Maintaining self-determination in palliative phase in residential care

A model to facilitate person-centred care for older persons

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To Niklas
Alvin
Elsa

Allow yourself to dream and you will discover
that destiny is yours to design.
Jacqueline Stavros

Abstract

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

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

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

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

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

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

Keywords

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

Sammanfattning på svenska

Att vara självständig och bestämma över sitt eget liv är en självklarhet för de flesta vuxna människor i Sverige. Dock kan ålder och sjukdom medföra beroende av andra för att klara sitt dagliga liv vilket i sin tur kan innebära minskade möjligheter till självbestämmande. Majoriteten av äldre personer som behöver hjälp i vardagen får det i sitt ordinarie boende men de som behöver mer omfattande stöd kan beviljas en lägenhet på ett särskilt boende för äldre. På särskilt boende finns personal tillgänglig dygnet runt för att stödja äldre personer att upprätthålla så mycket självständighet som möjligt trots fysiska eller kognitiva funktionsnedsättningar. Den vanligaste orsaken till flytt är problem i samband med demenssjukdom men många har också flera samtidigt förekommande fysiska sjukdomar som hjärt-kärlsjukdom, diabetes och cancer. Medianåldern för flytt till särskilt boende är 86 år och många har en kort förväntad överlevnad eftersom de befinner sig i palliativt skede redan vid inflyttningen. Boendetiden varierar men två år efter inflyttningen har hälften avlidit och efter fyra år finns mindre än 20 % av männen och 30 % av kvinnorna kvar i livet. Lagstiftningen säger att personer på särskilt boende ska få leva värdiga liv och känna välbefinnande och att deras självbestämmande ska respekteras. Tyvärr måste de boende ofta anpassa sig till rutiner och bemanningsnivåer vilket medför att de förlorar inflytande över sin vård och omsorg. Avsikten med avhandlingen var att undersöka upplevelsen av självbestämmande och utveckla en modell för att främja självbestämmande i palliativt skede på särskilt boende. Självbestämmande definieras som att ha möjlighet att, med eller utan andras stöd, fatta och genomföra beslut som är i linje med den egna viljan.

Avhandlingen har ett teoretiskt ramverk som består av ett relationellt synsätt på autonomi och personcentrering. Ett relationellt synsätt på autonomi innebär att en person kan betraktas som självständig och självbestämmande trots att han eller hon behöver andras stöd för att fatta och genomföra sina beslut. Personcentrering handlar om att vården och omsorgen utgår från den äldre personens upplevelse och kunskap om sin situation och att planering, utförande och utvärdering av vården sker tillsammans med personalen som bidrar med sin professionella kunskap.

Avhandlingen består av fyra delstudier som alla genomfördes på särskilt boende. De tre första studierna låg till grund för modellen som utvecklades i den fjärde studien samt till en syntes om kontextspecifika problem med självbestämmande i palliativt skede på särskilt boende.

I den första delstudien intervjuades 20 personer som bodde på särskilt boende, och bedömdes vara i sitt sista levnadsår, om innebörden av självbestämmande. Resultatet visar att de boendes upplevelse av att leva ett värdigt liv hotades av bristande självbestämmande. Sjukdom, åldrande och beroende tvingade de boende att anpassa sig till nya omständigheter vilket fick dem att uppleva en förändrad självbild, känna sig ensamma, förlora inflytande över sina liv och förminska sina behov. För att navigera i den nya situationen försökte de ta kontroll över sina liv, hålla fast vid sina identiteter och ta hjälp av betrodda personer. De boende ville bli betraktade som personer och inte som arbetsuppgifter men beskrev att personalen inte alltid hade tid eller intresse att lära känna dem. För att bevara sin känsla av värdighet behöver de boende känna sig respekterade och tillmätas samma värde som personalen.

I delstudie två deltog 112 boende som bedömdes vara i sitt sista levnadsår och 83 av deras närstående i en enkätundersökning om upplevelsen av vårdkvalitet och självbestämmande på särskilt boende. Enkäten Kvalitet Ur Patientens Perspektiv (KUPP) användes. I majoriteten av frågorna fanns en signifikant skillnad mellan hur de boende och deras närstående upplevde att det var i verkligheten och hur de ville att det skulle vara. Lägst medelvärden fick frågor om stöd vid ensamhet, oro, ångest eller rädsla samt möjlighet att vistas utomhus och personalens tid för samtal. I studiespecifika frågor om självbestämmande i vardagen och i livsavgörande situationer skattade både boende och närstående att personalen inte vet hur de boende vill ha det i vardagen eller i frågor om till exempel sjukhusinläggning och hjärt-lungräddning. De boende trodde att deras närstående skulle kunna fatta beslut utifrån deras vilja om de skulle ta över beslutsfattandet medan de närstående var mer osäkra.

I tredje delstudien intervjuades 20 personer från tre olika personalkategorier: sjuksköterskor, undersköterskor och läkare om hur de upplevde de boendes självbestämmande. Resultatet visade att självbestämmande är kopplat till de boendes identitet. Faktorer som stärkte självbestämmandet och därmed de boendes identitet var att deras beslutsfattande underlättades, andra handlade i enlighet med deras vilja och agerade talespersoner när det behövdes. Faktorer som underminerade självbestämmandet och därmed de boendes identitet var de boendes beroende av andra, att andra satte villkoren till exempel att rutinerna gick före de boendes individuella önskemål, otillräcklig kommunikation till exempel i utebliven planering inför livets slut, samt att andra kränkte de boendes personliga integritet.

I den fjärde delstudien deltog totalt 27 personer. En modell för att främja självbestämmande togs fram genom deltagande design i ett samarbete mellan forskargruppen och olika grupper av intressenter (boende, personal, chefer samt experter på demens, äldrevård och forskning). Utgångspunkten för modellen var de strategier för att främja självbestämmande som framkommit i de tre första delstudierna samt i en litteraturgenomgång. Appreciative Inquiry användes för att ha en positiv ingång i utvecklingen av modellen och fokusera på de arbetssätt som redan fungerade. Dessa arbetssätt utvecklades vidare i fokusgruppsdiskussioner. Det teoretiska ramverket med relationell autonomi och personcentrering användes för att ytterligare förankra modellen teoretiskt. Resultatet blev modellen Att fatta och genomföra beslut- livet ut. Modellen har ett kärnbudskap: På mitt sätt, i min takt, med hjälp av dig. Kärnbudskapet backas upp av sju kategorier med strategier som främjar självbestämmande nämligen: Se mig som en kompetent person, Visa mig professionell omtanke, Möt mig i en trygg relation, Ge mig möjlighet till en meningsfull och trygg dag, Stöd mig i att vara självständig, Låt mig ha makt över mitt liv och Hjälp mig att planera min sista tid i livet. För svensk version av modellen, se Appendix.

För att kartlägga de kontextspecifika problem med självbestämmande i palliativt skede som finns på särskilt boende gjordes en syntes av utvalda resultat från de tre första studierna. Syntesen visar att de boende befinner sig i en sårbar situation eftersom deras fysiska och kognitiva funktionsnedsättningar gör att de dels bli beroende av andra och dels får reducerat självbestämmande. Detta leder till att de riskerar att förlora kontrollen över sina egna liv och att deras självbild liksom känslan av att leva ett värdigt liv hotas. En övergripande tolkning är att deras identitetsvärdighet utmanas. Identitetsvärdighet beskrivs i litteraturen som en slags grundläggande självrespekt. Syntesen och de enskilda studierna visar att reducerat självbestämmande har allvarliga konsekvenser för de boendes syn på sig själva och deras känsla av att leva ett värdigt liv. Slutsatsen är därför att det finns goda grunder att arbeta för att personer på särskilt boende ska få vara så självbestämmande som möjligt. Detta kan bland annat ske genom att tillämpa modellen Att fatta och genomföra beslut- livet ut.

List of papers

This thesis is based on the following studies, referred to in the text by their Roman numerals.

I. Schenell, R., Henoch, I., Strang, S., & Ozanne, A. (2020). Struggling for a dignified life: The meaning of self-determination in palliative phase in residential care. *International Journal for Human Caring*, *24*(2), 147–157. doi:10.20467/HumanCaring-D-19-00029

II. Schenell, R., Ozanne, A., Strang, S., & Henoch, I. (2019). Residents' and family members' perception of care quality and self-determination in palliative phase in residential care. *Palliative and Supportive Care*, *18*(1), 69–81. doi:10.1017/s1478951519000178

III. Schenell, R., Ozanne, A., Strang, S., & Henoch, I. (2019). Balancing between maintaining and overriding the self: Staff experiences of residents' self-determination in the palliative phases. *International Journal of Older People Nursing*, *14*(4), e12255. doi:org.ezproxy.ub.gu.se/101111/opn.12255

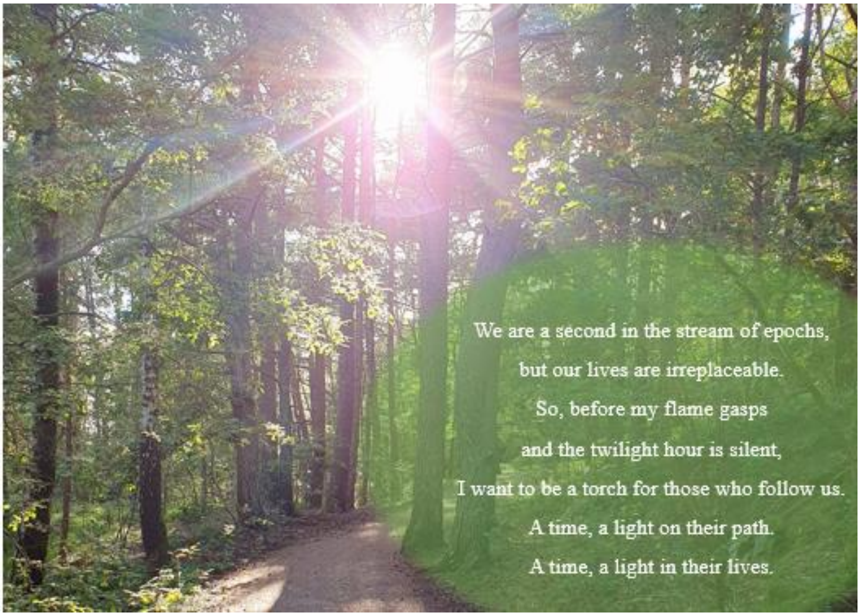
IV. Schenell, R., Ozanne, A., Strang, S., & Henoch, I. (2020). To make and execute decisions throughout life: A person-centred model that facilitates self-determination in residential care, developed through participatory research. *Applied Nursing Research*, *55*(October). https://doi.org/10.1016/j.apnr.2020.151318

Contents

Abbreviations

AI	Appreciative inquiry
PR	Perceived reality
QoC	Quality of care
QPP	Quality from the patients' perspective
SFS	Svensk Författningssamling (Swedish Code of Statutes)
SI	Subjective importance
SOU	Statens Offentliga Utredningar (The government's official investigations)
WHO	World Health Organisation

Introduction



We are a second in the stream of epochs,
but our lives are irreplaceable.
So, before my flame gasps
and the twilight hour is silent,
I want to be a torch for those who follow us.
A time, a light on their path.
A time, a light in their lives.

Text translated from Björn Afzelius Ljuset. Photo by Ramona Schenell

The majority of people dying in our society are older persons with slowly progressing, chronic disease or multiple coexisting problems that result in multisystem failure (Ferrell & Coyle, 2010). However, being close to the end of life in old age is not just about being severely ill: it is also to have lived a long life. It is to have travelled through the years from being a totally dependent infant, to have become a child and an adolescent who has learned from but also liberated itself from others, and to have transitioned into adulthood. It is to have lived a unique life as a grown-up, as a middle-aged person, and finally to have reached a high age with all these experiences gathered in one body and mind. It is to experience new things still and to continue to develop as a person. Because of these experiences, it is to have the capacity to be a torch that yet for another time, can spread light on the path of others and into others' lives. However, as Rodgers and Neville (2007) state, ageing is sometimes seen as a social problem rather than a natural process, and older persons are portrayed in terms of their functional status and as a set of health problems instead of being recognised as individuals with rights, needs and desires.

In this thesis, the old person is recognised as a unique individual, but also as a part of a context and as a partner in different relationships. The focus of the thesis is on autonomy or self-determination for persons in residential care in the palliative phase (life expectancy of maximum one year). The experience of autonomy is tied to the present as it varies in different periods of life and because of specific circumstances, such as illness and dependency. In palliative care, autonomy is fundamental as it represents the opportunity to build one's own life until the very end (Lavoie et al., 2011), an opportunity that should be provided to all older persons nearing the end of their lives.

Background

Ageing population

Around the globe, the population is ageing, and in 2018, for the first time in history, persons aged 65 years or over outnumbered children under five years of age. By 2050, they will also have outnumbered adolescents and youths aged 15 to 24 years. Life expectancy at birth reached 72.6 years for the world's population in 2019 and is expected to increase to 77 years by 2050. However, in the least developed countries, life expectancy is lower compared to the global average due to high levels of child and maternal mortality, conflicts and violence, and the continuing impact of the HIV epidemic (United Nations, 2019). In Sweden, life expectancy at birth is considerably higher than the global average at 84.7 years for women and 81.3 years for men (Statistics Sweden, 2020a), and the number of persons 80 years and over is estimated to increase by 50 per cent by 2050 (Statistics Sweden, 2020b).

There has not only been a major increase in longevity in recent decades, but also been improvements in the quality of human ageing, especially for the younger old, persons in the third age. The third age is a conceptualisation of a healthy and independent life after retirement beyond middle age and is characterised as a time of agency and action but without the responsibilities of younger adulthood (Radtke et al., 2016). Older persons can now approach high age in a more healthy and vital condition than previous generations due to advanced medical practice, an improved economic situation, and increased psychological resources such as reading, writing and computer literacy (Baltes & Smith, 2003). Positive ageing is thus not only about adding more years to life, but also about high levels of physical and psychological function, as well as active engagement with life (Brownie & Horstmanshof, 2012).

However, living a long life has its costs, and the oldest old who have entered the fourth age face physical and cognitive dysfunction, illness, dependency, negative psychological effects such as loss of identity and sense of control, and impending death. In developed countries, the beginning of the fourth age has been calculated to the chronological age of 80–85 years (Baltes & Smith, 2003). This is consistent with the Swedish condition, as shown in a longitudinal study that followed persons from entering the fourth age, that is, from the day they could not manage their daily living by themselves and were granted social services or healthcare in their home or moved to residential care. These ‘debutants’ in elderly care had a mean age of 84 years; the majority received help in their own homes, but one in five moved directly to residential care. The duration of the fourth age was relatively short, as more than half of the debutants had died after three years and after six years only one in four was still alive (Lagergren, 2013). Another Swedish study found that when older persons apply for social services for the first time, they already have extensive care needs which have often been met by family members for several years (Larsen, 2016).

This thesis comprises persons that have reached the fourth age, not only in that they have a high chronological age but also in that they have cognitive or physical limitations that entail dependency on others to such an extent that they have been granted accommodation in residential care.

The frail and ill older person

Becoming an old person is associated with frailty, this being a clinical expression that implies concern about older persons’ vulnerability and future perspectives. Frailty is often described as a consequence of age-related decline in several physiological systems which collectively make the person vulnerable to sudden changes in health status triggered by minor stressor events (Clegg et al., 2013). In a more holistic view, frailty is not only a consequence of physical decline but also of losses in the psychological and social spheres (Gobbens et al., 2010). Frailty is thus a complex and multidimensional concept, where several aspects such as bodily weakness, dementia, dependency, lack of motivation, and absence of close relations interact and affect the extent to which a person is frail (Gustafsson et al., 2012). Frailty is connected to loss of decisional capacity and independence at the end of life (Grenier, 2006), and being regarded as frail and vulnerable is in itself a threat, as it can cause others to infantilise and patronise older persons and prevent them from exercising control over their lives (Tuckett, 2007). The development of frailty in older persons can be temporarily stopped or slowed, but it will eventually lead to the older person’s death (Gustafsson et al., 2012).

High age is also associated with chronic diseases, which are diseases of long duration and generally slow progression. The four main types of chronic disease are cardiovascular disease, cancer, chronic respiratory diseases and diabetes (United Nations, 2013). Older persons with chronic disease have greater need of hospital care and social services than people without chronic diseases. In Sweden, 85 per cent of the population 65 years or older have at least one chronic disease and 66 per cent have two or more. For persons in municipal care, the rate of chronic disease is even higher at 90 per cent (Swedish Agency for Health and Care Services Analysis, 2014).

Another chronic disease that is increasing worldwide because of longevity is dementia. In 2015, about 47 million people were living with dementia, and the number is projected to triple by 2050. Dementia causes the loss of cognitive abilities, changes in behaviour, neuropsychiatric symptoms, problems with activities of daily living, dependency, and impaired decision-making capacity (Livingston et al., 2017). Sweden is following the global trend with increasing numbers of persons affected by dementia, and the prevalence is expected to increase further as the many persons born in the 1940s are now reaching high age (National Board of Health and Welfare, 2017). Problems in relation to dementia are the most common cause for older persons to move to residential care (SOU 2017:21).

Residential care in Sweden

Swedish municipalities are obliged to provide special housing with service and care for older persons who need support in their daily living (SFS 2001:453). This responsibility can be outsourced (SFS 2017:725), and nearly a fifth of residential care facilities are operated by actors other than the municipality (National Board of Health and Welfare, 2020b). There are a number of accommodations with varying level of services available for older persons in Sweden, but the residential care referred to in this thesis concerns permanent housing in group settings with access to professional care and healthcare around the clock, managed by municipal or private operators.

