. My chances to decide when I want to go to the toilet and when I need to are good	39	88	-0.03	(-0.08 to 0.03)	0.00	(0.00 to 0.03)
9. My chances to decide when I want to eat and drink are good	39	87	0.02	(-0.03 to 0.08)	0.00	(0.00 to 0.03)
Activities in and around the house (4 items)						
10. My chances to get light tasks done around the house, either by myself or by others the way I want are good	38	82	0.08	(0.03 to 0.13)	0.01	(0.00 to 0.03)
11. My chances to get heavier tasks done around the house, either by myself or by others the way I want are good	38	61	0.13	(0.08 to 0.19)	0.03	(0.01 to 0.06)
12. My chances to get housework done, either by myself or by others when I want are good	38	63	0.11	(0.06 to 0.16)	0.09	(0.06 to 0.12)
13. My chances to get minor repairs and maintenance work done in my house and garden either by myself or by others the way I want are good	26	69	0.15	(0.11 to 0.19)	0.02	(0.00 to 0.04)
Financial situation (1 item)	38	100	0.00	(-0.05 to 0.05)	0.00	(0.00 to 0.03)
14. My chances to choose how I spend my own money are good						
Use of time (1 item)	39	67	-0.14	(-0.20 to -0.09)	0.04	(0.01 to 0.06)
15. My chances to use leisure time the way I want are good						
Social relationship (5 items)	37	97	0.00	(-0.05 to 0.05)	0.00	(0.00 to 0.03)
16. My chances to talk to people close to me on equal terms are good						
17. The respect I receive from people who are close to me are good	37	95	0.05	(0.00 to 0.10)	0.00	(0.00 to 0.03)
18. My chances to talk to acquaintances on equal terms are good	38	76	-0.00	(-0.05 to 0.05)	0.01	(0.00 to 0.04)
19. The respect I receive from acquaintances are good	38	89	-0.03	(-0.08 to 0.02)	0.00	(0.00 to 0.03)
20. My chances to see people as often as I want are good	36	72	0.02	(-0.03 to 0.07)	0.05	(0.02 to 0.07)
Help and support others (1 item)						
21. My chances to help or support people in any way are good	38	63	0.03	(-0.02 to 0.08)	0.04	(0.01 to 0.06)
Summary (1 item)						
22. My chances to live the way I want are good	39	64	0.11	(0.06 to 0.17)	0.03	(0.01 to 0.06)

6.3 Self-determination and related variables

Dependence in ADL was related to perceiving reduced self-determination in daily life. Persons dependent in I-ADL and persons dependent in P-ADL showed a general pattern of perceiving reduced self-determination in daily life (study III). Self-determination was reduced in the dimensions of *social relationship* (78 %), *mobility* (73 %), *chances to live the way I want – summary item* (69 %), and *help and support others* (61 %) (Table II, study III). A number of explanatory factors were also related to reduced self-determination in daily life (study IV).

6.3.1 Dependence in ADL

Compared to the independent persons, persons dependent in I-ADL had statistically significant reduced self-determination ($p < 0.05$) in four of the IPA-O items: *going on trips/holidays* (item 4), *getting heavier tasks done* (item 11), *helping and supporting people* (item 21), and *chances to live the way I want* (item 22). The relative risk of perceiving reduced self-determination within these items was significantly higher (RR ranging from 1.52 to 2.48) among the I-ADL dependent persons. Persons dependent in P-ADL had statistically significant reduced self-determination ($p < 0.05$) in 15 of the 22 items within the IPA-O. The RR within these items ranged from 1.97 to 27.48, indicating a significantly higher risk of perceiving reduced self-determination in daily life among persons dependent in P-ADL (study III) (Table VII).

The odds of perceiving reduced self-determination in daily life were more than one and a half times higher among persons dependent in ADL (only I-ADL or both I-ADL and P-ADL). Being dependent in ADL, however, was not statistically significant with respect to reduced self-determination in daily life ($p = 0.054$) (study IV).

Table VII. The proportion (%) and *p*-value of perceived self-determination and the Relative Risk (RR) with a 95 % Confidence Interval (CI) of perceiving reduced self-determination (*n*=456)

