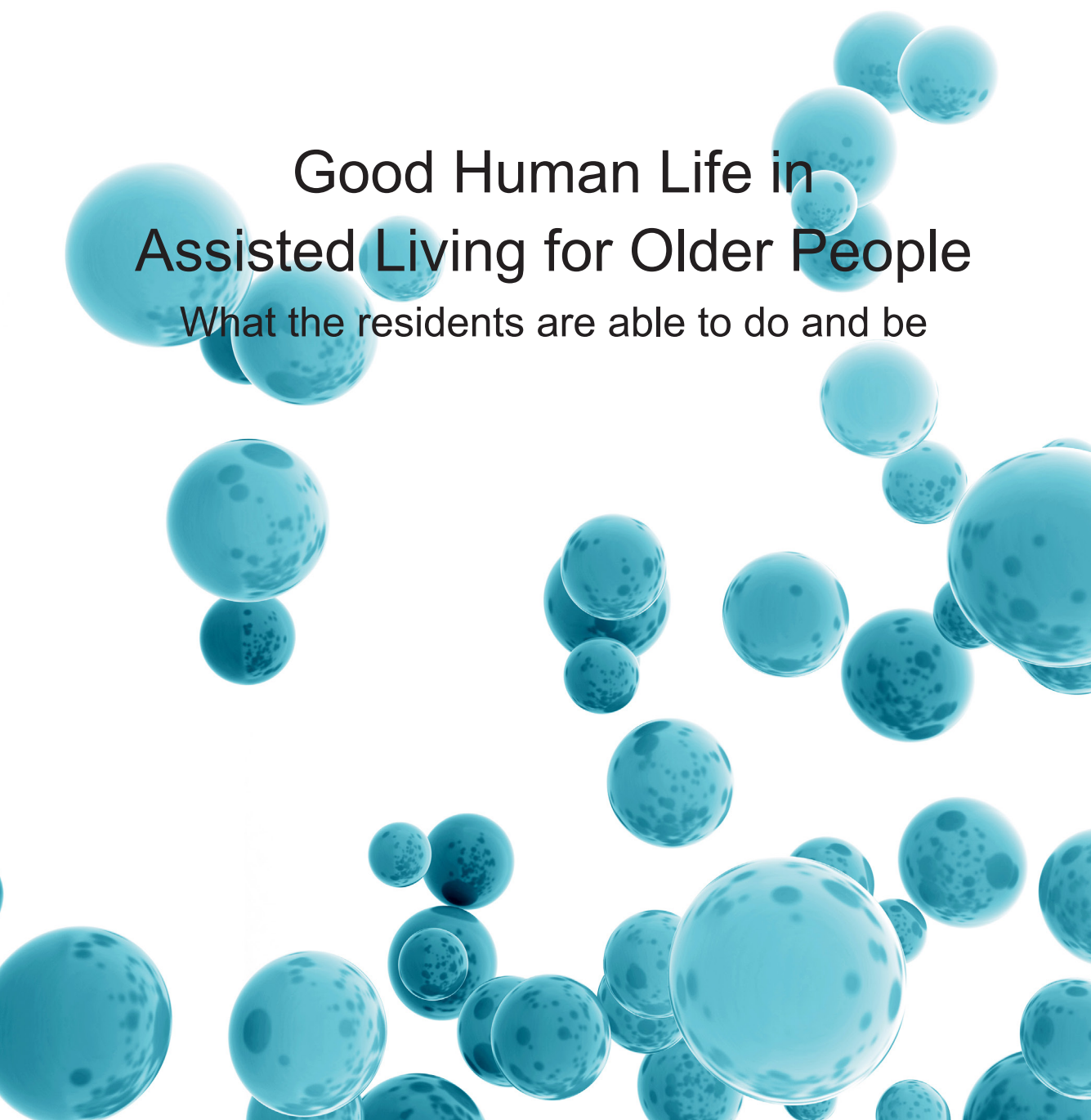


JARI PIRHONEN

Good Human Life in Assisted Living for Older People

What the residents are able to do and be





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ACADEMIC DISSERTATION

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JARI PIRHONEN

Good Human Life in
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List of original publications