Most residential care facilities offer residents their own apartments of about 30–40 square metres with one room, a hall, and a bathroom (Swedish Association of Local Authorities and Regions, 2020). In addition to their own apartment, there are also common areas where residents can interact, and areas for cooking and daily activities may partly be merged into these shared spaces of the facility (National Board of Housing Building and Planning, 2020). The residents pay rent for their apartments as well as fees for care and meals (Swedish Association of Local Authorities and Regions, 2020). Accommodation in residential care is means tested and the trend for many years has been that older persons are primarily granted care in their ordinary homes. This is a result of the increased health and functional capacity amongst older persons, as well as deliberate political decisions to steer resources from institutional services to home care services. As a consequence, the number of persons who are granted accommodation in residential care is decreasing despite the growth of the older population (National Board of Health and Welfare, 2020b). The rise of the threshold for accommodation in residential care might explain why persons are older and have shorter survival time when moving in compared to ten years ago (Sund Levander et al., 2016).

During 2019, a total of 108.500 persons were living in residential care; 66 per cent were women and 34 per cent men (National Board of Health and Welfare, 2020a). Women comprised the majority in all age groups except the lowest ages (see Table 1). The median age in 2017 when moving in was 86 years (National Board of Health and Welfare, 2019). The needs of the residents are very varied, as some live for several years in the facility and others die just a few days after moving in (Schön et al., 2016; Smedbäck et al., 2017). The median length of residency is two years, but 20 per cent of the residents have died six months after moving in. After four years, 82 per cent of the men and 72 per cent of the women are deceased (National Board of Health and Welfare, 2018).

Table 1. Women and men residing in residential care in Sweden, 31 October 2019 (National Board of Health and Welfare, 2020a)

Age	👵	👴	👵👴
65-74 years	4.076 (46%)	4.729 (54%)	8.805
75-79 years	5.492 (55%)	4.567 (45%)	10.059
80-84 years	9.296 (62%)	5.600 (38%)	14.896
85-89 years	13.965 (70%)	6.095 (30%)	20.060
90-94 years	14.086 (75%)	4.577 (25%)	18.663
95-	7.938 (82%)	1.796 (18%)	9.734
Total	54.853 (67%)	27.364 (33%)	82.217

Most persons who live in residential care need extensive care and healthcare. The majority have multiple chronic diseases and cognitive impairments (National Board of Health and Welfare & Swedish Association of Local Authorities and Regions, 2017). There are no overall national statistics on the types of unit in residential care, but it is estimated that about 30.000 persons reside permanently in special care units for persons with dementia. However, many persons with dementia reside in general care units and the total amount of persons with dementia in residential care is estimated to approximately 70 per cent (National Board of Health and Welfare, 2014). A national study found that 92 per cent of persons in residential care had neuropsychiatric symptoms such as agitation, depression, hallucinations, anxiety, and aberrant motor behaviours. More than half of the residents in general units had cognitive impairments, and the prevalence of neuropsychiatric symptoms was significantly higher for those who had cognitive impairments or who resided in special care units for dementia. Furthermore, the findings showed that 48 per cent of the residents had pain and 56 per cent were dependent in terms of the activities of daily living, bathing, dressing, transferring, toileting, eating and continence (Björk et al., 2016).

The day-to-day care in residential care facilities is mainly provided by enrolled nurses with upper secondary care education, but there are also staff with lower education. During weekdays, about 80 per cent of the care staff is estimated to have appropriate care education, ranging between 43 per cent and 100 per cent in different municipalities. The numbers are slightly lower during weekends. On average, three care givers are responsible for ten residents on weekdays, while the corresponding number for weekends is 2.5 care givers (National Board of Health and Welfare, 2019). There is no specified minimum number of care givers for residential care facilities, but the residents should have access to staff around the clock who, without delay, can pay attention to their need for support and assistance (SFS 2001:937). Healthcare in residential care is delivered by registered nurses, physiotherapists, occupational therapists and nutritionists, and 92 per cent of the residents receive health care interventions (National Board of Health and Welfare, 2020b). Registered nurses are on average responsible for 25 residents each on weekdays and 150 on weekends (National Board of Health and Welfare, 2019). Physicians are not included in the municipal healthcare responsibility (SFS 2017:30) but are located in the primary healthcare centres and do home visits to the persons residing in residential care when necessary.

Palliative approach to care

There are about 90.000 deaths each year in Sweden, and the second most common place of death, after hospitals, is residential care. The probability of dying in residential care is highest in the oldest age groups. In the group aged 80–89 years, 45 per cent die in residential care, while in the age group 90 years and over, the corresponding number is 62 per cent. Compared to other countries, Sweden has a larger proportion of older persons dying in residential care (Håkanson et al., 2015).

According to the Swedish Palliative Register, the majority, 80 per cent of the deaths in residential care are expected, and the most common underlying causes of death are circulatory diseases (42%), dementia (23%), cancer (15%) and respiratory disease (5%) (Smedbäck et al., 2017). The high proportion of expected deaths in residential care indicates that there is also a high proportion of palliative care needs in these facilities (Morin et al., 2016).

According to the World Health Organisation (WHO), most adults in need of palliative care have chronic diseases (WHO, 2020a). The WHO defines palliative care as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual." The WHO also states that palliative care is applicable early in the course of an illness and in combination with life-prolonging treatments (WHO, 2020b).

Although there are specialised units and teams whose main activity is to provide palliative care for persons with complex symptoms, palliative care should be available for all persons with life-threatening diseases regardless of where and by whom the care is provided. The level of non-specialised palliative care is called the palliative care approach and can be described as a way to integrate palliative care principles, such as a focus on autonomy, dignity, quality of life, patient-healthcare provider relationships, and communication, into settings not specialising in palliative care (Radbruch & Payne, 2009). In Sweden, the palliative approach is defined as making a professional assessment of the patient's condition, needs and wishes based on physical, mental, social and existential dimensions. Furthermore, the approach means that possible interventions are preceded by a balance of pros and cons for the patient's wellbeing (Regional Cancer Centres, 2016).

A key characteristic of the palliative approach is to ensure that the needs of persons with chronic life-limiting conditions and their families are addressed both early on and throughout the illness trajectory. This requires the ability to understand different illness trajectories and to identify where persons are on these trajectories (Sawatzky et al., 2016). Three main illness trajectories with fatal outcomes have been identified. 1) Long maintenance of good physical function capacity despite a fatal disease, typically cancer, followed by a rapid decline leading to death. 2) Slow decline in physical capacities punctured by serious exacerbations that might lead to a sudden death. If the person survives the exacerbation, the level of physical function might only decrease a little each time. Typical diagnoses are heart failure and emphysema. 3) Long-term dwindling of physical function, with frailty or dementia causing extensive care needs for many years. Death often follows a minor physical challenge such as influenza, a fracture, or a urinary infection. These three different trajectories, comprising both rapid and slow decline, indicate a need for different types of arrangement around severely ill persons and their families (Lynn, 2005). Assessments and treatments must be individualised and based on the recognition that death is inevitable but may take a long time to occur (Sawatzky et al., 2016).

The prevalence of symptoms increases over time for persons in residential care (Estabrooks et al., 2015), and for most persons with life-threatening conditions the treatment goal will gradually shift from prolonging life to preserving the quality of life (Radbruch & Payne, 2009). This indicates that the WHO statement about palliative care is applicable early in the course of illness and, in combination with life-prolonging treatments (WHO, 2020b), is beneficial for persons in residential care. When disease-specific treatment no longer has a life-prolonging effect and death is expected within a foreseeable period, there is a transition to end-of-life care (see Figure 1). By identifying the time for transition to end-of-life care and providing information about the probable course of the illness, the needs and wishes of the ill person and the family for the last period of life can be addressed and met (Regional Cancer Centres, 2016).

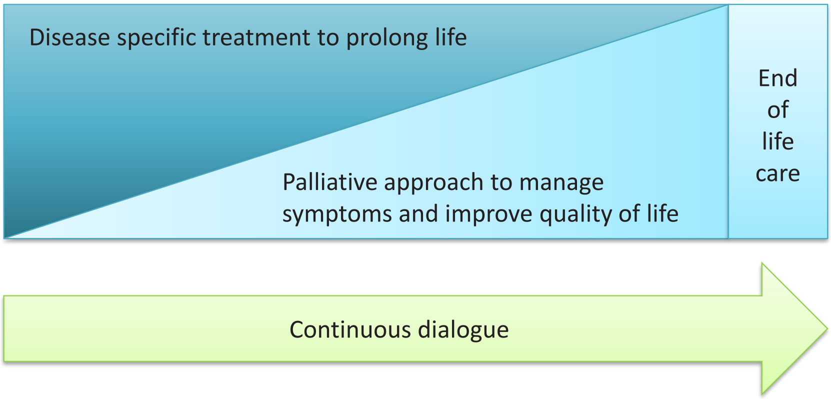


Figure 1. Parallel disease-specific treatment and palliative approach

As most persons die from slowly progressing chronic diseases, there ought to be time to address questions about needs and wishes, not only in the transition to end-of-life care, but earlier on in the illness trajectory. A continuous dialogue about the progression of the illness, hopes, fears and understandings will help the healthcare professionals to respect the person's autonomy and integrity and enable decisions to be made in line with the person's values (Regional Cancer Centres, 2016). However, when applying a palliative care approach in the management of chronic diseases, healthcare professionals must be aware that these persons might not identify themselves as persons with an illness that will lead to death (Sawatzky et al., 2016). Although many older persons with chronic diseases are aware of their short life expectancy, they might not want to dwell on it and destroy the hope they need to enjoy their day-to-day lives (Gott et al., 2008). Dame Cicely Saunders, who founded the modern hospice philosophy, highlighted the need and right of dying persons to preserve their self and exercise self-determination despite illness. She stated that dying persons have the right to be seen as whole persons, to identify their own needs, and to maintain autonomy in decision-making as far as possible. Furthermore, she stated that dying persons should be met where they are in relation to their needs and how they perceive them (Ternestedt, 2017). These statements show that self-determination and person-centredness are important parts of the palliative approach.

Autonomy and self-determination

The concepts of autonomy and self-determination are closely related to each other and are both described in the online versions of the Cambridge Dictionary, the Oxford Learner's Dictionaries, and Collins Dictionary as the right and the ability to make one's own decisions and act without influence and control by others. In this thesis, self-determination is the main concept, not because it differs a lot from autonomy, but because it is a less abstract and more commonly used term in the everyday language among residents and staff in residential care facilities and it is used in Swedish laws directing residential care services. However, to explore the concept of self-determination, there is a need also to explore the concept of autonomy, as self-determination is often described as synonymous with or an important part of autonomy.

The word autonomy derives from the Greek *autos* (self) and *nomos* (rule, governance or law), and originally referred to the state of nations as being self-governed and not dependent on or ruled by other nations (Beauchamp & Childress, 2013). Autonomy is both a status and a capacity. As a status, autonomy refers to the idea that persons are entitled to exercise self-determining authority over their own lives. As a capacity, autonomy refers to the capacity to make decisions and act based on values, preferences or commitments that are authentically one's own

(Mackenzie, 2019). The precise meaning of an ‘autonomous person’ is disputed, but two conditions seem to be essential in all theories of autonomy: liberty and agency. Liberty is about being independent from controlling influences, while agency is about having the capacity for intentional action. To respect a person’s autonomy is to acknowledge their right to hold views, make choices and act on their values and beliefs. A person with diminished autonomy is thus controlled by others or is incapable of deliberating or acting according to their own desires or plans (Beauchamp & Childress, 2013).

Autonomy is a central value in Western societies (Perkins et al., 2012; Sandman, 2005), and since the 1970s the concept has grown stronger and developed in the context of healthcare, gradually replacing the paternalistic physician-patient relationship where physicians could withhold information and make decisions based on their own ideas on the patient’s best interest. The shift has positioned the physician as a clinical expert who provides information to enable patients to make their own healthcare decisions (Walter & Ross, 2014). Decision-making based on the physician’s information is called informed consent and is described as the principal mechanism for respecting patient autonomy in clinical settings. It represents an individualistic view of autonomy (Sherwin & Winsby, 2011) consistent with the Western cultural values emphasising self-determination, liberty of choice and freedom from interference by others (Perkins et al., 2012). Informed consent requires a self-reliant patient who can make rational decisions and who is fully informed about diagnosis, prognosis and treatment options (Walter & Ross, 2014).

Sandman (2005) describes autonomy as consisting of four different aspects, of which self-determination (making decisions) is the most central. The other aspects are freedom (having valuable alternatives), desire fulfilment (the actual outcome of the decision), and independence (being involved in the execution of the decision). When defining self-determination, Sandman focuses on the decisional aspect and not the executional. This is also the case in a concept analysis of self-determination for frail older persons by Ekelund et al. (2014). Here, self-determination is defined as a process where the person has control, rights, knowledge and the ability to make decisions based on free choice. While Sandman (2005) states that being regarded as self-determinant does not require the ability to execute decisions independently, Collopy (1988) found that there is a risk of older persons losing decisional power if they cannot also execute their decisions by themselves. Furthermore, Collopy (1988) describes autonomy in long-term care as comprising a number of polarities, including decisional versus executional autonomy and direct versus delegated autonomy. Decisional autonomy is defined as the ability and freedom to make decisions without external coercion or restraints, while executional autonomy is the ability and freedom to act on these decisions. Direct autonomy is defined as residents deciding and acting independently with strong authorial control, while delegated autonomy is giving authority to others to decide and act in their place. According to Collopy (1988), self-determination might survive longer in older persons if they have the opportunity to delegate certain decisions and actions. In agreement with Collopy's view of autonomy, Bakitas' (2005) definition of self-determination in palliative care also comprises decision-making, activities and support: "A process of decision-making that includes personal appraisal, the support and advice of others (family, health-care professionals), and activities that result in successful life closure and peaceful death" (Bakitas, 2005, p. 33). Building on these definitions, self-determination in this thesis is defined as having the opportunity, with or without the assistance of others, to make and execute decisions that are in line with one's own wishes and values.

Self-determination in residential care

When dependent on others, the assistance available in residential care facilities can contribute to a more autonomous life compared to that in the ordinary home (Sandman, 2007). Autonomy, control and preservation of one's own habits and values are important factors to enable older persons to feel at home in residential care (Rijnaard et al., 2016). When residents have control over daily issues such as whether to participate in social activities and being able to decide over the rhythm of their day, what to eat or how to furnish their rooms, they feel self-determining (Nakrem et al., 2011), which is foundational to the experience of wellbeing (Vinsnes et al., 2012). Being involved in decisions about their everyday life and care can also ease the negative effects of dependency and bring about a feeling of managing their own lives (Saarnio et al., 2016).

The right to self-determination in residential care is highlighted in the Social Service Act and in the Health Care Act, which both stipulate that care should be given with respect for the person's dignity, self-determination and integrity (SFS 2001:453; SFS 2017:30). There is also the Patient Act, which aims to strengthen and clarify the patient's position within healthcare activities and to promote integrity, self-determination and participation (SFS 2014:821). Furthermore, persons residing in residential care facilities are, like all other persons in Sweden, protected from forced physical interventions and deprivation of liberty by the Constitution (SFS 1974:152). Thus, all laws regulating residential care are based on voluntary consent, which means that measures cannot be taken against the will of the residents unless there is an emergency situation that poses danger to life or health (National Board of Health and Welfare, 2013). Nevertheless, various types of constraint such as bedrails, belts, electronic surveillance, locked doors and medical sedation are being used in residential care. Despite such constraints being prohibited and not being used in connection with danger to health and life, they are not always regarded by staff as violating residents' human rights and freedom as the intention of using them is to protect the residents from harm (Lejman et al., 2013).

In order to consolidate a conscious approach to enable older persons to live according to their identity and personality, there are legislated core values in the Social Service Act. The core values are meant to permeate all activities in elderly care, and include the right to live a dignified life and feel wellbeing. Living a dignified life comprises things such as privacy and bodily integrity, self-determination, participation and individual adaption. In the core values, self-determination is described as the right to influence both the content and the provision of care. This includes, for example, when and what to eat, when to rise and when to go to bed, and to have a say in which staff should provide the support needed (Government Bill 2009/10:116). In the annual Swedish investigation into older persons' experiences of elderly care in 2019, almost 60 per cent of those residing in residential care did not experience that they could influence how and when support was given and did not think that the staff had enough time to perform their work (National Board of Health and Welfare, 2020c). In many cases, older persons in residential care must adapt to staffing levels and the staff schedule instead of the other way around (Health and Social Care Inspectorate, 2013). Even though staff recognise the importance of providing choices and of documenting and accommodating residents' preferences, their capacity to facilitate choice is restricted as their work follows routines and direct care tends to cluster into peak times (Murphy & Welford, 2012).

The institutional character of the residential care facility with organisational regulations and norms restricts residents' decision-making (Vaismoradi et al., 2016) and residents do not feel treated as individuals with their own personalities, values and desires (Murphy & Welford, 2012). The big asylums with paternalistic and institutionalising practices described by Goffman (1968) as "total institutions" are gone but the social processes that characterised these institutions remain. Total institutions can be described as places where people with a similar social situation, for example, those in need of care, live separate from the rest of the society. Activities are typically conducted in large groups of people at predetermined times, with one activity following the other in a carefully planned routine which often meets organisational rather than individual needs. It becomes difficult for the residents to pursue their own interests and make choices as the organisation's bureaucratic control restricts their self-determination, autonomy and freedom (Goodman, 2013). Adherence to a fixed institutional schedule for daily activities such as socialising, meals and sleep is a risk factor for poor quality of life in residential care (Vinsnes et al., 2012). Although the majority of the residents state that they feel satisfied with the care and healthcare (National Board of Health and Welfare, 2020c) it does not mean that they receive the care to which they are entitled. The residents' dependency on the persons who deliver the care must be considered when interpreting their responses (Health and Social Care Inspectorate, 2013). Residents are often loyal to the staff as they regard them as victims of organisational constraints and do not want to blame them for any shortcomings. As a result, residents take responsibility for the staff workload by adapting to the routines of the facility and downplaying their demands (Hedman et al., 2017; Holmberg et al., 2019).