	Independent (<i>n</i> =213)		Dependent in I-ADL (<i>n</i> =209)			Dependent in P-ADL (<i>n</i> =34)		
	% (<i>n</i>)	RR	% (<i>n</i>)	<i>p</i> -value	RR (95 % CI)	% (<i>n</i>)	<i>p</i> -value	RR (95 % CI)
Mobility <i>My chances to decide...</i>								
3. when to visit relatives/friends are good	94 (200)	1	93 (195)	1.000	0.95 (0.44-2.03)	71 (24)	0.018	3.28 (1.35-7.97)
4. to go on the sort of trips/holidays I want to are good	79 (169)	1	68 (143)	0.014	1.52 (1.09-2.13)	53 (18)	0.021	1.97 (1.18-3.29)
Self care <i>My chances to decide...</i>								
5. to get washed/dressed the way I want are good	99 (211)	1	96 (201)	0.170	3.09 (0.63-15.12)	79 (27)	0.003	13.74 (2.63-71.92)
6. when I get washed/dressed are good	100 (213)	1	99 (206)	0.493	-	73 (25)	0.000	-
9. when I want to eat/drink are good	99.5 (212)	1	97 (203)	0.365	3.10 (0.33-29.58)	79 (27)	0.001	27.48 (3.17-238.01)
Activities in and around the house <i>My chances to get... (either by myself or by others)</i>								
10. light tasks done around the house	99 (211)	1	98 (204)	0.682	1.54 (0.26-9.14)	76 (26)	0.002	14.20 (2.72-74.22)
11. heavier tasks done around the house	93 (198)	1	81 (170)	0.002	2.48 (1.40-4.39)	62 (21)	0.000	4.58 (2.26-9.28)
12. housework done	95 (203)	1	90 (188)	0.084	1.96 (0.93-4.10)	68 (23)	0.002	4.97 (2.05-12.07)
13. minor repairs/maintenance work done in my house/garden	87 (185)	1	85 (177)	1.000	0.98 (0.50-1.93)	56 (19)	0.000	4.33 (2.18-8.62)
Use of time <i>My chances to...</i>								
15. use leisure time the way I want are good	95 (202)	1	91 (191)	0.323	1.50 (0.71-3.15)	74 (25)	0.012	3.75 (1.49-9.41)
Social relationship								
18. My chances to talk to acquaintances on equal terms are good	94 (200)	1	93 (195)	0.835	0.87 (0.40-1.91)	71 (24)	0.006	3.70 (1.60-8.55)
19. The respect I receive from acquaintances are good	95 (203)	1	94 (196)	1.000	1.03 (0.42-2.55)	74 (25)	0.006	4.56 (1.74-11.93)
20. My chances to see people as often as I want are good	87 (186)	1	83 (174)	0.476	1.23 (0.76-2.00)	62 (21)	0.012	2.63 (1.41-4.91)
Help and support others <i>My chances to...</i>								
21. help/support people in any way are good	74 (157)	1	49 (103)	0.000	1.89 (1.45-2.46)	35 (12)	0.000	2.33 (1.63-3.34)
Summary <i>My chances to...</i>								
22. live the way I want are good	78 (167)	1	64 (134)	0.000	1.65 (1.20-2.26)	32 (11)	0.000	3.09 (2.17-4.39)

6.3.2 Explanatory factors for reduced self-determination

In the initial bivariate analysis, seven of the 11 explanatory factors were significantly associated with perceiving reduced self-determination in daily life ($p = \leq 0.05$) (Table II, study IV). In addition to dependence in ADL, the explanatory factors of high education, morbidity/disability, frailty, poor self-rated health, dissatisfaction with physical health and receiving help from public home care service were associated with perceiving reduced self-determination in daily life (study IV).

The result from the final bivariate Forced Entry logistic regression model showed that five explanatory factors were associated with perceiving reduced self-determination in daily life (Table VIII). High education (OR=2.83), frailty (OR=2.70), poor self-rated health (OR=2.54), unsatisfied with physical health (OR=6.50), and receiving help from public home care service (OR=2.46) were significantly associated with perceiving reduced self-determination.

Table VIII. Final logistic regression with Odds Ratio (OR), 95 % Confidence Interval (CI) and p -value of perceiving reduced self-determination ($n=384$)

Explanatory factors	OR	(95 % CI)	p-value
<i>Basic demographics</i>			
Gender (male)	0.74	(0.42-1.30)	0.290
Education (high education)	2.83	(1.46-5.49)	0.002
<i>Struggling against the ageing body</i>			
Age ($90 \geq$)	1.22	(0.74-2.00)	0.439
Morbidity/disability	1.69	(0.96-2.99)	0.069
Frailty	2.70	(1.62-4.51)	0.000
Self-rated health (poor self-rated health)	2.54	(1.42-4.56)	0.002
Satisfaction with physical health (unsatisfied)	6.50	(1.81-23.36)	0.004
<i>Guarding one's own independence/ Decision-making is relational</i>			
Dependence in ADL	1.68	(0.99-2.84)	0.054
Living conditions (living together)	0.95	(0.54-1.66)	0.847
Help from public home care service	2.46	(1.10-5.52)	0.029
Help from husband/wife/children	0.99	(0.59-1.66)	0.979

Nagelkerke R square = 0.354

Hosmer and Lemeshow Test: Chi-square=6.715, df =8, and p -value=0.568

7 DISCUSSION

7.1 Discussion of the results

The findings of self-determination in the context of the older persons could be separated into the following categories: *Internal factors*, *External factors*, *Actions against internal and external factors* and *The foundation of a self-determined dialogue*. Taken together, these categories are important and central when *Navigating towards a self-determined daily life in old age*. The exploration of self-determination in the context of community-dwelling older persons showed that self-determination was a shifting process that varied depending on both internal and external factors. To maintaining self-determination even when being dependent, the older persons took on actions directly related to the internal and external factors. Because the IPA-O proved to be valid and reliable for assessing older person's self-determination in daily life, it could be seen as a tool that healthcare professionals could use to encourage a self-determined dialogue. This thesis provides a scientific foundation and the tools that could enable healthcare professionals to navigate older people towards a self-determined daily life (Figure IV).