Theoretical framework

This thesis has a theoretical framework of relational autonomy and person-centred care. These two concepts are intertwined and have a common point of departure in the assumption that persons, throughout their lives, are involved in social relationships and communities which define their identities and ground their values (Ells et al., 2011; Kristensson Uggla, 2014; Mackenzie, 2019). The relationships and communities can be voluntarily chosen, such as friends and association memberships, or imposed, such as those relating to relatives, gender, ability and class (Mackenzie, 2019).

Relational autonomy

In healthcare, the understanding of autonomy has for the last five decades been individualistic and based on the patient's right to make decisions without interference from others. In this view of autonomy, independence is of great value and healthcare providers are considered to act paternalistically if they get involved in the decision-making process in ways other than providing information (McCormack, 2017; Walter & Ross, 2014). This view of autonomy that isolates the ill person in their decision-making works against the collaborative nature of person-centred practice (Ells et al., 2011). Instead of just offering information, the relational view suggests that autonomy can be better enhanced if healthcare providers assist in reflecting upon preferences, values and how different decisions might affect the person's life (Dodds, 2000; Walter & Ross, 2014). In the relational view, autonomy is to be understood as reciprocal and collaborative (Donchin, 2000), and therefore important people from the person's own support system should be invited into the decision-making process, especially in the context of ageing and dependence (Cole et al., 2014). The social constructs that surround the person are considered factors of influence as they can both enable and hinder autonomy (Mackenzie, 2019). Social contexts need to be fair and supportive to enable relationships that allow persons to participate in decision-making, ask questions, voice feelings, take responsibility and thereby develop and exercise their autonomy (Dodds, 2000).

In residential care, autonomy can be compromised due to illness, frailty and dependency, but that does not imply a total loss of autonomy as autonomy, in the relational view, is a matter of degree (Dodds, 2000; Mackenzie, 2019). In this perspective, the person is seen as having interrelated capacities and vulnerabilities, making autonomy a scalar concept where the person is more or less autonomous, not possessing complete autonomy or lacking autonomy altogether (Gómez-Vírseda et al., 2020). Persons with reduced cognition usually have some capacity for understanding, decision making, and expressing their preferences (Beauchamp & Childress, 2013; Ibrahim & Davis, 2013), but the individualistic view of autonomy, which requires independent decision making, excludes persons with dementia from being regarded as autonomous (Boyle, 2008). The focus on particular characteristics, such as the older person's inability to make decisions, and not the person as a whole, increases the risk of the person being reduced to a thing (McCormack, 2004). To respect personal autonomy can in some contexts mean to build up or maintain others' capacity for autonomous choice and to remove hindering factors. Healthcare providers must disclose information, ensure understanding and voluntariness, and foster adequate decision-making (Beauchamp & Childress, 2013). This emphasises the importance of a relational view of autonomy, as it provides a framework that regards the person as a unique individual and at the same time as belonging to a context and allows for partnership in decision-making.

Person-centredness

In the 1960s, nursing theorist Ida Jean Orlando stated that the purpose of nursing is to supply the required help so that the patient's needs are met. One of Orlando's guiding principles was that the need for help must be explored together with the patient to be valid. Although it is natural for the nurse to automatically interpret, react and perform actions based on the patient's behaviours, these actions might not fulfil the purpose of being helpful to the patient. Instead of acting automatically, the nurse should continuously reflect on what actions might be needed and verify these thoughts with the patient. This makes the nursing process deliberate and able to adjust to each individual person and situation (Orlando, 1961).

The ability to engage in reflective evaluation of action is, according to a number of philosophers, what distinguishes humans from other creatures. This ability enables the person to derive a set of principles that guide decision-making throughout life. Because of reflexivity, persons are capable of seeing life as a whole and able to make choices that are their own (McCormack, 2017). In nursing science, the human being is regarded as a unique, free individual, who has the ability to make choices and take responsibility (Swedish Society of Nursing, 2011). This is also emphasised by Ricœur, who stated that a human is to be understood as a capable person, homo capax. The capable person can rank preferences, act for reasons, and take responsibility for actions. However, the capability is not without limitations as a person is also vulnerable, and human action is an interaction between intentions, causes and coincidences (Ricœur, 2011). Taking responsibility may seem an advanced task to accomplish for some persons, for example, those with cognitive impairment. However, according to the definition of selfhood by Sabat and Harre (1992), responsibility can be as easily expressed as to use the first-person pronouns me, myself, and mine, as this demonstrates responsibility for actions, feelings and experiences as being one's own. Sabat and Harre (1992) divide selfhood into Self 1, Self 2 and Self 3. Selfhood as Self 1 is called "self of personal identity"; it means that every person has his or her own unique view of the world and that continuous events form the autobiographical narrative of our lives. Selfhood as Self 2 comprises a person's physical and mental attributes, such as height, eye colour, educational achievements, and religious and political convictions. The person's beliefs about these attributes, for example, feeling proud or ashamed of them, is also part of Self 2. Selfhood as Self 3 is constructed in relation to others and comprises the various social personas we present in different contexts in society. The same person can, for example, be a loving mother, a hot-headed football coach and a respected work colleague. As Self 3 is dependent on others' views to be constructed, it is vulnerable to others' definitions. If a person with dementia is viewed as a dysfunctional Alzheimer's patient, it will be hard for the person to construct another Self 3 (Sabat & Harre, 1992). An ill person is in a situation of dependence, and the caregiver has influence over both the concrete physical care and the person's understanding of him/herself (Swedish Society of Nursing, 2011). This constitutes a threat against Self 3 in all types of illness situations where the focus is solely on cure and treatment and not on the autobiography and how the illness is affecting the person (Sabat & Harre, 1992). To gain insight into how the ill person interprets the situation and to understand the impact of care and treatment decisions, caregivers must pay attention to the person's narrative (McCormack & McCance, 2017).

It is through narrating life experiences that persons construct and explore their personal identity and open up for others to see who they are (Kristensson Uggla, 2014). In person-centred care, the narrative is the first step to establish a partnership between the patient and the caregiver (Ekman et al., 2011) and for the caregiver to learn about the patient's beliefs and values. Knowledge about these beliefs and values helps the caregiver to support the ill person to follow the path of their own choosing and in their own way (McCormack & McCance, 2017). To allow a person to make their own decisions in healthcare is not synonymous with caregivers abdicating from their professional responsibilities (Ternestedt et al., 2017): it is rather to place equal value on the expertise of the person and the caregiver, to learn from each other, to negotiate, and to achieve commonly agreed goals through shared decision-making (Ekman et al., 2011; McCormack & McCance, 2017). Shared decision-making about treatment, care options and processes can be regarded as a manifestation of the view of the right to self-determination as essential in person-centred practice (McCormack & McCance, 2017).

Rationale

The number of older persons is increasing in Sweden as well as in the rest of the world, and there are now many persons that can enjoy the positives of having lived a long life. As old age also entails chronic illnesses and dependency, many older persons spend their last years in life in residential care. There is a need to enable continued positive ageing for persons in residential care so that they can remain engaged in life despite lowered levels of physical and psychological functions and limited life expectancy. The Swedish National Board of Health and Welfare stated that being autonomous does not assume independence of other people; instead, assistance and support can increase the degree of autonomy for persons with disabilities. Thus, being dependent on others does not need to mean that autonomy is decreased: what is crucial is the possibility of self-determination (National Board of Health and Welfare, 2016). Swedish laws stipulate that older persons should be able to live dignified lives in accordance with their own personalities and values, and that they have the right to decide about and influence their own care. Nevertheless, previous research shows that many persons in residential care experience that the routines of the facility are given precedence before their individual wishes and that the staff do not know them or their values. As self-determination is essential to the experience of wellbeing and feeling in control of one’s own life, further knowledge is needed on how to ensure person-centred care based on the residents’ own values and wishes throughout their residency. Self-determination needs to be investigated from the perspective of the residents themselves, but also from the perspective of those involved in making and executing their decisions, as autonomy must be regarded as relational in residential care. Furthermore, there is a need to provide staff in residential care with tools to facilitate self-determination for the residents. The objective of this thesis is to contribute to the knowledge about self-determination for persons with limited life expectancy in residential care and to develop a model that facilitates self-determination for these persons.

Aims

The overall aim of this thesis was to develop a model that facilitates self-determination for residents in the palliative phase in residential care, building on experiences described by residents, family members, staff, and managers.

Specific aims of each study

I. To understand the meaning of self-determination in residential care, as experienced by residents in the palliative phase.

II. To provide knowledge about the perceptions of residents in the palliative phase and their family members of quality of care and self-determination, and to detect any differences between their experiences.

III. To investigate, from the staff perspective, residents' self-determination during the palliative phase in residential care.

IV. To develop a model that facilitates self-determination for residents in the palliative phase in residential care.

Methods

Design

The thesis comprises four studies, three qualitative and one quantitative. Data for the three first studies were collected, analysed and reported separately. At a later stage, the findings of the studies were compared, combined and integrated, together with a theoretical framework, as a base for the fourth study. Furthermore, selected findings from the first three studies were synthesised to describe the context-specific problems with self-determination in residential care. The synthesis is presented in the Findings section of the thesis. An overview of the studies is provided in Table 2.

Table 2. Overview of studies

Study	Design	Participants	Data collection	Analysis
I	Qualitative	N 20 Residents	Interviews	Hermeneutic analysis
II	Quantitative Cross sectional	N 195 112 Residents 83 Family members	Questionnaire Quality from the Patient's Perspective (QPP)	Descriptive statistics Wilcoxon's signed rank test
III	Qualitative	N 20 6 Registered nurses 10 Enrolled nurses 4 Physicians	Interviews	Qualitative content analysis
IV	Qualitative Participatory	N 23 2 Registered nurses 5 Enrolled nurses 2 Physicians 4 Residents 4 Mangers 4 Scientific reference persons 2 Dementia specialist nurses	Focus group interviews, mail conversations	Constant comparative analysis

Study context and participants

All studies were conducted in residential care facilities located in a municipality in the southwest of Sweden with approximately 580.000 inhabitants. All ten city districts of the municipality were included in the studies. There are about 65 residential care facilities in the municipality, 40 of which participated, representing both municipal and private operators. To broadly explore the phenomenon of self-determination, a maximum variation purposive sample comprising participants who were expected to benefit the studies the most (Polit & Beck, 2016) was sought, and the studies were designed to involve not only the residents themselves, but also persons who had an influence over their decisional and executional autonomy. A total of 136 residents, 83 family members, 33 staff and 4 managers from general care units and special care units for persons with dementia or geropsychiatric care needs participated in the studies. In addition, six expert reference persons participated in the fourth study. An overview of participants is presented in Table 3. For studies I and II, the main inclusion criterion was that the participating residents should be in a palliative phase, defined as having a maximum life expectancy of one year. Registered nurses at the residential care facilities assisting in the recruiting procedure used the surprise question, asking themselves ‘Would I be surprised if this resident were to die within one year?’ (Lynn, 2005). If the answer was no, the resident could be invited to participate.

Study I

The participants in this study were 20 residents from general care units in 18 different residential care facilities. The participants were between 77 and 100 years old (mean 90); twelve were women and eight were men. Heart disease was the most reported illness and several residents had comorbidities.

Study II

The study participants consisted of 112 residents and 83 family members from general care units in 33 different residential care facilities. The included residents asked a family member to participate, but some residents did not have any family members or did not want to ask them to participate. In total, 83 dyads of residents and family members were included in the study. The residents were between 68 and 102 years old (mean 90); 77 were women and 35 were men. Heart disease was the most reported illness and several residents had comorbidities. The majority of the family members were children to the participating residents. Their mean age was 65 years; 52 were women and 31 were men. The majority were retired, and most visited the residents at least once a week.

Study III

The participants in this study were 20 staff members from three professions, selected as they were involved in the residents' day-to-day or medical decision-making or day-to-day care. The heads of the residential care facilities assisted in recruiting the participants. There were six registered nurses, ten enrolled nurses, and four physicians representing 13 different residential care facilities with general care units and specialised units for dementia care and geropsychiatric care. Of the participants, 16 were women and four were men and all had worked in residential care for at least three months. They were between 25 and 60 years old (mean 44) and had 2–38 years of experience (mean 18) of working in elderly care.

Study IV

The study was conducted in four phases, engaging different groups of participants. The group compositions were inspired by Elwyn et al. (2011) and consisted of researchers, stakeholders and expert reviewers. In total, 27 persons participated in the study throughout the different phases.

Research group: The four persons who had conducted the three previous studies and were responsible for the fourth study.

Advisory group: Staff from three different residential care facilities, registered nurses, enrolled nurses, and physicians, a total of nine persons, all women.

Stakeholder consultant group, residents: Four persons residing at the same residential care facility, three women and one man.

Stakeholder consultant group, residential care managers: Four managers from three different residential care facilities, three women and one man.

Scientific reference group: Four persons, three women and one man, employed at three different Swedish universities, with extensive experience of research in the fields of health and welfare theory, philosophy, improvement knowledge, person-centred care, participatory research, geriatric care, palliative care and dementia care.

Dementia-specialist reference group: Two female registered nurses specialising in dementia and employed as dementia-specialist nurses in municipal healthcare services.

Table 3. Participating residents, family members, and staff- studies I, II, III, and IV

	Residents studies I, II, IV	**Family members study II**	**Staff studies III, IV**
N=	136	83	33
Age			
Median	91	65	47
Min-max	66-102	47-86	25-63
Sex			
Men	44 (32%)	31 (37%)	5 (15%)
Women	92 (68%)	52 (63%)	28 (85%)
Time of residency			
< 6 months	15 (11%)		
6-12 months	29 (21%)		
1-2 years	30 (22%)		
2-3 years	28 (21%)		
3-4 years	12 (9%)		
> 4 years	22 (16%)		
Country of birth			
Sweden	127 (93%)	83 (100%)	
Remaining Scandinavia	5 (4%)		
Remaining Europe	4 (3%)		
Education			
Elementary school	67 (49%)	14 (17%)	
High school	40 (29)	31 (37%)	
University	28 (21%)	37 (45%)	
Other	1 (1%)	1 (1%)	
Relation to resident			
Spouse/partner		5 (6%)	
Child		64 (77%)	
Other relative		10 (12%)	
Friend		2 (2%)	
Other relation		2 (2%)	
Profession			
Registered nurses			8 (24%)
Enrolled nurses			15 (45%)
Physicians			6 (18%)
Managers			4 (12%)
Type of care unit			
General	136 (100%)	83 (100%)	22 (55%)
Dementia			19 (48%)
Geropsychiatric			2 (5%)
Care operator			
Municipal	116 (85%)		29 (88%)
Private	20 (15%)		4 (12%)

Data collection and analysis

Study I

To understand the meaning of self-determination as experienced by the residents, this study had a philosophical hermeneutic design inspired by Gadamer (2004). Data were collected in 2017–2018 by face-to face interviews supported by an interview guide with open-ended questions. To gain an understanding about the residents' situation, all interviews started by asking why the person had moved to residential care. The interview guide contained questions like: 'Can you describe a situation when you were self-determinant?' 'How did it feel to be self-determinant?'' Can you describe a situation when you were not self-determinant?' 'How did it feel not to be self-determinant?' Follow-up questions such as 'Can you tell me more about that?' 'Can you give an example?' 'What does that mean to you?' were used to deepen the narratives. The interviews lasted between 25 and 87 minutes (mean 56) and took place in the residents' apartments at the residential care facilities. All interviews were recorded and transcribed verbatim.

According to Trankell (1973), understanding is to gain insight into another person's life conditions and perspectives and to discover the circumstances under which the person must act. Using this as a starting point, the analysis was conducted in a modified four-step Gadamerian approach as described by Fleming et al. (2003).

Step 1: All interviews were read for an understanding of the text as a whole.

Step 2: Each interview was read separately and meaning units, which described the resident's life conditions and actions taken by the residents or others (e.g. fellow residents, family members, staff, or management) in relation to self-determination, were separated from the text. These meaning units formed the foundation for an overall understanding of each interview. In this step, the meaning units were also divided into four categories answering the questions: How and why is self-determination reduced? What does it mean to the person that their self-determination is reduced? How and why is their self-determination strengthened? What does it mean to the person that their self-determination is strengthened? The text was also searched for additional content answering these questions.

Step 3: Meaning units with related content were brought together into tentative sub-themes which were discussed, questioned and reconstructed through the movement between different parts of the text and the text as a whole. According to Gadamer (2004), the circular movement from the meaning of the text as a whole to the meaning of the parts of the text and back to the whole allows interpretations to build on each other and culminate in a new understanding. By questioning and comparing the first insights together in the research group, prejudice was challenged and interpretations became more nuanced. Gadamer (2004) states that the prejudice, which is based on our worldview and previous experiences, is a prerequisite for understanding and can be described as assumptions made without having examined all elements that determine a situation. In the process of reflecting upon the text, the prejudice is challenged and new insights arise which, in turn, also are reflected upon and questioned to avoid hasty conclusions or misinterpretations. To further deepen the analysis, the question 'What is this about?' was constantly asked and the level of abstraction increased. Seven sub-themes were abstracted into two themes and an expanded meaning of the whole text emerged. When comparing the sub-themes, the themes and the expanded meaning with the fundamental meanings of each interview, the parts were found to harmonise with the whole.

Step 4: To illustrate the understanding of the text, representative passages were identified and used as quotations in the findings.

Study II

To investigate residents' and their family members' perceptions of care quality and self-determination, this study had a cross-sectional, quantitative design. Data were collected during 2017 and 2018 using an abbreviated version of the instrument Quality from the Patients' Perspective (QPP) (Larsson & Larsson, 2002) specially designed for residential care (see Appendix). The QPP measures quality of care (QoC) by comparing the perception of the actual care received, called perceived reality (PR), to the perceived importance of each aspect of care, called the subjective importance (SI). If the PR is significantly lower than the SI, there is a need for quality improvement (Wilde et al., 1994). The items in the QPP are formulated as statements, such as "I/My family member is treated with respect", and evaluated on a four-point Likert scale ranging from "Do not agree at all" to "Fully agree" for PR, and from "Of little or no importance" to "Of very great importance" for SI. The QPP was not originally developed to measure perceived self-determination, but the instrument was considered suitable by the research group as it measures both decisional and executional activities. In this study, significantly lower SI than PR was interpreted as a low influence over the measured aspect of care and thereby a low level of self-determination. To further focus on self-determination, six items about decision-making in everyday life and in life-changing situations and four items about handing over decisions to staff and family members were added to the 24 original items. These ten study-specific items derived from previous research. Due to impaired vision, paresis or reduced strength, 83 residents received assistance from the main researcher to complete the questionnaire. Two residents and one family member declined participation. Two of the residents' questionnaires had to be excluded because of the amount of missing data, and 18 family members did not return their questionnaires.

Demographic and clinical characteristics were examined with descriptive statistics. In the analyses, the perception of QoC and self-determination was first calculated separately for the group of residents (N = 112). Secondly, differences in perceptions between residents and family members were calculated pairwise using data from residents whose family members had completed the questionnaires (N = 83+83). Wilcoxon's signed-rank test was used both to calculate differences between PR and SI in the group of residents and to detect any differences in perceptions of PR and SI between residents and family members in the paired analyses. A p-value of <0.05 was considered statistically significant.

Study III

To investigate the residents' self-determination from the staff perspective, face-to-face semi-structured interviews were conducted at the staff members' places of work during 2016. The interviews lasted between 25 and 77 minutes (mean 50). The introductory questions in the interview guide were inspired by the Critical Incident Technique as described by Flanagan (1954). The Critical Incident Technique is used to gather facts concerning behaviours in defined situations. A critical incident is an observable human activity that is described in such detail that consequences of behaviours are clear and conclusions can be made about the person performing the act. The critical incidents in this study concerned situations when staff in residential care experienced residents as being or not being self-determinant. All interviews started with the questions: "Can you tell me about a situation when a resident, in an early or late palliative phase, could be self-determinant?" and "Can you tell me about a situation when a resident, in an early or late palliative phase, could not be self-determinant?" Follow-up questions such as "What did the involved persons do that obstructed the possibility of self-determination?” and “What did the involved persons do that facilitated self-determination?” were asked, as well as questions to deepen the narratives and additional questions about self-determination in residential care. The interviews were transcribed verbatim.

The transcribed interviews were analysed inductively using Qualitative Content Analysis as described by Graneheim and Lundman (2004). First, the text was read several times to gain a sense of the whole. Meaning units with aspects relating to each other through content and context were then separated from the text and condensed to shorter texts with the core meaning intact. The condensed meaning units were labelled with codes which were compared for differences and similarities and sorted into categories. These categories showed the visible components of the text, the manifest content (Graneheim & Lundman, 2004). As the analysis continued, the latent content, which is an interpretation of what the text is about (Graneheim et al., 2017; Polit & Beck, 2016), was searched for. Through a process of interpretation, asking ‘What is this about?’, the categories were abstracted into seven descriptive sub-themes which, in turn, were lifted to higher logical levels and subsumed under two descriptive themes. Further interpretation and abstraction resulted in an overarching theme of meaning, illuminating the comprehensive interpretation, distant from the text but close to the lived experiences of the participants (Graneheim et al., 2017).

Study VI

To develop a model that facilitates self-determination, the research group worked together with different stakeholders and expert reviewers in a participatory research process during 2019 and 2020. Participatory research originates from the striving for equity for marginalised and oppressed people and the notion that these persons are the ones best equipped to construct and implement knowledge that benefits their own social groups and communities. It integrates the experiential knowledge of the stakeholders with the academic knowledge of the researchers in a mutual learning process. This contributes to an increased degree of autonomy and control for the stakeholders and gives them a voice throughout the research process. Participatory research is an umbrella term that covers several methodological genres, of which appreciative inquiry (AI), which was used to develop the first tentative model, is one (Higginbottom & Liamputtong, 2015). A basic assumption in AI is that there is always something in an organisation that works well, and this strength can be used to initiate a positive change (Cooperrider et al., 2008).

Data were collected through focus group interviews, which were recorded and transcribed verbatim. Constant comparative analysis, inspired by Boeije (2002), was used throughout the study to make comparisons within and between the different datasets, and to inform the next step of the study. The analysis followed the steps: 1. comparison within a single interview; 2. comparison between interviews within the same group; and 3. comparison of interviews from different groups. Data were also compared with the theoretical framework of relational autonomy and person-centred care. The data collection and the analysis were divided into four phases:

Phase 1. Preparations. The affirmative topic 'to make and execute decisions throughout life' was decided upon by the research group. An affirmative topic is an idea about the future that is positively stated, desirable, interesting and moves in the direction that the group wants to go. It is positively stated as the anticipatory principle, which is an important concept in AI, suggests that the way people think about the future affects how they move towards it. An anticipated bleak and hopeless future will not be worth investing any energy in, while an anticipated future of possibilities will provoke actions to achieve these possibilities (Reed, 2007). To enable a positive approach to the topic, the CINAHL and PubMed databases were searched for strategies that facilitate self-determination in residential care and in palliative care. The result of the literature search was brought together with the strategies found in the three previous studies about self-determination conducted by the research group. The strategies were divided into five categories which were put together in three positively stated discussion areas: independence and support promote self-determination; planning for the future promotes self-determination; and to see the person and build relationships promotes self-determination. When the discussion areas were decided upon, the research group proceeded to plan the design for the rest of the study, starting with the development of the interview guides for the first focus group interviews. The five categories from the literature search, the study plan, and the interview guides were audited by the scientific reference group before entering the next phase of the study.

Phase 2. Developing the first tentative model. The discussion areas were explored in four focus group interviews with the advisory group following the 4D cycle of the AI process: discovery (the best of what is), dream (what might be), design (how can it be), and destiny (what will be) (Cooperrider et al., 2008) (see Figure 2). In the three first focus group interviews, the discussion areas were examined with a focus on peak experiences, where the stakeholders shared experiences from the past and the present to identify what worked well (discovery) and envisioned an improved future (dream). The interview guide contained questions like: “How do you work when you really succeed in helping a resident to be as independent as possible?” and “Five years from now, all the residents perceive that they have trustful relationships with the staff: what have you done to achieve that?” All focus group meetings started with a short summary and reflections on the previous meeting.

The three first focus group interviews were coded separately as soon as they were transcribed. Tentative codes and categories from each interview were compared to the codes and categories from the following interviews to develop possibility statements (design). Possibility statements are inspiring statements of intention, shared images of what might be that challenge the status quo and are based on what has worked in the past and the new ideas from the dream discussions. At the fourth focus group meeting, six possibility statements were presented to the advisory group. The texts in the possibility statements were written from the perspective of the staff, for example: “We always use our professional competence to assess risks and protect the residents from harm, but at the same time reflect on how our position of power, our assessments, and our actions affect the residents’ self-determination.” The content of the possibility statements was discussed to decide if the statements were desirable and to find innovative ways to move closer to the ideals described (destiny). The transcribed discussion of the possibility statements and how to fulfil them was compared to the previous data sets from the focus group and a tentative model was developed. The model was audited by the scientific reference group and the dementia-specialist reference group. In this phase, the perspective in the texts was changed from that of the staff to that of the residents to strengthen the person-centred approach.

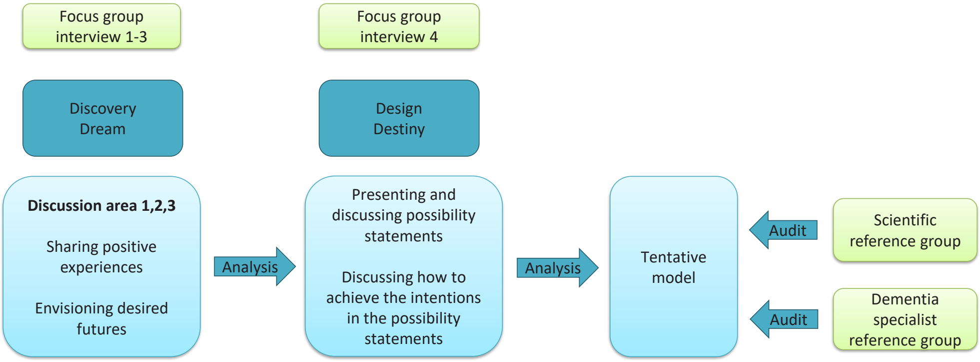


Figure 2. Phase 2, developing the first tentative model using appreciative inquiry

Phase 3. Refinement of the tentative model. The tentative model was presented to two stakeholder consultant groups: one focus group with persons residing in residential care and one focus group with residential care managers. The two groups' overall impressions and comments on the content and the headings of the categories, the wording of the texts, and the feasibility of the strategies in the model were compared to each other and to the datasets from the advisory group. To further refine the model, the findings from the three previous studies in the project and the theoretical framework were consulted.

Phase 4. Final revision of the model. The refined tentative model was presented to the advisory group for discussion and approval. This last focus group discussion had similarities to a workshop, as the advisor group and the representants from the research group processed the texts together and came to a consensus. The tentative model was audited one last time by the scientific reference group and the dementia-specialist reference group before the research group decided upon a final version with only minor revisions.

Synthesising the findings of studies I, II and III

To deepen understanding about the context-specific problems with self-determination in the palliative phase in residential care, data from studies I, II and III were triangulated to achieve a synthesis. The term 'triangulation' originates from navigation, where the sightings of two or more landmarks are used to locate a third position. In research, triangulation similarly involves using multiple data collection methods and gathering data from different sources to gain the most complete and detailed data possible on the object of research (Morris, 2017). The core assumption is that the use of multiple methods and sources contributes to a broader, deeper and more comprehensive understanding than each approach alone can yield (Flick, 2018). The studies included in the synthesis comprised two qualitative and one quantitative study, and data were gathered from three different sources: residents, family members, and staff from three different professions.

The data from the three first studies had been analysed separately, as described in the previous pages. In the first step of triangulation, the findings from each study were read several times to gain an understanding of the data as a whole. In the second step, a joint display, a table with one column for each study, was created to organise and visualise data from the different datasets (Fetters et al., 2013). The themes describing obstacles to self-determination and the consequences of reduced self-determination in the qualitative studies (I and III) were mapped onto the display. The items in the quantitative study (II) with significantly lower perceived reality than subjective importance in the ratings by residents and family members were also mapped onto the display, as they represent areas where the residents' self-determination is reduced. In the third step, reasons for the obstacles and consequences found in the qualitative studies were sought and divided into internal and external influencing factors, that is, if self-determination was affected by residents' own prerequisites and thoughts or others' treatment and behaviour. Related content from all three columns in the display was brought together into categories. The categories were further processed by searching for similarities, differences, and how the categories were connected to each other. In a more interpretative approach, the question 'What is this about?' was asked. The new conclusions were visualised in a figure as themes in a process. As content in the themes of threatened self-image and threatened dignity was recognised as relating to the concept of dignity of identity, literature was consulted. Dignity, conceptualised as dignity of identity (Nordenfelt, 2009), was found to cohere with the new conclusions and provided an overall interpretation of the context-specific problems with self-determination in the palliative phase in residential care (see Figure 4, page 40).

Ethical considerations

As the studies in the thesis involved human subjects, they were conducted in accordance with the ethical principles of the World Medical Association's (WMA) Declaration of Helsinki (World Medical Association, 2013) and were approved by the Swedish Ethical Review Authority (dnr 1036-15 and 2019-02861). All potential participants received oral and written information about the study design, purpose, potential risks, and the voluntary nature of the participation prior to signing the informed consent form. The participants were informed that they could withdraw their consent whenever they wanted without reprisal. The Declaration stipulates that every precaution must be taken to protect the privacy of the participants and the confidentiality of their personal information. Thus, questionnaires and transcribed interviews were stored in safe archives at the University of Gothenburg and personal information was removed and replaced with codes. The code lists were kept in password protected computers.

An ethical consideration concerning Study I (interviews with residents) and Study II (questionnaires with residents and their family members) is the inclusion criterion that residents should be in a palliative phase, defined as having a maximum life expectancy of one year. When designing the studies, the plan was to include residents who had received information about their limited life expectancy by their physician and knew that they were in a palliative phase. This was not possible, however, as it turned out that persons in residential care usually do not receive this kind of information until the last weeks or days before death. Instead, the surprise question was used as an inclusion criterion and registered nurses asked residents to participate of whom the nurses would not be surprised if they were deceased within one year. As information about health conditions and prognoses should be provided by the responsible physician, information on the inclusion criterion of a palliative phase was not revealed in the study information. This meant that the residents were not aware that they were included because they were assessed as being in the palliative phase.

Research involving humans should be preceded by a careful assessment of the predictable risks and burdens in comparison to foreseeable benefits. Special consideration should be given to vulnerable persons who are at greater risk of getting harmed. When vulnerable persons are involved, the research should be responsive to their health needs and priorities and they should benefit from the study results (World Medical Association, 2013). The participating residents can be regarded as vulnerable persons, as they were living with several illnesses, depended on others for their daily living, and had an estimated survival of one year or less. On an individual level the residents that participated in the studies did not benefit from the results, but on a group level the results can enable improvements for residents in the future. In conjunction with the data collection, some residents said that they hoped their participation would change things for the better for others in the long run, while some said that they did not think that their participation would make any difference. Several residents expressed gratitude for the possibility of making their voices heard and being listened to.

The potential risks of participation were mainly connected to the residents' limited physical and cognitive strength. Both the interviews and the questionnaires were exhausting for some of the residents: they were encouraged to stop when they needed to, and pauses were offered when residents showed signs of being tired. The study design allowed the findings from the first three studies to be reused in the fourth study (and in the synthesis of the findings in the thesis), which contributed to making good use of the participants' efforts. The World Medical Association's Declaration also states that underrepresented groups should be provided appropriate access to participation in research. The majority of participants in the quantitative study could not fill in the questionnaire independently because of physical and cognitive limitations, but were given access to participation by being offered assistance.

Findings

This chapter will provide a short individual summary of the studies and thereafter a synthesis of the context-specific problems with self-determination found in the three first studies.

Study I

The meaning of self-determination in residential care was interpreted as the struggle for a dignified life. The findings show that due to age and illness, the residents are subject to extensive life changes that affect their self-determination, and they try to find ways to cope with these changes. The theme of being forced to adapt to new circumstances and the subthemes of experience changed self-image, being lonely among others, losing influence over one's life, and diminishing one's needs describe the consequences of lacking self-determination. The theme of navigating in a forced situation and the subthemes of keeping and regaining control, striving to be oneself, and sharing the responsibility describe strategies that residents use to maintain their self-determination and diminish the consequences of lacking self-determination.

Study II

The findings show that in the majority of both the items measuring QoC and the study-specific items about decision-making, there were significant differences between the perceived reality (PR) and the subjective importance (SI) in the ratings by both the residents and their family members. Only three items did not have significant differences in either the residents' or the family members' ratings. There was high consistency between residents and family members, although the residents were slightly more content than the family members rated them to be. Lowest mean values in the PR of QoC in items with significant difference between PR and SI for residents were found in support when feeling lonely, support when feeling worry, anxiety or fear, and staff's time to talk to the residents. Family members also rated support when feeling lonely and support when feeling worry, anxiety or fear low, but their lowest mean value was for residents' possibility to go outside. Lowest mean values in the study-specific items about decision-making in everyday life and in life-changing situations in both residents and family members ratings concerned the staff and family members' knowledge of the residents' will in life-changing decisions such as intravenous fluids, hospital admission and cardiopulmonary resuscitation, and the staff's ability to make the right decisions according to the residents' will if they were to take over the decision-making. In addition, there was a significant difference between PR and SI in the family members' but not the residents' ratings of the family members' ability to make the right decisions according to the residents' will if they were to take over the decision-making. This indicates that family members are not sure of their ability to make decisions on behalf of the residents, while the residents believe that their family members can do so.

Study III

The findings show that, according to staff, residents' possibility of self-determination is connected to their possibility of maintaining their self. The overarching main theme, balancing between maintaining and overriding the residents' self, illuminates that there are both facilitators and obstacles to self-determination, and thereby to the maintenance of the residents' self. The theme of residents' own abilities and others' active efforts strengthen and the subthemes of facilitating residents' own decision-making, acting in accordance, and acting as spokespersons represent facilitators to self-determination; while the theme of residents' vulnerability and others' dominance undermine, and the subthemes of depending relationship, setting the terms, lacking sufficient communication, and crossing the boundaries of the personal sphere represent obstacles to self-determination.

Study IV

The aim of Study IV was to develop a model that facilitates self-determination in the palliative phase in residential care. The three first studies focused on residents who had a life expectancy of a maximum of one year, thus being in a palliative phase. However, facilitators and obstacles for self-determination found in these studies were considered to apply to the whole time of residency, and because of that, the model does not exclusively focus on the palliative phase, although including it.

By combining practical and theoretical knowledge, the model 'to make and execute decisions throughout life', with a core message and seven categories with strategies to facilitate self-determination for the residents was developed (see

Figure 3). The theoretical framework of person-centred care and relational autonomy is visible through the core message and the categories, as they comprise both the strengths and the needs of the person (the resident) and the skills and support of the professional (the staff). Both person-centred care and relational autonomy highlight the importance of relationships. This is also visible in the model, as it is written from the perspective of the resident but includes the professional as an inalienable partner. To further enhance awareness of the residents as persons and autonomy as relational, the text in the model is written from the perspective of the resident and is directed towards the staff. The core message ‘in my way, at my pace, with the help of you’ highlights the residents’ right to decide and execute things as independently as they want, but also the need for assistance. The seven categories, see me as a competent person, show me professional consideration, meet me in a trustful relationship, give me opportunity to a meaningful and safe day, support me in being independent, let me have power over my own life, and help me to plan my end-of-life care, reinforce the core message.