Internal factors

One of the main findings was that self-determination during the development of dependence in daily activities shifted from self-governing to being governed. Being dependent in daily activities occasionally resulted in being governed and limited by the ageing body. Internal factors occasionally governed (study I) and were associated with perceiving reduced self-determination in daily life (study III and study IV) (Figure IV). Among the internal factors, *dependence in daily activities* limited the possibilities to exercise self-determination in daily life (study I, III and IV). Persons with dependence in I-ADL and person with dependence in P-ADL perceived reduced self-determination to a greater extent than the independent persons. Reduced self-determination was most pronounced among persons with dependence in P-ADL (study III). The odds of perceiving reduced self-determination were over one and a half times higher for persons with dependence in ADL. This association, however, was not quite statistically significant (study IV).

Another internal factor that was significantly associated with reduced self-determination in daily life was *frailty* (study IV). People who were frail had approximately three times higher odds of perceiving reduced self-determination in comparison to persons who were not frail. Frailty is not only directly related to morbidity and reduced ability to perform daily activities (57) but it is also significantly associated with lower degrees of life satisfaction (132). Interventions are more effective if they are directed to persons before they become frail (57, 133). Therefore, early proactive actions ought to be taken that address the physical needs of older frail people as well as improve their perceived self-determination.

The findings from study IV indicated that the older person's *subjective health* was strongly associated with perceptions of self-determination. People with poor self-rated health had two and half times higher odds of perceiving reduced self-determination in daily life. Furthermore, people who were *unsatisfied with their physical health* had six and half times higher odds of perceiving reduced self-determination than people who were satisfied with their physical health. The outcome of general self-rated health has been shown to be a central predictor for advanced functional decline and mortality in community-dwelling older people (134), and a strong association between reduced self-rated health and depressive symptoms has also been found (135, 136). On the contrary, the internal factors *morbidity/disability* and *high age* ($90 \geq$) could not explain perceptions of reduced self-determination. The odds of perceiving reduced self-determination were above one and a half times higher among persons with morbidity/disability (study IV). Gender differences have been found when comparing 85-year old women and men. Compared to the men, the women had lower health-related quality of life, were at higher risk for depression, and identified more problems with respect to performing occupations (137).

All these findings mentioned above suggest that older people who perceive their health as poor and are unsatisfied with their physical health need specialized help with respect to maintaining their self-determination. In order to fully understand the older person's health, both quantitative and qualitative measures are recommended (138). Hence, objective and subjective measures of a person's health could be beneficial. Using subjective outcomes of a person's health is not only important for creating an understanding of a person's functional decline, mortality, and mental status but is also important for understanding a person's perceived self-determination in daily life.

Although no significant association could be found between self-determination and morbidity/disability and self-determination and gender, these explanatory factors should not be overlooked when creating an awareness of barriers for a person's perceived self-determination.

Educational level, a factor of both internal and external elements, was important for the older person's perceptions of self-determination. Having tertiary education was significantly associated with reduced self-determination (study IV), as people with a higher education may have been more used to exercising self-determination earlier in life. A previous study (139) has shown that workplaces requiring a higher level of education imply higher responsibilities and autonomy among the employees. Workplaces where people are enabled to make own decisions concerning their work, contributes with higher levels of autonomy (140). Based on these findings, exercising self-determination in daily life is even more important for those people who are used to exercising self-determination.

External factors

Another main finding was that self-determination during the development of dependence in daily activities shifted from self-governing to being governed by others. The older person's possibilities to exercise self-determination in old age were directly related to other people. External factors governed (study I), and were linked to perceiving reduced self-determination (study IV) (Figure IV). The findings showed that *receiving help from public home care service* limited the community-dwelling older person's self-determination in daily life (study I and study IV). A significant association between receiving public home care service and perceiving reduced self-determination in daily life was found. People receiving help from public home care service had nearly two and a half times higher odds of perceiving reduced self-determination in daily life (study IV). According to Breitholtz et al. (4), dependent older persons experience organizational barriers to self-determination. Decision-making was not possible to perform, or even influence, since the decisions had already been made. Furthermore, public home care service may challenge a person's freedom to do what the person wants to do (141).

The findings in this thesis reflect a population of older persons living in their own homes. Reduced self-determination among persons living in nursing homes or being hospitalized has been explored earlier (6, 142). Hellström and

Sarvimäki (6) found that older people living in nursing homes experienced disempowerment based on having limited opportunities to influence their situation and not being valued. Furthermore, older people living in nursing homes felt strongly dependent when they had to wait for help. The desire to make more choices and the feeling of losing control were also related to being dependent on other persons (142). Thus, the knowledge generated from this thesis may also be beneficial for people living in nursing homes.

The findings showed that *dependence in daily activities* were related to limited possibilities to exercise self-determination in daily life (study I and study III). Consequently, a person's dependence degree should be taken into account when considering self-determination in daily life during old age, although the relationship between the people is even more essential. Study I showed that the relationship between the person receiving help and the person offering help was a central aspect for continued self-determination. When older people were treated with respect, they continued to exercise self-determination even when being dependent on other people, a finding that suggests that self-determination is relational (study I). Kristensson, Hallberg and, Ekwall (143) highlighted the importance of the relationship between the frail older persons and their healthcare and/or social care. Experiences of care could be illustrated as having power and being powerless when receiving healthcare and/or social care.