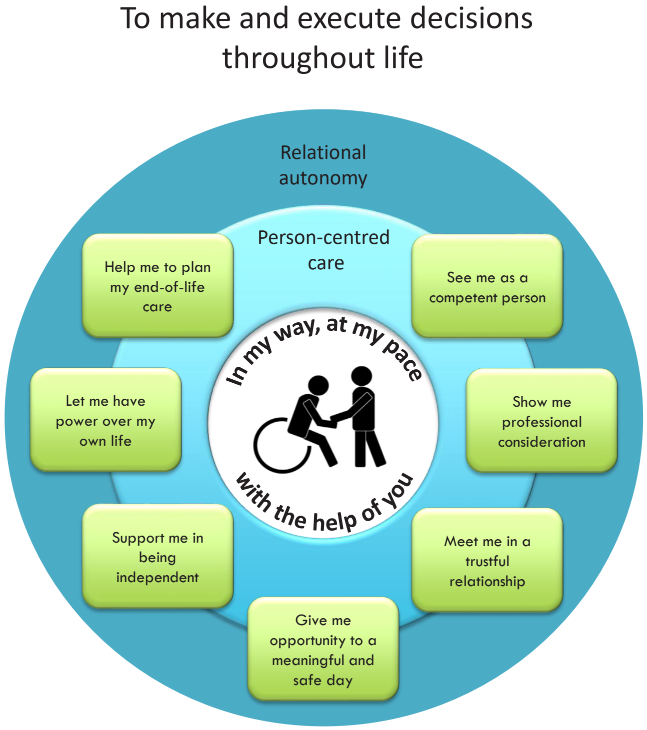


Figure 3. The model To make and execute decisions throughout life

Synthesis of findings of studies I, II and III

This section presents a synthesis of the context-specific problems with self-determination in the palliative phase in residential care based on selected findings from the three first studies (see Figure 4).

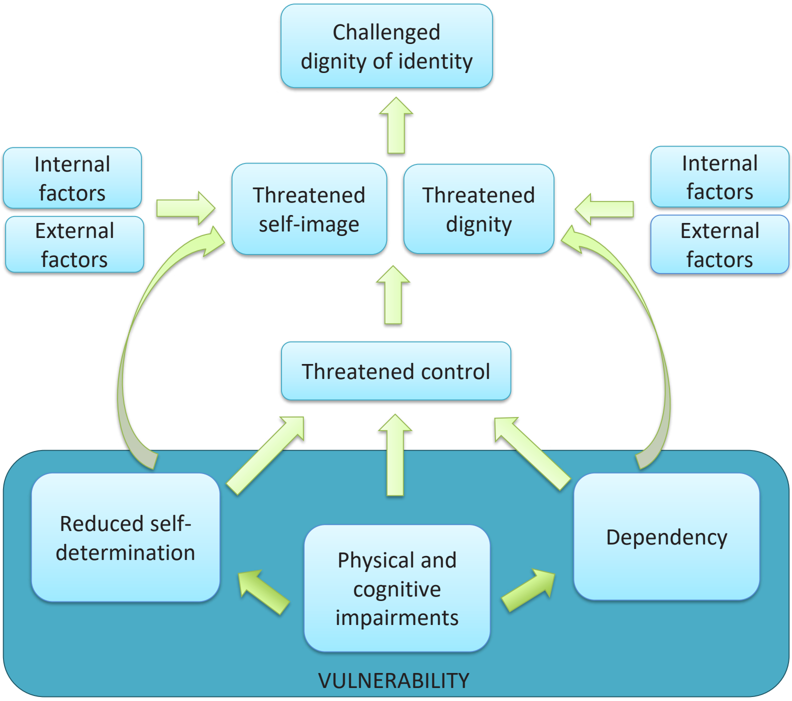


Figure 4. Synthesised findings from studies I, II and III

Vulnerability

The residents were in a vulnerable situation as, because of age or illness, they had physical or cognitive impairments. This made them dependent on others in their daily living and reduced their self-determination, as their ability to make decisions and act upon them was diminished.

Physical and cognitive impairments cause reduced self-determination and dependency

The residents in the studies had moved to residential care as their bodies and minds were affected by age and illness, which made it difficult for them to manage at home. In addition to the diseases described in studies I and II, the residents were also affected by, for example, repeated falls, fractures, repeated hospital admissions, impaired vision and hearing, depression, dementia, diabetes, loneliness, anxiety, side effects of stroke, and difficulty moving because of weakness, amputations or paralysis. Some had lived at home for a long time with these difficulties, but when their condition deteriorated or when their spouses died or were no longer able to help them, they had to move to residential care (studies I and III).

Because of their physical and cognitive impairments, the residents' self-determination was reduced. Things that they could previously decide about and act upon were now hard to accomplish or out of reach. Some could not express their wishes as they could not communicate verbally, and even though many residents could formulate their wishes, they could not act on them as, for example, they could not see, move, or find their way back if they left the facility (studies I and III). Some residents also had impaired decisional capacity due to dementia or a lowered degree of consciousness at the end-of-life. Staff considered residents that could not communicate as the most vulnerable (Study III).

Physical and cognitive impairments made the residents dependent on staff and family members to manage their daily lives and their health. This made them vulnerable as they were, to a great extent, in the hands of others. They were at a disadvantage in terms of power as they could not always set the terms for their own lives but had to adapt to frames set by other people. If the residents could not be assisted when they wanted or needed to be, or as they preferred, the dependency had a big impact on their lives (Studies I, II and III).

Threatened control

The vulnerable situation of functional impairment, reduced self-determination and dependency meant a threat against the residents' control over their own lives. In Study II, the PR differed significantly from the SI in the majority of the items, indicating that both decisional and executional control were affected, as the reality did not live up to expectations in items such as having the opportunity to participate in decisions about care or receiving support in different daily activities.

As there were many residents in need of assistance, individual wishes sometimes had to be set aside, and staff had to prioritise tasks. Basic practical tasks such as meals and bodily care were given precedence over psychosocial tasks such as talking to the residents when they felt worried or alone (Studies I, II and III). Residents lost control when the function of the residential care facility as a whole and other residents' needs had to be prioritised because of limited resources. This meant that residents had to wait to receive help with, for example, toilet visits or pain medication, and could not decide for themselves when to get out of the bed in the morning. It also meant an enforced bedtime before the start of the night staff's shift, not being able to go outside, and staff working and talking hastily. The staff did things in their own way and at their own pace without asking the residents' opinions (Studies I, II and III). The residents hesitated to ask for help or to protest at things that they thought were wrong as they saw that the staff were stressed, did not want to be a nuisance, and were afraid of punishment (Studies I and III).

Routines and rules set by the staff or organisation directed the residents' day and were considered necessary to make the facilities function and keep the residents safe. Specified shower days, a ban on using their stoves or handling their own medication, and locked doors were examples of the residents losing control over their situation. Intrusions into the residents' personal sphere also contributed to the loss of control when, for example, the residents had to receive help from staff they did not know or trust, when staff did not knock on the door before entering, did not present themselves, and went through the residents' belongings without asking permission. The control was also threatened by other residents who intruded into their apartments and behaved in threatening ways (Studies I and III).

It required a trusting relationship to be able to talk about sensitive things such as future deterioration, death, loneliness and anxiety (Studies I and III), but Study II showed that residents perceived that there was a lack of relationship with and engagement from the staff and that the staff did not have time to talk to the residents. Study II further showed that residents did not believe that the staff or family members knew about their will in life-changing situations such as end-of-life care, hospital admissions and life-saving treatments. Not having planned for these situations was also a threat to the residents' control, as it often was too late to ask for their opinion when a situation occurred (Study III).

Threatened self-image and dignity

Physical and cognitive impairments, reduced self-determination, dependency and loss of control over their own lives meant threats against the residents' self-image and dignity. Both internal and external factors, such as the residents' own thoughts about themselves and the staff's treatment of them, affected the residents' experiences.

Self-image. The residents in the studies had experienced many changes in life connected to their ageing and deteriorating bodies and minds. The weakness and dependency stood in stark contrast to their former lives where they had been independent, capable, strong and in control. They had lost physical and cognitive abilities, as well as social roles. Now they felt trapped in their own bodies, involuntarily lonely, and did not recognise themselves. Not being able to manage their own lives made the residents look down on themselves and feel useless and a burden to others. Some even thought that life was not worth living under these conditions (Studies I and III).

Living in residential care was also a threat to residents' individuality as they were now a part of an "anonymous grey mass" (male resident, Study I). Some residents who needed guidance to be able to make decisions in line with their personality did not get that help. Instead of taking the residents' life stories into account, the staff assisted them in the way that they considered to be the best. This was described as being less time consuming but deprived the residents of the possibility of being themselves (Studies I and III).

Dignity. The residents' feelings of being worthy of respect and living a dignified life were threatened by their own negative thoughts about themselves in relation to their lost abilities and their dependency. This was further reinforced when staff treated them disrespectfully (Study I). Study II indicated disrespectful treatment from the staff, as both residents and family members rated the importance of residents being treated with respect higher than the actual experience. This might be because the residents described that they were not listened to when they had complaints or suggestions, were treated as if they were children or had dementia, or were snapped at when they were too slow or when they spoke up for themselves. Some residents did not ask for help as they knew that their request would be denied, and they wanted to protect themselves from the humiliation of being rejected (Studies I and III). Although they felt that some staff did not care about them or show engagement (Studies I and II), did not have interest in them as persons and treated them as merely tasks, they did not complain in fear of being disliked or seen as whiners (I and III). The residents thought that the staff treated them in this undignified way because they were older persons. By accepting this condescending treatment without speaking up for themselves, their self-respect was further negatively affected (Study I).

Challenged dignity of identity

The threats to the residents' self-image and dignity can be interpreted as a challenge to their dignity of identity. Dignity of identity is described by Nordenfelt (2009) as a form of dignity that is attached to the person's integrity and identity as a human being. It is tied to the integrity of the body and mind, and often depends on the person's self-image. It is conceptualised as a basic self-respect based on who we are as integrated, autonomous persons, with a past and a future and with relationships to other human beings. This self-respect can be jeopardised by illness, disability, old age and cruel acts by other people. When others intrude into a person's personal sphere and tamper with their integrity and autonomy, for example, by preventing them from doing what they want, it contributes to feelings of humiliation, worthlessness and loss of self-respect. A person's feeling of worth is also to a great extent tied to how the person is looked upon by other people, and the feeling of worth can be diminished by others' opinions even though the person does not share these opinions (Nordenfelt, 2009).

In Study I, the residents thought that the staff treated them in a condescending way because of ageism. The residents themselves did not express a general disapproval of their age group, but some considered themselves to be less worthy because of their inability to perform as before. Their self-image and their self-respect were shattered because of their disabilities and dependency. They could no longer act like autonomous persons, and that challenged their identity. Being restricted by external factors like routines and rules reinforced the feeling of powerlessness and made them lose control over their situation. Not being in control, being treated like a child or a person with dementia or being treated as a task instead of a person affected the residents' self-image and self-respect, and thereby their dignity of identity. Dignity of identity is also about integrity. The bodily integrity of the residents was under constant threat because of physical and cognitive impairments and the need for assistance, but also because of intrusions in their personal spheres. The residents were prevented from doing things they wanted to, such as go outside or stay up in the evenings, or persuaded or forced to do things they did not want to do, such as shower with supervision or receive help from staff they did not trust (Studies I and III). In Study II, there were many indications that the care did not live up to the expectations of the residents and the residents did not feel cared for.

The findings in the studies showed that feelings of humiliation, loss of self-respect and changed self-image are part of the residents' experiences, and because of that, the overall interpretation of context-specific problems with self-determination in the palliative phase in residential care is challenged dignity of identity.

Discussion

This thesis contributes to an extended understanding of the obstacles to self-determination in the context of residential care. It also shows the negative impact reduced self-determination has on residents' self-image and experience of dignity. Nevertheless, and most importantly, the work within the thesis has resulted in a model that staff can use to facilitate self-determination for the residents despite these problems.

The vulnerable and dignified person

The vulnerability of the residents runs like a red thread throughout the studies as well as throughout the lives of all human beings. Vulnerability is an inherent fragility that is part of the human nature as, through our embodiment, we are susceptible to illness and death (Morberg Jämterud, 2016). Vulnerability is associated with becoming an old person, a process that involves many life changes. The loss of physical and mental capabilities is a natural part of ageing, but at the same time a concretisation of vulnerability, as the person cannot manage as before and is dependent on others (Sarvimäki & Stenbock-Hult, 2016). When human beings become seriously ill, we also become dependent on others (Morberg Jämterud, 2016). Humans are naturally subject to periods of dependency throughout life, and people without disabilities can be regarded as only temporarily abled (Kittay, 2011). Vulnerability and dependency are thus both natural parts of human life and there is a strong connection between them. Dependency is a form of vulnerability, but it does not have to be regarded as a problem, rather as an adequate description of the person's situation when in need of care (Morberg Jämterud, 2016). Dependency and reduced self-determination due to loss of physical or cognitive abilities were parts of the residents' vulnerability in the present studies. Although dependency does not have to be a problem, and lost abilities can to a great extent be compensated for by the actions of others, the studies showed that the residents' vulnerability had negative consequences for them, resulting in a threat to their control, self-image and dignity, and ultimately challenging their dignity of identity. Here, the organisation of residential care fails to diminish the residents' vulnerability when it sometimes does not provide access to staff who, without delay, can pay attention to the residents' needs for support and assistance, as stipulated in SFS 2001:937. If this is because the staff lack time, do not have adequate education, do not apply an empathic approach, or if the organisation is not communicating how to live up to the core values of elderly care, or if there are other reasons, ought to be discussed within the organisation. This is an important issue to address as it has big impact on the residents' wellbeing. When the residents are allowed to do things in their own way and at their own pace, as the model developed in Study IV advocates, they can remain in control even if they need assistance. The model also emphasises that all residents have some level of competence, and by being supported in practising these remaining competences, the residents can maintain some independence and control over their situation. Being in control and managing desirable things can be regarded as an important step to decrease the vulnerability induced by physical and cognitive impairment, reduced self-determination and dependency.

Dignity in healthcare can be described as the capacity to uphold one's standards and principles (Killmister, 2010), but persons who are losing control over their environment, bodies and minds depend on others to uphold the values central to their lives (Barclay, 2016). Ill persons experience inferiority in three ways: institutionally, as they depend on staff for care; existentially, as they are ill; and cognitively, as the staff have greater knowledge about medical aspects and the care organisation (Kristensson Uggla, 2014). This vulnerability and the asymmetric relationships it creates are important perspectives to consider in relation to respecting the ill person's dignity (Morberg Jämterud, 2016). There is a moral responsibility for others to consider the ill person's perspective (Kristensson Uggla, 2014) and to enable autonomous choice and decision-making (Morberg Jämterud, 2016). In the present studies, the residents could not independently uphold their standards and values, such as keeping bodily functions private, dressing themselves, or deciding what to do or when and how to do it. Because of this, their basic self-respect, that defines dignity of identity (Nordenfelt, 2009), was shattered. In addition, external factors such as staff's routine-based actions and condescending treatment had a negative impact on the residents' self-image and self-respect. This is also described by Barclay (2016), who stated that others' behaviours, institutional practices and interpersonal interactions can threaten a person's ability to uphold values and standards, especially in the context of vulnerability. When others make it impossible for a person to maintain standards and values, it signals that he or she is not respected as a person of equal rank, worthy of living according to his or her standards. The part of the residents' self that is constructed in relation to others and dependent on others' views, as described by Sabat and Harre (1992), is thus at risk of being negatively influenced by these signals. In contrast, when the person is treated with respect for his or her values and standards, it signals that the person is equally worthy and capable of the unique human ability to shape a life according to a set of standards and values (Sabat & Harre, 1992). In the model, the category ‘see me as a competent person’ highlights the importance of regarding the residents as adult, competent persons even when they need support to live according to their standards and values, and the category ‘meet me in a trustful relationship’ raises the issue of residents being of equal value to the staff members. Being treated as a competent person and being assigned the same value as the other person in the relationship can protect the self-image and dignity of the resident. To achieve this, staff members need to recognise that the residents have the right to make their own decisions, know the residents and their preferences, listen to their stories, meet them where they are, and treat them kindly and with respect even though they might describe a different reality from that of the staff.

Living with the remnants of the total institution

In the world outside residential care facilities, people live, work and socialise in different places, with different persons, under different authorities (Goodman, 2013). In residential care, the residents have their home, social arena and healthcare experiences under the same roof (Nakrem et al., 2011). In this sense, residential care is a total institution where all daily activities are experienced and controlled in the same place by the same authority (Goodman, 2013). As the residential care facility constitutes such an extensive part of the residents’ world, it can be assumed that the prevailing conditions in the facility strongly affect the residents’ lives. Although the hospital-like, paternalistic culture of the total institution is replaced by a home-like living environment and laws that emphasises the residents’ right to have influence over their own lives, residents, family members, staff and managers in the studies all experience that the residents’ self-determination is sometimes restricted. The residents describe that they fight for the right to have control over their own lives and try to be as independent as possible, but they also downplay their needs and adapt to the prevailing conditions with routine-based care and limited time for staff to get to know them as individuals. This is also described by Vaismoradi et al. (2016), who found that residents had to surrender to the conditions in the facility, and when they were dissatisfied with the care, they reduced their activities, felt resigned and worthless, lost their identity, and withdrew from participation in their own care. Nevertheless, not all routine-based care is bad. In Study I, routines were described as bringing structure to the day and allowing residents to go with the flow and leave responsibilities to the staff. This is consistent with the theoretical model on which the QPP questionnaire, used in Study II, is based. The model stipulates that the perception of quality of care from the patient's perspective has a rational aspect wherein patients strive for order, predictability and calculability. This rational aspect entails that whoever the person is, he or she should be provided with the necessary treatment and care by competent staff. The theoretical model also presents a human aspect, wherein quality of care depends on each person's own unique situation being taken into account (Wilde et al., 1993). Building on this theoretical model, the theoretical framework of person-centred care and the relational view of autonomy used in this thesis, it can be concluded that routines and structures are good as long as they allow for individual considerations. However, when the routines take precedence over individual wishes, they challenge both QoC and self-determination.

Another context-specific problem with self-determination described in the studies is the tension between the residents' right to self-determination and the staff's obligation to provide good and safe care. Self-determination is described as the gold standard in all interviews with staff; however, as the interviews proceed, there is always a 'but'. Self-determination is self-evident, *but* what if the person does not understand what is in his or her own best interest? This entails an ethical dilemma wherein the ethical principle of autonomy is weighed against the principles of non-maleficence and beneficence (Beauchamp & Childress, 2013). In the fourth study, this ethical dilemma is handled in the category of 'show me professional consideration'. The category describes a real concern for the residents' wellbeing and safety that is grounded in the staff's professional responsibilities. The principles of non-maleficence (to do no harm) and beneficence (to prevent or remove harm and to promote good) (Beauchamp & Childress, 2013) direct the staff when they try to protect the residents from decisions and actions that would affect them negatively. However, when staff give precedence to protection over autonomy, the residents lose influence over their lives. When focusing on protection, the interpretation of 'do no harm' and 'promote good' does not include the facilitation of self-determination. This was also found by Jacobs (2014), who saw that although staff see benefits with increased autonomy for the residents, the risk of physical injury seems to outweigh the risk of decreased psychological wellbeing caused by restrained autonomy. To promote wellbeing for persons with dementia, the positive benefits of taking risks should be balanced against the effects of attempting to avoid risk altogether (Department of Health, 2010). Residents in the studies felt restricted and treated like children when they were not allowed to do things that they knew they could, such as handle their own medication and shower without supervision. This confirms Tuckett's (2007) conclusion that being regarded as vulnerable and frail may cause others to patronise and infantilise the older person. The culture of the total institution is still present in some respects, which can be illustrated by comparing the residential care facility to an ordinary apartment in a house. No landlord in an ordinary apartment would, for example, consider turning the stoves off for all tenants because of an incident in one apartment, but in residential care that is the reality. As a rule, residents' own decisions should be respected, as described in the category 'let me have power over my own life' in the model in Study IV. Staff also need to acknowledge the uneven power distribution between them and the residents and reflect upon the consequences of this imbalance. Of course, there are many situations in residential care where the residents need guidance and support to them keep safe, experience wellbeing and uphold their dignity. The results of the present studies show that there is a need to consider how this can be done while at the same time keeping the paternalistic approach at arm's length to fight the remnants of the total institution.

A meaningful life and a dignified death

The studies show that, although the residents need assistance in their daily living, they still want to experience meaning and quality of life and be seen as important valuable persons. They want the possibility to take part in a social community and to have influence over their lives. Adra et al. (2015) found that regardless of their personal health and circumstances, residents need to occupy themselves with stimulating and meaningful activities to experience quality of life. Engaging in worthwhile activities can enable residents to maintain a sense of self, personal dignity and continuity with the past. Reciprocal activities such as conversations and helping other residents also contribute to feelings of being included and valued. However, the residents in the present studies saw their own and others' physical and cognitive impairments as obstacles to meaningful interaction. Naess et al. (2016) found that to achieve a successful social experience in residential care, staff must assist in shaping social situations that are adjusted to the residents' abilities. This includes, for example, composing social groups, offering participation in social activities, and slowing down the rhythm of interaction to enable residents to be presented to each other as competent persons. The presence of staff in social interactions is crucial to initiate and maintain conversations and to help residents who would otherwise not be able to make themselves heard or reply in a meaningful way. Donchin (2000) describes this collaborative and reciprocal interaction as a way for staff to support residents to create new personal meanings out of experiences of illness and disability. It is an example of relational autonomy, where the resident's relational network strengthens his or her individual efforts to be a self-determining and responsible agent in his or her own life. Unfortunately, both the present studies and that of Kihlgren et al. (2020) show that staff have limited time to talk to the residents and that the staff do not always know the residents. This dilutes the opportunities for staff to be a part of the residents' relational network and help them to a meaningful life. Finding meaningful activities for persons in residential care can be a challenge, as the residents do not represent a homogenous group. Nakrem et al. (2013) found that persons residing in the same facility could experience their day quite differently, ranging from busy to boring and from meaningful to devastating. This highlights the need to involve the residents in the planning of their own day, as well as in the overall planning of activities in the facility. As suggested in the category 'give me the opportunity for a meaningful and safe day' in the model, this can be achieved through agents if necessary.

After moving in, most of the residents spend the remainder of their life in the residential care facility. When death is nearing and becomes a reality, the meaning of what a good life is might change (Ternestedt et al., 2017). Persons nearing death are concerned that control over their lives will be taken from them when they are too ill to prevent it (Ferrell & Coyle, 2010) and they oppose decisions being taken without their consent (Bonin-Scaon et al., 2009). Therefore, it is important to identify persons with limited life expectancy and to talk about how they want to live their remaining life, as described in the category 'help me to plan my end-of-life care' in the model. As increasing need of medical and practical support is to be expected at end of life, it is important to create a plan to meet foreseeable needs (Milberg & Karlsson, 2016). This is in line with the palliative approach that stipulates that assessments of the person's condition, needs and wishes should be made throughout the illness trajectory to enable decisions to be made according to the person's values (Regional Cancer Centres, 2016). However, the present studies show that there is a lack of timely routines for raising questions about end-of-life care, and that neither the staff nor the family members know about the residents' preferences regarding life-prolonging or life-saving treatments such as hospital admissions and cardiopulmonary resuscitation. To ensure the best possible care for residents, caregivers want to discuss and plan the end-of-life care but find it hard if the discussion is not initiated by the residents or their family members (Häggström et al., 2010). Although some residents do not want to talk about death, most are prepared to do it with trusted persons such as their family members or empathetic staff but can hesitate to raise the question for fear of burdening them (Klemmt et al., 2020). Failing to address end-of-life issues is a threat to the residents' self-determination, as it is often too late to ask them about their preferences when their health deteriorates. Staff in the present studies also describe that family members sometimes demand and are granted treatments and hospital admissions for the residents that the staff know or believe that the residents do not want. This was also found by Romøren et al. (2016), who saw that residents are often not included in decisions about their end-of-life care and that family members are given greater decision-making authority than they should have. However, in the present studies, family members are also described as important resources that can help the staff to understand who the residents are and represent them by acting as spokespersons when needed. Family members can share the decision-making based on their knowledge of residents' previous wishes, but that requires that they are also provided with information about the current situation, receive adequate information about prognosis and treatment options, and are offered support in their task. In both the present studies and that by Romøren et al. (2016), the hesitation to engage residents in end-of-life discussions is explained by an urge to protect the residents from unpleasant feelings and worries that the subject of illness and death can evoke. Nevertheless, ill persons have been found to prefer candid information about their health status and prognosis if framed in a compassionate way that acknowledges the distressing emotions that might arise from such conversations. Hope can be maintained despite being given bad news, but it may centre on preserved quality of life or achieving a good death rather than on survival or a prolonged-lifespan (Abdul-Razzak et al., 2014). To ensure a dignified death in accordance with the residents' standards and values, staff need to take responsibility for addressing questions about end-of-life preferences and help residents and family members to plan ahead to the extent they wish.

Methodological considerations

Framework and concepts

This thesis had a theoretical framework of relational autonomy and person-centredness, and the concept of self-determination was defined as having the opportunity, with or without assistance from others, to make and execute decisions in line with one's own wishes and values. According to Flick (2018), the studied phenomenon is marked by the researcher's theoretical conceptualisation as the conceptualisations influence how methods are designed and used, as well as the interpretation of data and findings. If autonomy had been conceptualised in a more traditional way, as individualistic, or if self-determination had a narrower scope, focusing on just decision-making capacity, as suggested in some definitions, it would have guided the thesis in quite another direction. These conceptualisations were rejected, however, as they do not take into account the aspect of dependency on others to make and execute decisions, which must be regarded as crucial in the context of residential care.

Persons in palliative phase, defined as having a maximum life expectancy of one year, were the intended focus of the thesis. As this inclusion criterion was not disclosed to the participating residents or their family members for ethical reasons, the focus on the palliative phase shifted from sometimes being in the foreground and sometimes in the background when conducting the studies. In the fourth study, the focus on palliative phase was set aside as all participating groups considered the findings from the previous studies to apply not only to the last year of life but to the whole time of residency. Nevertheless, focusing on the palliative phase in the first studies contributed to valuable insights that were brought into the model and made it live up to the name of making and executing decisions *throughout life*.

Participatory research used in the fourth study was found to cohere with both the relational view of autonomy and person-centredness. In the process of participatory research, the stakeholders' experience-based knowledge and researchers' academic knowledge meet (Higginbottom & Liamputtong, 2015). This can be compared to the partnership described in person-centred care, where both the ill person and the staff are regarded as competent and important actors in planning and conducting the care (Ekman et al., 2011). This partnership is also found in the relational view of autonomy, where reciprocity and cooperation are central concepts (Donchin, 2000). The model developed through participatory research takes into account both the competence and the vulnerability of the older person and can be described as a negotiated agreement between different stakeholders.

Inclusion of participants and selection of instrument

To attain credible results, research must include participants who have experience and are able to talk about the phenomenon under study (Graneheim et al., 2017). A maximum variation purposive sample (Polit & Beck, 2016) was sought in order to gain a heterogeneous group of participants who could illuminate the phenomenon of self-determination from different perspectives. This was achieved by including a variety of stakeholders (residents, family members, registered nurses, enrolled nurses, physicians, managers and expert reference persons) from different residential care units (general care units, specialised dementia care units, and specialised geropsychiatric care units) operated by the municipality or by private actors in all districts of the municipality. When including the residents and some of the staff (mostly the enrolled nurses), the research group was assisted by registered nurses and residential care managers. Although this procedure was necessary to get in contact with the intended participants, it also carried a risk of selection bias. Potential participants might have been excluded if they were considered too frail to participate, so-called gate keeping (Sharkey et al., 2010), or as bad representatives of the facility.

In Studies I and II, the surprise question was used as an inclusion criterion to assess if the residents were in a palliative phase, defined as having a life expectancy maximum of one year. If the registered nurse would not be surprised if the resident died within one year, the resident could be asked to participate. The surprise question has been found to be useful to identify persons in need of palliative care, but can also produce a high proportion of false positives (Gómez-Batiste et al., 2017). This might have rendered the inclusion of residents who were not likely to die within one year, thereby failing to address the inclusion criterion of the palliative phase.

The instrument used in Study II, the QPP questionnaire, is based on a theoretical model that stipulates that a person's perception of what constitutes quality of care is formed by their encounter with the existing care structure and the person's own expectations, norms and experiences (Wilde et al., 1993). Thus, the items in the QPP questionnaire are measured in two ways, assessment of perceived reality (how the person thinks it is) and evaluation of subjective importance (how the person wants it to be) (Wilde et al., 1994). However, in Study II, the instrument was not only used to measure quality of care but also to make inferences about self-determination. This is, of course, a limitation, as self-determination is not the scope of the instrument. Despite this, the QPP questionnaire was considered to be the best choice, as no instrument measuring self-determination or autonomy in residential care was found. As mentioned, autonomy refers to having the capacity to make decisions and act according to one's own values and preferences (Mackenzie, 2019), and a person with diminished autonomy is controlled by others or incapable of acting based on their own desires or plans (Beauchamp & Childress, 2013). When using the QPP questionnaire to make inferences about self-determination, the subjective importance, how the person wants it to be, represents the person's values, preferences, desires and plans, while the perceived reality represents the possibility to act upon these preferences. If there were significant differences between the subjective importance and the perceived reality, self-determination was interpreted as compromised. It was also important to consider the context of residential care when selecting an instrument, and the items in the QPP questionnaire specially developed for residential care were assessed as relevant to the participants. The Impact on Participation and Autonomy, Older Persons questionnaire (Ottenvall Hammar et al., 2014) was also considered but was found not to fit the context.

Furthermore, the QPP questionnaire was considered appropriate for the thesis as a whole as the theoretical model on which it is based comprises both a person-centred and a relational view in the domains of identity-oriented approach and socio-cultural atmosphere. These domains describe the importance of seeing the patients as unique persons, having a trustful and equal relationship, and providing care based on preferences and not routines (Wilde et al., 1993). The relational view that allows for dependency and support is also seen in the QPP questionnaire in the formulation of items such as "I receive the best possible support with personal hygiene". This formulation had a good fit with the theoretical framework of the thesis, but also constituted a problem as it assumed that all participants needed support. To handle items that addressed situations where participants did not need any assistance at all or where the family members did not know how it was for the residents, two additional alternatives were added to the Likert scales in the QPP questionnaire: "not applicable" and "do not know". In the statistical analyses, these alternatives were treated as missing values and were not included.

Study-specific questions about decision-making in daily activities and in life-changing situations were added to the QPP questionnaire. These questions were not tested for face validity on residents or family members before the study, but were formulated in cooperation with the company that provided the QPP questionnaire to fit in with the other items.

Integrated findings

The studies in the thesis comprised different methodological approaches, each considered suitable for the separate aims of the studies, but also to provide complementary perspectives on the phenomenon of self-determination in residential care as a whole. The study designs contributed to a deep understanding of experiences and meaning in the interview studies and to a broad and comparative description in the quantitative study. To gain a comprehensive understanding of the concept of self-determination, findings from the three first studies were integrated at two times, first to constitute a base for the development of the model in the fourth study, and then to describe the context specific problems with self-determination in residential care as a synthesis in the findings section of the thesis. Integrating data by triangulating different methods and data from several sources allows for comparison to explore convergence and divergence. Convergent findings fit into each other and complement each other, but do not have to be identical (Flick, 2018). This was the case when triangulating the data for the synthesis. There were a lot of similarities between the studies but also different aspects of self-determination which made the datasets complement each other and contribute to an expanded understanding. The majority of the studies in the thesis were qualitative, nevertheless, the quantitative study contributed to valuable insights and strengthened the findings of the other studies by confirming them. However, there was divergence between the findings of Study I (interviews with residents) and Study II (the quantitative) as Study II show that the residents are satisfied with the opportunity to socialise with others while the residents in Study I feel lonely as there are few persons to socialise with. A possible explanation is that the residents downplay the importance of social interaction when answering the questionnaire in Study II as they know that it is not possible for them to participate in social activities to the extent they really want. The divergent finding in Study I can be the result of the opportunity interviews give to delve into a subject and distinguish nuances and deeper meanings which is not possible in questioners.

Trustworthiness of qualitative findings

The trustworthiness of the qualitative studies will be discussed in relation to the criteria credibility, dependability, confirmability and transferability as described by Lincoln and Guba (1985). Credibility is the overriding goal and refers to the confidence in the truth of the data and its interpretations, that is, if the findings represent the participants' reality. This criterion stipulates that the research must be carried out in a way that enhances credibility and presented in a way so that credibility is demonstrated. Credibility is not possible if there is not dependability. Dependability refers to the stability of data over time and conditions, that is, if the findings would be the same were the study repeated within a similar context and with similar participants. Confirmability concerns objectivity, meaning that the data and the interpretations represent the voices of the participants and the conditions of the inquiry, not the researchers' perspectives. Transferability is about the extent to which the findings can be transferred or have applicability in settings or groups other than the one investigated (Polit & Beck, 2016).

Besides a maximum variation sample and triangulation of data, member checks, where the participants were given an opportunity to react to the interpretations made by the researchers (Lincoln & Guba, 1985), were used to enhance credibility and confirmability. When developing the model in Study IV, member checks were used throughout the participatory research process. The focus group meetings with the advisory group started with a summary and a short discussion about the subject of the last meeting to validate the interpretations. When the model was developed, it was audited by several stakeholder groups and brought back to the advisory group for approval. In the individual interviews with staff and residents in Studies I and III, member checks were used during the interviews by asking the participants to develop their reasoning, explain their thoughts, and confirm or reject summaries made by the interviewer. Much effort was spent on being adaptable to each participant's individual narrative and asking follow-up questions to deepen understanding of individual experiences. Also, to strengthen dependability in terms of consistency in the data collection of Studies I and III, interview guides were used so that all participants in the same study were asked the same questions. Dependability was further reinforced in all three qualitative studies as the interview guides were constructed, interviews evaluated, and the various analyses made with cooperation between the researchers, allowing the prejudice to be recognised and challenged. This is also a question about confirmability, that the findings reflect the participants' voice and are not just products of the researchers' perspectives. All persons in the research group had access to the transcribed interviews, and the codes, subthemes and themes were discussed until consensus. This approach prevented hasty conclusions and allowed the prejudice of the persons in the research group to enrich the interpretations.

Confirmability, dependability and credibility were further established in the studies by providing clear, stepwise descriptions of the processes of data collection and data analysis, as well as by providing quotes from the interviews to support the subthemes and themes in Studies I and III and the categories in Study IV. Descriptions of the participants and the context of residential care were also included in the studies to enable judgements about the transferability to other contexts. Even though the studies were accomplished in a context where grown-up persons are dependent on others for their daily living, the findings might not be transferable to all such contexts. Many of the stories told by residents in the interviews relate to becoming less and less independent, a consequence of once being in possession of abilities which they are now losing. Persons with congenital disabilities and persons who became dependent on others at an early age might not share the same views, as they have not experienced independence in the same way. They can compare themselves to others, but not to what they once had themselves. The studies were conducted in Sweden, which is a part of the Western culture where autonomy and self-determination are generally valued in healthcare (Sandman, 2005). Furthermore, the right to receive information about prognosis and treatment options and to make decisions about one's own healthcare and care is statutory. The findings of these studies might not be applicable in other cultural contexts with different values, for example, those who see the family and not the individual as the most important factor, or those who regard information about possible deterioration and bad prognoses as self-fulfilling.