Emphasis should be on creating good relationships. Well-balanced relationships between the person receiving care and the person offering care ought to be based on mutual trust, understanding, and sharing of collective knowledge, aspects that are central for the person-centred approach (144, 145). Using a person-centred approach could be the key for continued self-determination in old age. In order to establish a good relationship, the relationship should be based on mutual respect (111, 144, 146). Morgan and Yoder (147) found that the attributes of *holistic, individualised, respectful, and empowering* were relevant within the notion of person-centredness. As holistic care values and recognises the a whole person (148), individualized care should take a person's specific needs and preferences into account rather than being based on institutional routine or rules (149). Being respectful refers to a person's right to be treated with respect, which is directly related to acknowledging a person as capable to make his or her own decisions (111). Finally, empowerment was seen as an important attribute. Empowerment promotes self-confidence, which enables people to exercise

self-determination (150). Thus, the care for older persons should be individualised, respectful, and empowering. It should also take the whole person into account, which hopefully results in a partnership based on shared decision-making (107).

In occupational therapy literature, the client-centred approach is often put forward (15, 75, 104). Both the client-centred approach (15) and the person-centred approach emphasise the importance of creating a partnership (107). Although the approaches are similar in some ways, the person-centred approach could be seen as a development of the client-centred approach. This thesis advocates the person-centred approach since equality between persons involved in a caring relationship is even more evident within the person-centred approach. Moreover, the partnership within the person-centred approach involves shared decision-making in all steps of the care process (107), which is important if the person is going to be as self-determined as possible.

Society's view of older people also plays an important role. Societal attitudes towards older people are sometimes rather negative as *ageism* is a real phenomenon (151). Ageism is a social construct, shaped by societal beliefs, attitudes, and behaviours (152). Ageism can be tied to cultural views of or fear of death (153). According to the Self-determination Theory (17), environmental support is essential for continued self-determination. Furthermore, the environment, including the cultural environment, promotes opportunities for self-determination (154). Hence, if dependent older people do not have support from others and society at large, their possibilities to exercise self-determination may be reduced. Therefore, creating good relationships based on a partnership could be the key for continued self-determination into old age.

Actions against internal and external factors

In order to maintain self-determination in daily life, the older people took on actions directly related to the internal and the external factors (Figure IV). Actions towards the internal factors comprised a *struggle against the ageing body*. The result from study I showed that when older people began experiencing dependence in daily activities, this occasionally meant they were being governed by their own ageing body rather than their own will, which in turn resulted in a *struggle against the ageing body*. This changing process gave rise to frustration, a sign of not yet being totally in harmony

and accepting the changing process and its consequences. According to a previous study (155), frail older persons were in harmony with their own bodies when they were able to master their daily life in spite of their level of frailty. Moreover, when older people were able to accept and adjust to their constantly changing conditions, their perceived harmony in life improved. Haak et al. (156) found that older people avoided dissatisfaction by lowering their demands when performing daily activities; that is, they handled their declined performance by adjusting their expectations. Also, they handled their functional decline by voluntarily giving up a range of activities. This result is in line with study I, which showed that the older persons sacrificed a number of activities despite the struggle because they accepted and understood the limitations of their ageing body.

Actions directly related to the external factors were taken by constantly *guarding one's own independence*. Study I showed that the older people guarded their independence by not receiving more help than they required, which in turn resulted in feelings of governing. A previous study (88) showed that older people who managed without home care service had a better chance of being satisfied with everyday life. The findings from study I showed that the particular action to guarding one's own independence was related to the desire not to intrude and be a burden on family, friends, and neighbours. The desire to stretch one's limits so as not to become dependent and a burden on others has been described in a previous study (156) with older people. Furthermore, the findings from study I showed that although trying to be as independent as possible, consulting trustworthy persons such as family and friends was considered important, a direct action for maintaining one's self-determination in daily life. Hammarström and Torres (157) found that older people had varied feelings about being dependent on others. People who felt too dependent on their public home care service strived to become less dependent, while others accepted their dependency on home care services but did not want to be dependent on their family and friends.

The foundation of a self-determined dialogue

For the older persons, it was relevant and important to being asked about their chances of exercising self-determination in daily life; they valued that their voice could be heard (study II). When navigating towards a self-determined life, a simple way to start could be by asking older people about whether they are given the opportunity to make their own decisions. The

IPA-O could facilitate such a dialogue (Figure IV). IPA-O captures diverse aspects in a person's life, from one's chances to decide what to eat and drink, to one's chances to help or support others, which is a major advantage. IPA-O could be used as an evaluation tool for older persons (70 years and older) in the planning of their health and public home care. With respect to rehabilitation for older persons, the IPA-O could also be an effective tool to capture perceptions of self-determination. It could be especially important in health and social care for people who are dependent on others in their daily activities.

When navigating towards self-determination in daily life, it is important to keep in mind that self-determination in old age is experienced as constantly shifting process. Ebrahimi et al. (158) found that frail older people experienced their body as unpredictable and untrustworthy, a barriers to performing everyday activities. This unpredictability refers to the ageing body as well as a person's perceived self-determination and must be considered when assessing a person's condition. Because experiences of exercising self-determination in daily life may shift radically, questions and conversations about self-determination must be repeated several times. The self-determined dialogue based on the items within the IPA-O, from a person-centred approach, could be performed in several ways. One way could be by following the statements step-by-step. When recognising dimensions where there is a need for improvement, interventions could be initiated. This dialogue should focus on the dimensions that are of interest to the older person. The self-determined dialogue could be improved by expanding and including self-determined questions such as *one's overall chances of deciding in one's life, how the help should be given, when the help should be given, the extent of help, and if others should perform decisions* (Figure IV).