Conclusion

The overall conclusion of this thesis is that self-determination in the palliative phase in residential care can be facilitated and the model ‘to make and execute decisions throughout life’ presents several strategies for that purpose. The core message, ‘in my way, at my pace, with the help of you’, illustrates that self-determination is possible if the wishes and the prerequisites of the resident are the point of departure and necessary assistance is provided. Other conclusions that can be drawn from the model are that staff need to respect the residents’ decisions and regard them as competent adult persons, but that they also have a professional responsibility to balance the residents’ right to self-determination against risks in situations where the residents’ decisions and actions might affect them negatively. Knowing the residents and their life stories can help the staff to assist the residents to live according to their values, to feel safe, and to have a meaningful day. This requires good relationships between the staff and the residents, where the residents are treated as persons with equal value to the staff. Residents’ preferences should not be taken for granted: instead they should be asked about their wishes both in everyday living and in case of deterioration and life-changing situations. Paternalistic behaviour on behalf of the organisation, the staff, or family members must be recognised and thwarted.

Based on the synthesis of the findings, it can be concluded that the facilitation of self-determination is important as it is connected to the residents’ self-image and sense of dignity, and therefore to their dignity of identity. The residents are in a vulnerable situation as they can no longer trust their body and mind to make decisions and act upon them as before. As both their decisional and executional autonomy are affected, the residents are dependent on others to be able to live according to their values. When the residents’ needs are not met and they must adapt to staffing levels and routines, they are at risk of diminished self-determination and of losing control over their lives. The model ‘to make and execute decisions throughout life’ cannot solve all the negative consequences that residents' dependence, understaffing and other organisational problems have for self-determination; nevertheless, it can serve as a helpful tool in the staff’s response to the residents, as it provides an approach to care that sees each resident as a unique, competent person who can live a dignified life in accordance with his or her own values if provided with the right assistance.

Future Perspective

The laws that direct residential care emphasise that older persons should live dignified lives in accordance with their identities. This thesis shows that there is a continuous need to safeguard the residents' right to self-determination in order to protect their dignity and their identity. One way to do that is to put the model 'to make and execute decisions throughout life' into practice. Even though there are no instructions on how to use the model as a whole, there are implications for practice in the different parts of the model, as well as in the findings from the separate studies. Building trustful relationships, raising issues about deterioration and end-of-life care in time, listening to the residents' stories and wishes, facilitating the residents' own decision-making instead of taking over, and reflecting upon how the actions of staff affect the residents are examples of strategies to facilitate self-determination that can be immediately practised. Further research is needed to test the model and the best way to use it, and this is preferably done in cooperation with the stakeholders. Methods for measuring effects, implementation and long-term follow-up need to be considered.

The model is directed towards the staff and places great responsibility upon them to enable self-determination for the residents. They are required to provide professional care and healthcare that is individually tailored to meet each resident's needs. Although the model focuses on the needs of the residents, the needs of the staff must also be recognised. The organisation must provide necessary preconditions to allow staff to use and develop their skills. Staff cannot be expected to provide person-centred care if, for example, they are not given the opportunity to get to know the residents as persons and to build trustful relationships in continuous meetings. To make proper use of the model, the organisation must analyse what the staff need to be able to work according to it.

There is a lack of instruments measuring self-determination in residential care. The present studies might constitute a theoretical base for the development of such an instrument in the future.

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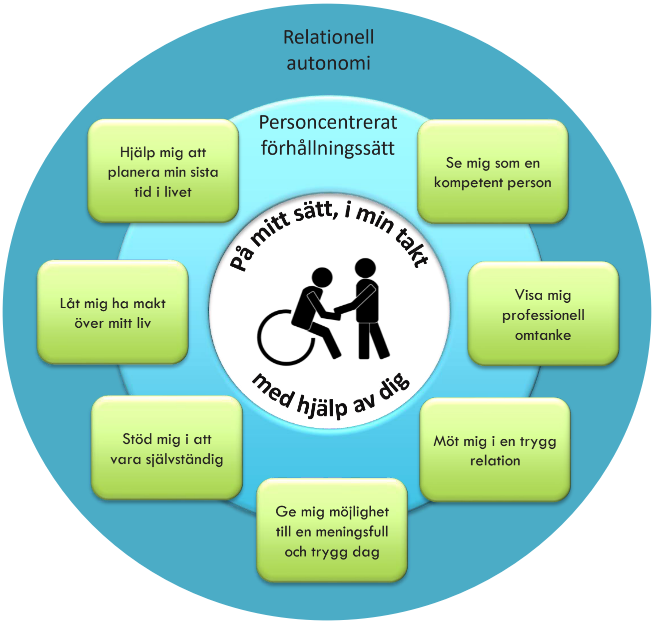
Appendix

Att fatta och genomföra beslut- livet ut



Ramona Schenell, 2020

Bakgrund

Modellen syftar till att stärka självbestämmande för personer på särskilt boende och är framtagen i samarbete mellan en forskargrupp och boende, personal och chefer på särskilt boende för äldre samt två expertgrupper inom områdena demens, äldrevård, palliativ vård och forskning. Självbestämmande definieras som att ha möjlighet att, med eller utan stöd från andra, fatta och genomföra beslut som är i linje med den egna viljan. Modellen har ett teoretiskt ramverk bestående av relationellt synsätt på autonomi och personcentrering. Relationellt synsätt på autonomi innebär att en person både ses som kapabel och sårbar och att människor genom hela livet är beroende av varandra. Om en person på grund av fysiska eller kognitiva funktionshinder har svårt att fatta och genomföra beslut självständigt kan personens självbestämmande upprätthållas genom stöd från personal eller närstående. Personcentrering innebär att vård och omsorg utgår från den äldre personens upplevelse och kunskap om sin situation. Den äldre personens erfarenhetsbaserade kunskap och personalens professionella kunskap tillmäts samma värde och tillsammans planerar, genomför och utvärderar de vården.

Modellen

Modellen heter Att fatta och genomföra beslut- livet ut och har kärnbudskapet På mitt sätt, i min takt, med hjälp av dig. Kärnbudskapet visar hur en äldre persons självbestämmande kan upprätthållas genom att hänsyn tas både till personens kapacitet och behov av stöd. Kärnbudskapet stärks av sju kategorier med strategier som främjar självbestämmande nämligen: Se mig som en kompetent person, Visa mig professionell omtanke, Möt mig i en trygg relation, Ge mig möjlighet till en meningsfull och trygg dag, Stöd mig i att vara självständig, Låt mig ha makt över mitt liv och Hjälp mig att planera min sista tid i livet.

Se mig som en kompetent person

Jag vill att ni bemöter mig som en vuxen, kompetent person som har samma rätt att bestämma över mitt liv som övriga vuxna i samhället. Utgå ifrån att jag vet vad jag vill och att vården och omsorgen ska utformas utifrån mina önskemål även när jag behöver stöd för att komma fram till och genomföra mina beslut. Ibland känner jag att ni behandlar mig som ett barn, särskilt när jag inte tillåts göra saker som jag vet att jag kan, som att använda spisen eller att duscha utan tillsyn. Jag vill därför att ni reflekterar över vilket stöd just jag behöver eftersom det kan se annorlunda ut än för andra som bor här. Att förlora förmågor, bli beroende av andra och att inte kunna göra saker som tidigare varit självklara, som att gå på toaletten, kan göra att jag känner mig mindre värd. Ni som personal behöver uppmärksamma och bekräfta de känslor jag har kring mina förlorade förmågor och hjälp mig att känna mig som en vuxen, kompetent person genom att kompensera för de förluster som jag har gjort och hjälpa mig att ta till vara på de förmågor jag har kvar.

Visa mig professionell omtanke

När jag berättar hur jag mår, eller på annat sätt visar att något inte är bra, vill jag att ni lyssnar på mig och använder er professionella kompetens för att lindra mina symptom. Ibland behöver jag hjälp att ta till vara mina egna intressen för att skyddas från skada och bevara min värdighet. Om jag inte själv kan ansvara för att till exempel klä mig i rena kläder eller borsta håret, som jag brukar innan jag träffar andra, måste ni som personal hjälpa mig med det. Om jag gör något som är riskfyllt för mig själv eller någon annan behöver jag få hjälp att förstå konsekvenserna. Om vi är oense om vad som ska göras kan jag, om möjligt, föreslå egna lösningar på problemet. Om ni tycker att mina egna lösningar verkar för riskfyllda kan vi förhandla om en annan lösning. Utifrån er yrkeskompetens får ni förklara och motivera, på ett sätt som jag förstår, varför ni förespråkar vissa beslut och insatser när jag själv känner mig tveksam eller inte vill. I situationer där mitt självbestämmande ställs mot ert professionella ansvar kan ni låta någon annan försöka hjälpa mig, avvakta en stund eller distrahera mig. När ert yrkesmässiga ansvar gör att ni känner att ni måste göra något mot min vilja måste ni också noga reflektera över om ni hjälper mig eller om ni passerar gränsen och utsätter mig för tvång.

Möt mig i en trygg relation

För att skapa bra förutsättningar för mitt självbestämmande behövs en relation mellan mig och er där jag känner mig trygg, vänligt bemött och sedd som en person som har samma värde som er som personal. En trygg relation gynnas av att vi träffas kontinuerligt och kan utvecklas i både korta och långa möten om ni visar intresse och lyssnar på vad jag har att säga. Ni behöver visa att ni är tillgängliga för samtal och att ni har den kompetens och det engagemang som krävs för att hjälpa mig på det sätt jag vill. Jag behöver få utrymme att berätta om mitt liv i den utsträckning som jag själv vill och känna att ni är intresserade av vad som är viktigt för mig. Mina närstående kan vara till hjälp om jag själv inte kan berätta om vem jag är. Ibland missförstår jag saker och kan till exempel tro att jag är ung igen eller att jag måste resa någonstans. Om det händer, försök att möta mig där jag är, och om du måste säga att jag har fel, gör det på ett sätt så att jag inte känner mig dum eller skäms. Jag vill ha en särskilt utsedd kontaktperson som har tid avsatt för att regelbundet planera, genomföra och utvärdera sådant som är viktigt för mig. Kontaktpersonens uppdrag ska vara tydligt så att jag vet vad jag kan förvänta mig av vår relation.

Ge mig möjlighet till en meningsfull och trygg dag

Med stigande ålder, beroende av andras hjälp och flytt till särskilt boende har vardagen förändrats för mig. Trots att jag inte kan leva precis som förr vill jag känna mening och trygghet och jag vill fortsätta att utvecklas och uppleva saker som får mig att må bra och ger mig livskvalitet. Jag vill kunna känna mening och trygghet även när det är mindre personal på plats som på kvällar och helger. Även om jag är i behov av hjälp vill jag inte bara vara en passiv mottagare, jag vill också kunna ge och känna att jag är av betydelse för andra. Jag vill inte uppleva ofrivillig ensamhet utan ha möjlighet att delta i social gemenskap och kunna påverka min tillvaro genom att själv eller via ombud delta i möten med personal och andra personer som bor här. Jag kan behöva hjälp att skapa och genomföra meningsfulla aktiviteter och ibland måste ni tolka vad ni tror att jag uppskattar, då kan mina närstående vara till hjälp. När jag känner mig orolig behöver jag er hjälp för att bli trygg igen. För att alla som är berörda ska veta vad som gör mig trygg och hur jag vill ha det behöver mina önskemål och hur de ska genomföras dokumenteras, utvärderas och uppdateras regelbundet i samverkan mellan mig, er och eventuellt mina närstående

Stöd mig i att vara självständig

Trots att jag är beroende av andras hjälp ska jag ha möjlighet att fatta och genomföra beslut så självständigt som jag vill. Genom att jag får göra saker på mitt sätt och i min egen takt bevarar jag kontrollen över mitt liv och upprätthåller de förmågor jag har. Om jag kan och vill knäppa mina knappar själv ska jag få göra det även om ni som personal gör det snabbare. Jag vill att ni tar er tid och visar mig hur jag kan göra olika saker och ibland behöver ni utmana mig till att klara sådant som jag känner mig osäker inför. Om jag behöver stöd i att fatta beslut kan vi diskutera tillsammans eller ta hjälp av mina närstående. Ni kan också erbjuda mig olika valmöjligheter och ge mig det stöd jag behöver för att kunna välja. Ibland lämnar jag över beslut och genomförande helt eller delvis till er som personal eller till mina närstående. Om ni som personal är stressade eller verkar ointresserade kan jag tveka att uttrycka min åsikt eller be om hjälp. Genom att ni tar er tid att prata med mig och visa att ni är intresserade av vad jag har att säga kan ni underlätta självbestämmandet för mig så att jag inte drar mig för att säga min åsikt i rädsla för att vara till besvär.

Låt mig ha makt över mitt liv

Jag vill ha makt över mitt eget liv, även om jag är i behov av er hjälp. Det får jag om ni som personal frågar hur jag vill ha det istället för att ta för givet eller göra saker på ert sätt. Makten över mitt liv ökar också när ni knackar på dörren innan ni kommer in och när ni presenterar er om vi inte har träffats tidigare eller om jag inte kan se eller höra vem det är. Ni måste också hjälpa mig, i den utsträckning jag behöver, att utföra de aktiviteter jag vill göra. Även om andra tycker annorlunda ska mina beslut respekteras och jag kan behöva er hjälp att föra min talan gentemot annan personal eller närstående. Ibland tror jag att jag måste anpassa mig och göra som andra säger eftersom jag bor på ett äldreboende, då behöver jag hjälp att förstå att jag har samma rätt att bestämma över mitt liv som innan jag flyttade till boendet. Eftersom jag är beroende av er hjälp befinner jag mig i ett maktunderläge. Ni behöver vara medvetna om er maktposition och hur den påverkar mig. Mitt självbestämmande kan öka genom att ni tänker er in i min situation, diskuterar med varandra och reflektera över vad den ojämna maktbalansen innebär.

Hjälp mig att planera min sista tid i livet

För att jag ska ha inflytande över beslut som handlar om försämringar i mitt hälsotillstånd och livets slutskede måste samtal om detta påbörjas i tid. Ni som personal behöver vara uppmärksamma på förändringar och kommunicera om dem med mig och med varandra, både inom och mellan era olika yrkeskategorier. Eftersom jag levt ett långt liv och känner min kropp så kommer de frågorna troligen inte som en överraskning för mig. Ni ska inte vänta på att jag själv lyfter frågor om försämring, livsuppehållande behandling, som till exempel hjärtlungräddning, eller döende. Det är ert, och särskilt läkarens, ansvar som professionella att erbjuda information om prognos, behandlingsalternativ och vilken vård som kan erbjudas på boendet respektive sjukhuset men samtalen ska ske i den takt som passar mig och jag bestämmer själv i vilken omfattning och med vem jag vill diskutera detta. Om jag inte kan berätta själv hur jag vill ha det kan mina närstående vara till hjälp men de kan också behöva stöd av er i dessa frågor och deras önskemål ska inte ges företräde framför mina. I livets slut kan andra saker bli viktiga för mig än det som tidigare gett mening, välbefinnande och trygghet och därför behöver planer kring min vård och omsorg uppdateras. Det är också viktigt att alla som är berörda känner till hur jag vill ha det. För att öka mina möjligheter att vara självbestämmande livet ut ska rutiner kring planering av livets slut finnas och vara kända av all personal.

KUPQ

KVALITET UR PATIENTENS PERSPEKTIV

1. Din ålder (antal år)

____

2. Ditt kön

☐ Man
☐ Kvinna
☐ Annat

3. Var är du född?

☐ Sverige
☐ Övriga Norden
☐ Övriga Europa
☐ Övriga världen

4. Din utbildning (ange högsta)

☐ Folkskola/Grundskola (motsvarande)
☐ Yrkesskola/Gymnasium (motsvarande)
☐ Högskola/Universitet
☐ Annan utbildning

5. Hur länge har du bott på särskilt boende?

☐ Mindre än 6 månader
☐ 6-12 månader
☐ 1-2 år
☐ 2-3 år
☐ 3-4 år
☐ Mer än 4 år

6. Hur tycker du att ditt fysiska hälsotillstånd är nu?

☐ Mycket dåligt
☐ Ganska dåligt
☐ Varken bra eller dåligt
☐ Ganska bra
☐ Mycket bra

7. Hur tycker du att ditt psykiska hälsotillstånd är nu?

☐ Mycket dåligt
☐ Ganska dåligt
☐ Varken bra eller dåligt
☐ Ganska bra
☐ Mycket bra

8. Har du någon eller några av dessa sjukdomar?

☐ Hjärtsjukdom
☐ Lungsjukdom
☐ Cancer
☐ Neurologisk sjukdom
☐ Annan

9. Om du har svarat 'Annan' på föregående fråga - Vilka andra sjukdomar har du?

....
....
....
....
....

10. Hur ofta låter du din närstående fatta beslut åt dig?

☐ Aldrig
☐ 1 gång i månaden
☐ 2-3 gånger i månaden
☐ En gång i veckan
☐ Flera gånger i veckan
☐ Varje dag

11. Hur ofta fattar din närstående beslut mot din vilja?

☐ Aldrig
☐ 1 gång i månaden
☐ 2-3 gånger i månaden
☐ En gång i veckan
☐ Flera gånger i veckan
☐ Varje dag
☐ Vet ej

12. Hur ofta låter du personalen fatta beslut åt dig?

☐ Aldrig
☐ 1 gång i månaden
☐ 2-3 gånger i månaden
☐ En gång i veckan
☐ Flera gånger i veckan
☐ Varje dag

13. Hur ofta fattar personalen beslut mot din vilja?

☐ Aldrig
☐ 1 gång i månaden
☐ 2-3 gånger i månaden
☐ En gång i veckan
☐ Flera gånger i veckan
☐ Varje dag
☐ Vet ej

14. Kommentarer:

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Markera ditt svar med **två kryss på varje rad**.
1) sätt ett kryss under **A** (☐☐☐☐☐) som graderar upplevelsen.
2) sätt ett kryss under **B** (○○○○○) som graderar betydelsen.