Navigating towards a self-determined daily life

Self-determination is a universal and natural need (103). From an occupational therapy perspective, it seems to be natural to enable young as well as older people to exercise self-determination regarding their own healthcare. Self-determination has been described as one of the fundamental concepts in occupational therapy practice (14). A central goal in occupational therapy is to support a person's ability to perform daily activities and to participate in society (16). Although self-determination in general is obvious for most healthcare professionals, the findings in this thesis indicated that both internal and external factors determined an older person's possibilities to

exercise self-determination. Exercising self-determination is possible in old age, but many complex factors interact. People need support from others to exercise self-determination (17), being supported and comforted by other people can improve the chances of being self-determined (14). People also need to feel competent and connected to their lives, to others, and to their surroundings to control diverse outcomes (103). With regard to this, healthcare professionals play an important role in supporting the older persons in exercising self-determination. Therefore, healthcare professionals should enable through navigate the older people towards a more self-determined daily life. Both the internal and the external factors must be addressed in an early stage and in a proactive sense.

The ultimate goal in healthcare should be to acknowledge what older people are able to do and to be, central aspects of the capability approach. The capability approach recognises what a person can achieve, which includes the freedom of choice (93-95). People should be treated as unique individuals who are experts on their own needs. The person-centred approach has earlier been highlighted as a crucial part in healthcare since it offers a conceptual foundation for care of older persons (159). The findings showed that exercising self-determination in daily life was relational (study I). Hence, the meeting between the person offering help and the person receiving help may take different turns due to the approach that the caregiver is following. The relationship between the person receiving and the persons offering help is therefore crucial. From this point of view, combining the capability approach with the person-centred approach could be beneficial. This combined approach demands that person's subjective experiences, unique biography, social context, and relationships are acknowledged and respected (160). By combining the person-centred approach with the core characteristics in the capability approach, the older person's self-determination could be enhanced (Figure IV).

One might draw the conclusion that exercising self-determination is the ultimate goal for everyone in every single activity. This thesis advocates a more self-determined daily life where the older persons are allowed and supported to participate and exercise self-determination. Still one can't assume that all people have a desire to exercise self-determination in daily life. Making a decision not to decide in a specific activity is, however, to fully exercise self-determination in one's own daily life.