	A SÅ HÄR ÄR DET FÖR MIG					**B** SÅ HÄR BETYDELSEFULLT ÄR DET FÖR MIG				
	Instämmer helt	Instämmer till stor del	Instämmer delvis	Instämmer inte alls	Ej aktuellt	Av allra största betydelse	Av stor betydelse	Av ganska stor betydelse	Av liten eller ingen betydelse	Ej aktuellt
15. Jag får bästa möjliga stöd/hjälp vid måltider	☐	☐	☐	☐	☐	○	○	○	○	○
16. Jag får bästa möjliga stöd/hjälp att komma utomhus	☐	☐	☐	☐	☐	○	○	○	○	○
17. Jag får bästa möjliga stöd/hjälp med min personliga hygien	☐	☐	☐	☐	☐	○	○	○	○	○
18. Jag får bästa möjliga stöd/hjälp med munvård	☐	☐	☐	☐	☐	○	○	○	○	○
19. Jag får bästa möjliga stöd/hjälp i samband med toalettbesök	☐	☐	☐	☐	☐	○	○	○	○	○
20. Jag får bästa möjliga stöd/hjälp med att sitta och ligga bekvämt	☐	☐	☐	☐	☐	○	○	○	○	○
21. Jag får bästa möjliga stöd/hjälp när jag känner mig ensam	☐	☐	☐	☐	☐	○	○	○	○	○
22. Jag får bästa möjliga stöd/hjälp när jag känner oro, ångest eller rädsla	☐	☐	☐	☐	☐	○	○	○	○	○
23. Jag får bästa möjliga stöd/hjälp att tillgodose mina andliga/kulturella behov	☐	☐	☐	☐	☐	○	○	○	○	○
24. Jag får effektiv smärtlindring	☐	☐	☐	☐	☐	○	○	○	○	○
25. Jag får effektiv symtomlindring (avser andra symtom än smärta)	☐	☐	☐	☐	☐	○	○	○	○	○

Markera ditt svar med **två kryss på varje rad**.
1) sätt ett kryss under **A** (☐☐☐☐☐) som graderar upplevelsen.
2) sätt ett kryss under **B** (○○○○○) som graderar betydelsen.

	A SÅ HÄR ÄR DET FÖR MIG					**B** SÅ HÄR BETYDELSEFULLT ÄR DET FÖR MIG				
	Instämmer helt	Instämmer till stor del	Instämmer delvis	Instämmer inte alls	Ej aktuellt	Av allra största betydelse	Av stor betydelse	Av ganska stor betydelse	Av liten eller ingen betydelse	Ej aktuellt
26. Personalen bemöter mig med respekt	☐	☐	☐	☐	☐	○	○	○	○	○
27. Personalen visar engagemang ”bryr sig om mig”	☐	☐	☐	☐	☐	○	○	○	○	○
28. Personalen har tid att samtala/prata med mig	☐	☐	☐	☐	☐	○	○	○	○	○
29. Personalen har god kompetens för sina arbetsuppgifter	☐	☐	☐	☐	☐	○	○	○	○	○
30. Jag har bra möjlighet att delta i beslut när det gäller min vård, omsorg och rehabilitering	☐	☐	☐	☐	☐	○	○	○	○	○
31. Jag har bra möjlighet att påverka hur hjälpen ska utföras	☐	☐	☐	☐	☐	○	○	○	○	○
32. Jag har bra möjlighet att utöva den förströelse/sysselsättning som jag önskar	☐	☐	☐	☐	☐	○	○	○	○	○
33. Jag har bra möjlighet att umgås med andra i den utsträckning som jag önskar	☐	☐	☐	☐	☐	○	○	○	○	○
34. Jag får hjälp av personal som jag känner igen	☐	☐	☐	☐	☐	○	○	○	○	○
35. Jag törs framföra mina synpunkter till personalen	☐	☐	☐	☐	☐	○	○	○	○	○
36. Jag har lätt att nå personalen via larmet	☐	☐	☐	☐	☐	○	○	○	○	○

Markera ditt svar med **två kryss på varje rad**.
1) sätt ett kryss under **A** (☐☐☐☐☐) som graderar upplevelsen.
2) sätt ett kryss under **B** (○○○○○) som graderar betydelsen.

		A SÅ HÄR ÄR DET FÖR MIG					**B** SÅ HÄR BETYDELSEFULLT ÄR DET FÖR MIG				
		Instämmer helt	Instämmer till stor del	Instämmer delvis	Instämmer inte alls	Ej aktuellt	Av allra största betydelse	Av stor betydelse	Av ganska stor betydelse	Av liten eller ingen betydelse	Ej aktuellt
37.	Personalen känner till hur jag vill ha det i vardagliga beslut, t ex mat, dryck, klädsel	☐	☐	☐	☐	☐	○	○	○	○	○
38.	Personalen känner till hur jag vill ha det i livsavgörande beslut, t ex livsuppehållande åtgärder som dropp, sjukhusinläggning, hjärt- och lungräddning	☐	☐	☐	☐	☐	○	○	○	○	○
39.	Personalen skulle fatta rätt beslut utifrån min vilja om de skulle ta över mitt beslutsfattande	☐	☐	☐	☐	☐	○	○	○	○	○
40.	Min närstående känner till hur jag vill ha det i vardagliga beslut, t ex mat, dryck, klädsel	☐	☐	☐	☐	☐	○	○	○	○	○
41.	Min närstående känner till hur jag vill ha det i livsavgörande beslut, t ex livsuppehållande åtgärder som dropp, sjukhusinläggning, hjärt- och lungräddning	☐	☐	☐	☐	☐	○	○	○	○	○
42.	Jag känner mig säker på att min närstående skulle fatta rätt beslut utifrån min vilja om han/hon skulle ta över mitt beslutsfattande	☐	☐	☐	☐	☐	○	○	○	○	○
43.	Jag får mat och dryck som jag tycker om	☐	☐	☐	☐	☐	○	○	○	○	○
44.	Jag har tillgång till de hjälpmedel jag behöver	☐	☐	☐	☐	☐	○	○	○	○	○

Tack för din medverkan!

KUPQ

KVALITET UR PATIENTENS PERSPEKTIV

1. Min närståendes ålder (antal år)

____

2. Min närstående är

☐ Man
☐ Kvinna
☐ Annat

Markera ditt svar med **två kryss på varje rad**.
1) sätt ett kryss under **A** (☐☐☐☐☐☐) som graderar upplevelsen.
2) sätt ett kryss under **B** (○○○○○) som graderar betydelsen.
Eller sätt ett kryss under **Ej aktuellt** eller **Vet ej**.

	A SÅ HÄR VAR DET FÖR MIN NÄRSTÅENDE						**B** SÅ HÄR BETYDELSEFULLT ÄR DET FÖR MIN NÄRSTÅENDE				
	Instämmer helt	Instämmer till stor del	Instämmer delvis	Instämmer inte alls	Ej aktuellt	Vet ej	Av allra största betydelse	Av stor betydelse	Av ganska stor betydelse	Av liten eller ingen betydelse	Ej aktuellt
3. Min närstående får bästa möjliga stöd/hjälp vid måltider	☐	☐	☐	☐	☐	☐	○	○	○	○	○
4. Min närstående får bästa möjliga stöd/hjälp att komma utomhus	☐	☐	☐	☐	☐	☐	○	○	○	○	○
5. Min närstående får bästa möjliga stöd/hjälp med sin personliga hygien	☐	☐	☐	☐	☐	☐	○	○	○	○	○
6. Min närstående får bästa möjliga stöd/hjälp med munvård	☐	☐	☐	☐	☐	☐	○	○	○	○	○
7. Min närstående får bästa möjliga stöd/hjälp i samband med toalettbesök	☐	☐	☐	☐	☐	☐	○	○	○	○	○
8. Min närstående får bästa möjliga stöd/hjälp med att sitta och ligga bekvämt	☐	☐	☐	☐	☐	☐	○	○	○	○	○
9. Min närstående får bästa möjliga stöd/hjälp när han/hon känner sig ensam	☐	☐	☐	☐	☐	☐	○	○	○	○	○
10. Min närstående får bästa möjliga stöd/hjälp när han/hon känner oro, ångest eller rädsla	☐	☐	☐	☐	☐	☐	○	○	○	○	○
11. Min närstående får bästa möjliga stöd/hjälp att tillgodose sina andliga/kulturella behov	☐	☐	☐	☐	☐	☐	○	○	○	○	○
12. Min närstående får effektiv smärtlindring	☐	☐	☐	☐	☐	☐	○	○	○	○	○
13. Min närstående får effektiv symtomlindring (avser andra symtom än smärta)	☐	☐	☐	☐	☐	☐	○	○	○	○	○

Markera ditt svar med **två kryss på varje rad**.
1) sätt ett kryss under **A** (☐☐☐☐☐☐) som graderar upplevelsen.
2) sätt ett kryss under **B** (○○○○○) som graderar betydelsen.
Eller sätt ett kryss under **Ej aktuellt** eller **Vet ej**.

	A SÅ HÄR VAR DET FÖR MIN NÄRSTÅENDE						**B** SÅ HÄR BETYDELSEFULLT ÄR DET FÖR MIN NÄRSTÅENDE				
	Instämmer helt	Instämmer till stor del	Instämmer delvis	Instämmer inte alls	Ej aktuellt	Vet ej	Av allra största betydelse	Av stor betydelse	Av ganska stor betydelse	Av liten eller ingen betydelse	Ej aktuellt
14. Personalen bemöter min närstående med respekt	☐	☐	☐	☐	☐	☐	○	○	○	○	○
15. Personalen visar engagemang ”bryr sig om min närstående”	☐	☐	☐	☐	☐	☐	○	○	○	○	○
16. Personalen har tid att samtala/prata med min närstående	☐	☐	☐	☐	☐	☐	○	○	○	○	○
17. Personalen har god kompetens för sina arbetsuppgifter	☐	☐	☐	☐	☐	☐	○	○	○	○	○
18. Min närstående har bra möjlighet att delta i beslut när det gäller sin vård, omsorg och rehabilitering	☐	☐	☐	☐	☐	☐	○	○	○	○	○
19. Min närstående har bra möjlighet att påverka hur hjälpen ska utföras	☐	☐	☐	☐	☐	☐	○	○	○	○	○
20. Min närstående har bra möjlighet att utöva den förströelse/ sysselsättning som han/hon önskar	☐	☐	☐	☐	☐	☐	○	○	○	○	○
21. Min närstående har bra möjlighet att umgås med andra i den utsträckning som han/hon önskar	☐	☐	☐	☐	☐	☐	○	○	○	○	○
22. Min närstående får hjälp av personal som han/hon känner igen	☐	☐	☐	☐	☐	☐	○	○	○	○	○
23. Min närstående törs framföra sina synpunkter till personalen	☐	☐	☐	☐	☐	☐	○	○	○	○	○
24. Min närstående har lätt att nå personalen via larmet	☐	☐	☐	☐	☐	☐	○	○	○	○	○

Markera ditt svar med **två kryss på varje rad**.
1) sätt ett kryss under **A** (☐☐☐☐☐☐) som graderar upplevelsen.
2) sätt ett kryss under **B** (○○○○○) som graderar betydelsen.
Eller sätt ett kryss under **Ej aktuellt** eller **Vet ej**.

	A SÅ HÄR VAR DET FÖR MIN NÄRSTÅENDE						**B** SÅ HÄR BETYDELSEFULLT ÄR DET FÖR MIN NÄRSTÅENDE				
	Instämmer helt	Instämmer till stor del	Instämmer delvis	Instämmer inte alls	Ej aktuellt	Vet ej	Av allra största betydelse	Av stor betydelse	Av ganska stor betydelse	Av liten eller ingen betydelse	Ej aktuellt
25. Personalen känner till hur min närstående vill ha det i vardagliga beslut, t ex mat, dryck, klädsel	☐	☐	☐	☐	☐	☐	○	○	○	○	○
26. Personalen känner till hur min närstående vill ha det i livsavgörande beslut t ex, livsuppehållande åtgärder som dropp, sjukhusinläggning, hjärt- och lungräddning	☐	☐	☐	☐	☐	☐	○	○	○	○	○
27. Personalen skulle fatta rätt beslut utifrån min närståendes vilja om de skulle ta över beslutsfattandet från honom/henne	☐	☐	☐	☐	☐	☐	○	○	○	○	○
28. Min närstående får mat och dryck som han/hon tycker om	☐	☐	☐	☐	☐	☐	○	○	○	○	○
29. Min närstående har tillgång till de hjälpmedel han/hon behöver	☐	☐	☐	☐	☐	☐	○	○	○	○	○

Följande frågor gäller dig som besvarar formuläret

30. Din ålder (antal år)

____

31. Ditt kön

☐ Man
☐ Kvinna
☐ Annat

32. Var är du född?

☐ Sverige
☐ Övriga Norden
☐ Övriga Europa
☐ Övriga världen

33. Din utbildning (ange högsta)

☐ Folkskola/Grundskola (motsvarande)
☐ Yrkesskola/Gymnasium (motsvarande)
☐ Högskola/Universitet
☐ Annan utbildning

34. Din sysselsättning

☐ Yrkesarbetande
☐ Pensionär
☐ Studerande
☐ Annat

35. Din relation till den som bor på särskilt boende

☐ Make/Maka/Partner
☐ Barn
☐ Annan släkting
☐ Vän
☐ Annan

36. Hur länge har din närstående bott på särskilt boende?

☐ Mindre än 6 månader
☐ 6-12 månader
☐ 1-2 år
☐ 2-3 år
☐ 3-4 år
☐ Mer än 4 år

37. Hur många gånger har du träffat din närstående den senaste månaden?

☐ Ingen gång
☐ 1 gång i månaden
☐ 2-3 gånger i månaden
☐ En gång i veckan
☐ Flera gånger i veckan
☐ Varje dag

38. Hur ofta har du haft telefonkontakt med din närstående den senaste månaden?

☐ Ingen gång
☐ 1 gång i månaden
☐ 2-3 gånger i månaden
☐ En gång i veckan
☐ Flera gånger i veckan
☐ Varje dag

39. Hur tycker du att din närståendes fysiska hälsotillstånd är nu?

☐ Mycket dåligt
☐ Ganska dåligt
☐ Varken bra eller dåligt
☐ Ganska bra
☐ Mycket bra

40. Hur tycker du att din närståendes psykiska hälsotillstånd är nu?

☐ Mycket dåligt
☐ Ganska dåligt
☐ Varken bra eller dåligt
☐ Ganska bra
☐ Mycket bra

41. Hur ofta fattar personalen beslut åt din närstående?

- ☐ Aldrig
- ☐ 1 gång i månaden
- ☐ 2-3 gånger i månaden
- ☐ En gång i veckan
- ☐ Flera gånger i veckan
- ☐ Varje dag
- ☐ Vet ej

42. Hur ofta fattar personalen beslut mot din närståendes vilja?

- ☐ Aldrig
- ☐ 1 gång i månaden
- ☐ 2-3 gånger i månaden
- ☐ En gång i veckan
- ☐ Flera gånger i veckan
- ☐ Varje dag
- ☐ Vet ej

43. Hur ofta fattar du beslut åt din närstående?

- ☐ Aldrig
- ☐ 1 gång i månaden
- ☐ 2-3 gånger i månaden
- ☐ En gång i veckan
- ☐ Flera gånger i veckan
- ☐ Varje dag

44. Hur ofta fattar du beslut mot din närståendes vilja?

- ☐ Aldrig
- ☐ 1 gång i månaden
- ☐ 2-3 gånger i månaden
- ☐ En gång i veckan
- ☐ Flera gånger i veckan
- ☐ Varje dag
- ☐ Vet ej

45. Kommentarer:

Markera ditt svar med **två kryss på varje rad**.
1) sätt ett kryss under **A** (☐☐☐☐☐) som graderar upplevelsen.
2) sätt ett kryss under **B** (○○○○○) som graderar betydelsen.

		A					**B**				
		SÅ HÄR ÄR DET FÖR MIG					SÅ HÄR BETYDELSEFULLT ÄR DET FÖR MIG				
		Instämmer helt	Instämmer till stor del	Instämmer delvis	Instämmer inte alls	Ej aktuellt	Av allra största betydelse	Av stor betydelse	Av ganska stor betydelse	Av liten eller ingen betydelse	Ej aktuellt
46.	Personalen bemöter mig med respekt	☐	☐	☐	☐	☐	○	○	○	○	○
47.	Personalen visar engagemang ”bryr sig om mig”	☐	☐	☐	☐	☐	○	○	○	○	○
48.	Jag har bra möjlighet att delta i beslut när det gäller min närståendes vård, omsorg och rehabilitering	☐	☐	☐	☐	☐	○	○	○	○	○
49.	Jag har bra möjlighet att påverka hur hjälpen till min närstående ska utföras	☐	☐	☐	☐	☐	○	○	○	○	○
50.	Jag får bra information om vem jag ska kontakta om jag har frågor om min närståendes vård, omsorg och rehabilitering	☐	☐	☐	☐	☐	○	○	○	○	○
51.	Jag får bra information om min närståendes sjukdom och dess förlopp	☐	☐	☐	☐	☐	○	○	○	○	○
52.	Jag får bra information om mina möjligheter till personligt stöd	☐	☐	☐	☐	☐	○	○	○	○	○
53.	Jag får bra information om mina möjligheter till avlösning	☐	☐	☐	☐	☐	○	○	○	○	○
54.	Jag får bra information om anhöriggrupper	☐	☐	☐	☐	☐	○	○	○	○	○
55.	Jag känner till hur min närstående vill ha det i vardagliga beslut, t ex mat, dryck, klädsel	☐	☐	☐	☐	☐	○	○	○	○	○
56.	Jag känner till hur min närstående vill ha det i livsavgörande beslut t ex, livsuppehållande åtgärder som dropp, sjukhusinläggning, hjärt- och lungräddning	☐	☐	☐	☐	☐	○	○	○	○	○
57.	Jag känner mig säker på att jag skulle fatta rätt beslut utifrån min närståendes vilja om jag skulle ta över beslutsfattandet	☐	☐	☐	☐	☐	○	○	○	○	○

Tack för din medverkan!