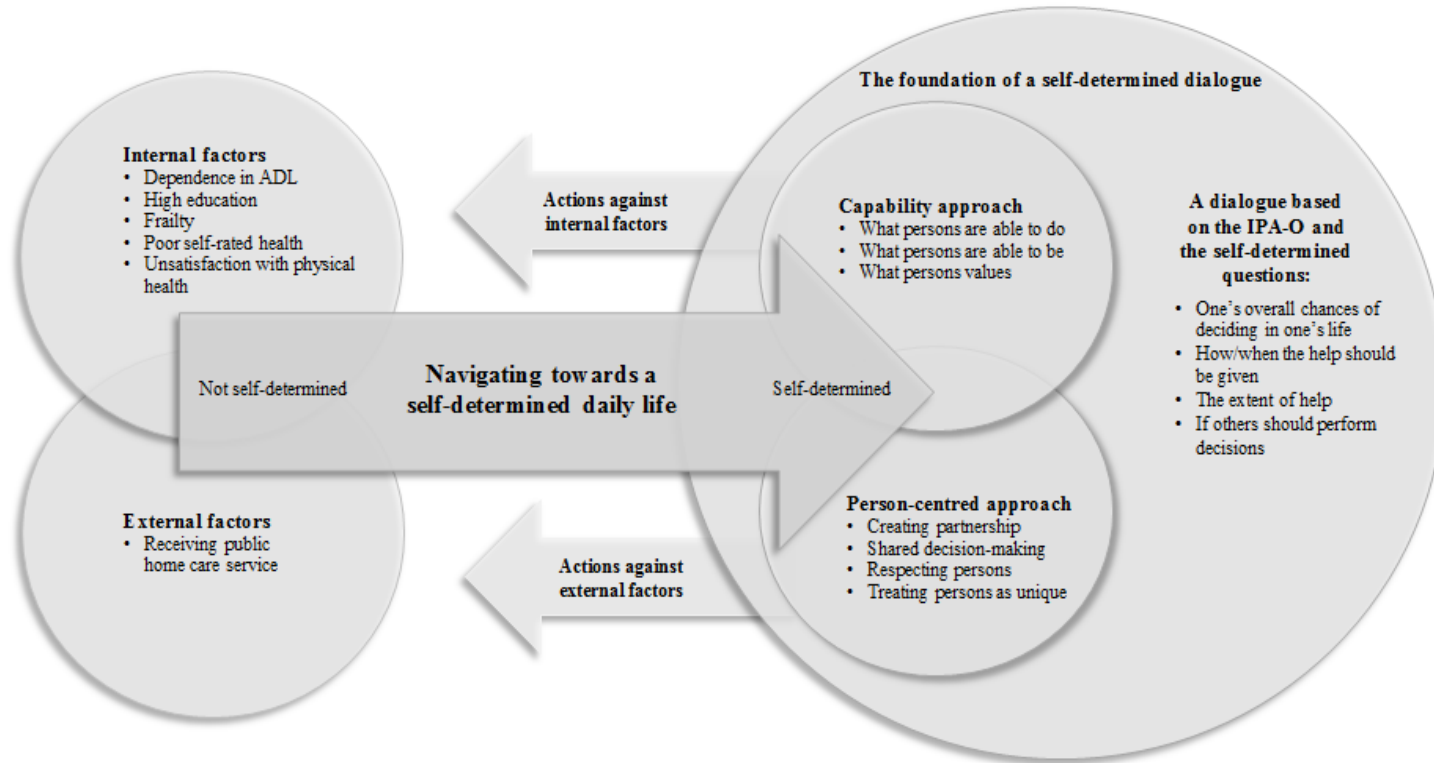


Figure IV. A model illustrating the central parts when navigating towards a self-determined daily life in old age

7.2 Methodological considerations

The overall aim of this thesis guided the methodological choices for each of the studies. Combining qualitative and quantitative methods made it possible to explore the older person's self-determination from different areas of interests. By using both qualitative and quantitative research methods, the weakness of each research method decreases (161). Using different methods could, however, be challenging, but by using different methods different knowledge is accessed with respect to the concept of self-determination. Each study in this thesis has its strengths and limitations. The fundamental methodological issues are discussed below.

Trustworthiness in qualitative studies

This thesis consisted of both qualitative and quantitative studies. In qualitative studies, it is the quality, and not the quantity that must be addressed. Study I employed a qualitative, grounded theory design inspired by the developments by Charmaz (112). This specific qualitative method was selected since it focuses on actions and processes (112). The purpose in Study I was to explore experiences of self-determination during the development of dependence in daily activities, processes were covered. With respect to this, the grounded theory design inspired by the developments by Charmaz (112) was the most suitable qualitative method for this study. The four central criteria for quality in a grounded theory study, according to Charmaz (112), are *credibility*, *originality*, *resonance* and *usefulness*. A heterogeneous group of participants in terms of gender, age, social status, varied home help service, and dependence degree resulted in a wide spectrum of experiences, which is important to ensure *credibility* (112). In addition, credibility of a study is reflected in how data are collected – i.e., remaining close to the participants own words during the whole analysis process is essential (112). This was achieved by analysing and writing the draft in the authors' native language. Ensuring the credibility of a study, according to Lincoln and Guba (162), is one of the most central parts when establishing trustworthiness. It reflects the confidence in the truth. Credibility was established by staying as close as possible to the essence of the participants' own words and experiences.

Charmaz (112) means that a study offers new insight of a specific phenomenon if the quality criteria of *originality* is ensured. The result in study I shed new light on older people's experiences of self-determination,

contributing with new insights about the phenomenon. The *resonance* of a study could be confirmed by capturing all aspects of a phenomenon (112). Having a heterogeneous sample is equally important for the resonance as for the credibility of a study. The heterogeneous sample was achieved by using a target selection when selecting persons. The contribution and the applicability of a study is understood as its *usefulness* (112). Lincoln and Guba (162) uses the word *transferability* to describe whether a study's results can be transferred to other populations. Even though a heterogeneous sample was achieved using a target selection, it is important to keep in mind that the participants in these studies were all born in Sweden, lived in two districts in Gothenburg and, compared to other Swedes of the same cohort, had less sickness, a slightly higher income, and slightly higher education levels, all characteristics that may limit the transferability of the study.

Unlike quantitative studies, the number of participants in a qualitative study is unimportant. Eleven persons participated in study I. The number of participants was not fixed from the beginning. On the contrary, the interviews were performed until no new codes were found, i.e., until saturation was achieved (112). In study II, focus group discussions and individual interviews were used to test the validity of the IPA-S questionnaire. In total, 13 people participated and nine of these participated in one of two focus groups (one of four people and one of five people). Using a limited number of persons in a focus group could be beneficial. Groups consisting of three to six people have been shown to be dynamic. That is, it is not the number, but the contribution of each person that influences the discussions (163).

To develop a deep understanding of older people's perceptions of the IPA-S questionnaire, both focus group discussions and individual interviews were performed (study II), which is a strength. Moreover, using two data collection methods made it possible for the participants to choose whether they wanted to take part in a focus group or in an individual interview. Offering individual interviews also enabled for people with hearing impairments to take part. The focus group discussions were performed before the individual interviews. This choice made it possible to deepen some questions in the individual interviews that were raised in the focus group discussions. Choosing focus groups as a methodology to gain new insight was considered an appropriate choice since it is an effective tool when exploring unexplored areas. Persons participating in a focus group may stimulate each other to explore new topics (117). However, the composition of participants is important for the outcome.

To facilitate discussions, a homogenous group is important. In contrast, a variance of discussions can be ensured by using a heterogeneous group (164, 165). The participants were homogenous in terms of being community-dwelling and dependent in daily activities. Their ages and social status varied, and they had different diseases or rest residues after stroke or cancer. Furthermore, the moderator plays an important role for the outcome of a focus group (166, 167). The moderator was familiar with the focus group methodology and had experience working with groups and older people, yet another advantage of the study.

The credibility of the validity test in study II must be addressed. An expert panel covering a broad area of expertise discussed and analysed the results in accordance with the recommendations for validity tests (168), another advantage of this study. The expert panel contributed with different perspectives, a triangulation that is an acknowledged powerful tool that strengthens the quality of a study (169). What must be kept in mind is that the composition of the expert panel could have affected the outcome. The participants' own comments and reflections guided all the adjustments of the IPA-S, so the composition is an advantage more than a limitation.

Conceptual considerations

This thesis focused on the concept of self-determination in daily life. Self-determination is a complex concept (170), and it often is treated synonymously with other concepts such as autonomy (26) or as a part of autonomy (22, 27, 28). Hence, some methodological issues may arise. A recently performed conceptual analysis (19) of frail older people showed that there is a clear distinction between the concept of self-determination and the concept of autonomy. In this thesis, self-determination and autonomy, in general, have been treated as related, but separate concepts. However, in study II, self-determination was viewed as a part of autonomy, i.e., decisional autonomy. In the original IPA, the concept of self-determination was equated to decisional autonomy (30), which refers to the capacity to make personal choices, irrespective of the ability to perform these choices (27). Based on this, self-determination was used synonymously with decisional autonomy in study II.

Validity test and adjustments of the IPA-S

The original version of IPA (33) and the Swedish version, IPA-S (39), assesses a person's perceived participation and autonomy. When examining the validity of the IPA-S questionnaire, the intent was to stay as close as possible to the original version of IPA. During the focus group discussions and the individual interviews, the participants answered the questions as if their executional autonomy was being assessed, not their decisional autonomy. In the original version of IPA, Cardol (30) aimed to assess both decisional and executional autonomy. In order to clarify the decisional part within the items, the questions were rephrased to statements. The number of items was also decreased. The choice of removing a number of items was based on the participants' recommendations. Only items not relevant or unclear were removed and no other changes were made. Although the questions were rephrased to statements and the numbers of items were decreased, the intent of the IPA-O is still to capture a person's perceived participation and autonomy. The decisional parts of autonomy, i.e. self-determined part, was strengthened in the adjusted version, participation in various activities are still assessed with the adjusted version.

Reliability test of the IPA-O

In the reliability test (study II), the retest was performed after 14 days. The timeframe was considered appropriate since it was long enough for the persons to forget the questions in the IPA-O (171). A longer timeframe might be negative because the person's health status could have deteriorated, potentially affecting their perception of their self-determination. To ensure that this was not the case, the participants were asked about their health status before taking part in the retest.

The first test was carried out in the participants' homes, and the retest was performed by telephone, except for two participants who had hearing impairment. To ensure that both the test and the retest were performed in the same manner, the participants had an enlarged copy of the answering alternatives in front of them in both tests. The interviewer read the questions in the same order to ensure that both interviews were conducted in a similar way.

The reliability test of the IPA-O showed that six of the 22 items had moderate agreement between the test and retest. Moreover, item 4 (*my chances to decide to go on the sort of trips and holidays I want to are good*) had low

agreement. This item is complex; it entails both trips and holidays that may involve a broad variation of traveling. The participants recommended this particular item be kept during the validity test. Therefore, it is considered to be an important item although having low agreement between the two tests. From a research perspective, the IPA-O had some items that were regarded as scientifically weak. From a clinically perspective, however, the items were regarded as important although somewhat scientifically weak.

Selecting related variables

In this thesis, the focus was on degree of dependence in daily activities, a unique way of exploring self-determination. It would, however, be a rather narrow way to explore and create an understanding of an older person's self-determination if it only focused on dependence in daily activities. Therefore, study IV used an explorative design where a set of explanatory factors was explored in relation to the older person's perceptions of their self-determination. Based on the findings from an earlier qualitative study (study I), a set of appropriate explanatory factors was selected. A limitation with this way of selecting explanatory factors is that other relevant explanatory factors might have been unexplored. The selection of factors was performed carefully by a research team with different expertise. Furthermore, the explanatory factors were taken from two sets of data (113, 114), which is another limitation. The assessments within the two sets of data had been performed earlier, so a restricted number of explanatory factors were offered.

Dichotomisation of the response variable

Before the analysis of data, the response options of perceiving self-determination in daily life, assessed with the IPA-O, was dichotomized. The response option *totally agree* was dichotomized into *perceiving self-determination*, and the remaining four response options (partly agree, neither agree nor disagree, disagree, and totally disagree) were dichotomised into *not perceiving self-determination*. In study III and IV the dichotomisation followed this pattern from the basis of only capturing people that perceived self-determination in their daily life without doubts. Another possible way of performing the dichotomisation could be to include the response options *partly agree* and *neither agree nor disagree* into *perceiving self-determination*. However, if the dichotomisation were performed in this manner, people who were unsure or who had doubts would be included and this would be incorrect.

Statistical considerations

Svensson's method (115, 119) was used to analyse the data in the reliability test-retest step (study II). This rank-invariant method was considered suitable since it is valid regardless of the number of answering alternatives, and it is developed for ordinal data. In addition, this statistical method identifies and separately assesses occasional and systematic disagreement (115, 116). A commonly used method for ordinal data is the Cohen's Kappa (172); however, the Svensson's method is superior in identifying and separately measuring systematic and random disagreement (173).

To explore the older persons' self-determination in relation to degree of dependence in daily activities, Fisher's exact test and the Relative Risk were used (study III). These two analysis methods were chosen since they contribute with different information of the explored phenomenon. By using Fisher's exact test, the differences in proportions of perceiving self-determination between the independent and dependent persons were achieved, whereas the Relative Risk contributed with the risk of perceiving reduced self-determination in daily life among independent persons in relation to the dependent persons. Fisher's exact test is suitable for small samples (172). Only 34 persons were dependent in P-ADL, a rather small sample. Therefore, Fisher's exact test was considered an appropriate choice. In study III, some items within the IPA-O had extremely wide CI. For example, item 9 (*my chances to decide when I want to eat and drink are good*) had a CI that ranged from approximately 3 to 238. This wide range may be due to the small sample size of persons dependent in P-ADL. Consequently, the findings concerning the items with a wide CI must be interpreted with caution.

In study IV, the older people's self-determination was explored in relation to a set of relevant explanatory factors. The association between the response variable and the explanatory factors were explored using a bivariate Forced Entry Method logistic regression. The stepwise methods have been criticised a lot, they have tendency to miss influential predictors (174). The explanatory factors were chosen on theoretical grounds. Hence, the most appropriate regression for this specific study was the Forced Entry Method.

Generalisability

In study III and IV, the sample comprised community-dwelling older persons with different ages, non-frail and frail, with varied degrees of dependence in daily activities and who lived in two municipalities in the County of Västra Götaland, Sweden. A heterogeneous sample was achieved by combining two sets of data (113, 114). One of the data sets, *Elderly persons in the risk zone* (113), in general consisted of people with a slightly higher income level and education. Thus, this sample does not represent the whole older population in Sweden, which is a limitation. In study III and IV, this data set was combined with the data set *Continuum of care for frail elderly people* (114), a sample more representative for the older population in general. Despite the heterogeneity within the sample, the sample can't represent the whole older population, which limits the generalizability of the studies. To develop a full picture of the phenomenon of self-determination in the context of older persons to ensure that the findings can be applied to a broader population, future studies need to use a more representative sample.

Additionally, this thesis represents a Western perspective. The importance of exercising self-determination may be different depending on cultural context (23-25, 175, 176). The possibility to exercise self-determination in daily life, and to be as independent as possible in daily activities, even when being dependent, reflects a Western perspective (23). From an Eastern perspective, dependence in daily activities means being helped by relatives, and one's family jointly makes decisions for the elderly members, which reflects a family-oriented self-determination in daily life (23). This difference must be kept in mind when analysing the generalisability of this thesis.

8 CONCLUSIONS AND CLINICAL IMPLICATIONS

In conclusion, this thesis showed that self-determination was experienced as a shifting process. Dependence was related to being governed by the ageing body or by other persons. Self-determination in old age was found to be highly related to the relationship between the person receiving and the person offering help. Thus, both internal and external factors limited the older person's possibilities to continue exercising self-determination. Therefore, the older people took on actions directly related to the internal and the external factors to maintain their self-determination in daily life.

For the older people to flourish and continue exercising self-determination when requiring help from others to perform daily activities, more focus must be placed on supporting and empowering older people in exercising self-determination. A way to navigate towards a self-determined daily life in old age could be by having a self-determined dialogue, a dialogue where the older people are encouraged to govern. The self-determined dialogue could be structured using the psychometrically tested and adjusted IPA-O. To maximise self-determination, the self-determined dialogue would benefit by acknowledging the older person's capabilities, focusing on what an older person is able to do and to be and what he or she values. The dialogue would also benefit by creating relationships based on a partnership with shared decision-making, where the older person's uniqueness is respected. Altogether, the findings suggest that the person-centred approach ought to be combined with the core characteristics within the capability approach, which could enhance an older person's self-determination in daily life.

9 FUTURE PERSPECTIVES

This thesis explored self-determination in the context of community-dwelling older persons with different degrees of dependence in daily activities. The sample, in general, consisted of older persons born in Sweden with the same cultural background. Therefore, it would be interesting to explore self-determination in the context of people with diverse cultural backgrounds. Another way to shed light on the phenomenon of self-determination could be by performing qualitative studies where healthcare professionals' points of view are captured. The findings in this thesis only reflect older people's perspectives on self-determination. Studies concerning healthcare professionals' views on self-determination and how healthcare professionals could actively work to enhance older people's self-determination would be beneficial.

The findings showed that the IPA-O could be important within the creation of a self-determined dialogue. It would be interesting to implement the IPA-O in a clinical setting with non-frail and frail older people with varied degrees of dependence. Furthermore, the IPA-O was psychometrically tested on cognitive intact persons. Having a psychometrically and adjusted instrument for older persons with reduced cognition that concerns their chances of exercising self-determination would be helpful. Therefore, the next step could be to test the IPA-O on people with mild reduced cognition.

Finally, more qualitative and quantitative studies focusing on older people's self-determination and capabilities would be interesting. Questions in these studies could address older people's views on capabilities and which capabilities that enhance the possibility to exercising self-determination. Healthcare professionals' perspective on older people's capabilities also needs to be explored.

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