1. Pirhonen, J. & Pietilä, I. (2016). Perceived resident-facility fit and sense of control in assisted living. *Journal of Aging Studies*, 38, 47–56.
2. Pirhonen, J. & Pietilä, I. (2016). Active and non-active agents: residents' agency in assisted living. *Ageing and Society*. Published online 30 August 2016. DOI: 10.1017/S0144686X1600074X.
3. Pirhonen, J. & Pietilä I. (2015). Patient, resident, or person: Recognition and the continuity of self in long-term care for older people. *Journal of Aging Studies*, 35, 95–103.
4. Pirhonen, J., Tiilikainen, E. & Pietilä, I. (2017). Ruptures of affiliation: social isolation in assisted living for older people. *Ageing and Society*, published online 14 March 2017. DOI: 10.1017/S0144686X17000289.

Abstract

Rapid structural change in long-term elderly care in Finland has increased the number of facilities providing assisted living services for older people. Assisted living carries the promise of providing older people with less institutional living arrangements, better chances to maintain individualistic lifestyles, and better prerequisites for autonomy. In Finland as in the rest of the West, person-centered care has become the new watchword for high quality assisted living services for older people. Person-centeredness entails service provision being guided by an individual's values and desires, aiming to secure the individual's independence. Since such an emphasis on the clientele's independence in assisted living might be slightly misleading, the aim of this research was to reassess the substance of person-centeredness.

The research question then became how older people could perform their personhood. Based on the Capabilities Approach, the question sharpened into what the residents were able to do and be while residing in assisted living. The residents' doings were approached through their autonomy and agency, and beings through their chances to be recognized as persons and to reach affiliation in their living surroundings.

An ethnographical research frame was chosen to study the residents' autonomy, agency, recognition, and affiliation in their ordinary living surroundings. Participant observation was conducted in two elderly care facilities in southern Finland in 2013. In addition, the residents of an assisted living facility were interviewed in 2014.

The residents' autonomy was found to be essentially relational. The residents' remaining functional abilities had a positive effect on their autonomy but did not dictate it. The residents sustained their feeling of autonomy for example by utilizing people outside the facility, compensating age-based losses in multiple ways, and emphasizing the possibilities to act instead of actual acting.

Due to reduced functional abilities, residents' agency was not action-oriented but encompassed being as well as doing. The major finding was that instead of traditional agency, we could speak about agentic spaces in assisted living. Agentic spaces were created when the residents' capabilities and motivations met the affordances of the surroundings.

The residents were recognized and misrecognized as persons for several reasons connected to the resourcing of care, the daily routines of the facility, and the staff's attitudes. Major reasons why residents were not recognized as persons were the residents' invisibility, staff timetables, standard treatment, the dominant role of documents, and shifting responsibility. On the other hand, residents were recognized through offering them privacy, giving them opportunities to continue life-long habits, joking and chatting with them, and putting an active emphasis on their wishes.

The residents' affiliation was studied via ruptures in it, i.e. feelings of isolation, which were based on multiple factors ranging from residents' life histories and their personalities to the resourcing of care and the facility's working culture. The residents' affiliation in a facility was based on their opportunities to bond with people on site on the one hand, and people outside the facility on the other hand.

Based on this empirical study, autonomy, agency, recognition, and affiliation were found to be central personhood-related capabilities since the four are important when people perform their personhood. When the emphasis shifts from being a person to performing one's personhood, we could define a person as a relationally autonomous individual utilizing agentic spaces, who is recognized and accepted by others. Being a person is thus a matter of both individuality and community. This definition secures dignity-supporting care for those older people unable to form a conception of good life and/or communicate it to others. Vulnerable older peoples' treatment should be based on their normatively relevant human features. In addition to this maxim, the recognition-oriented care philosophy, constructed in this study, is not a package of instructions but a constant process of ethical deliberation.

Tiivistelmä

Tehostettu palveluasuminen on kasvattanut nopeasti osuuttaan vanhojen ihmisten ympärivuorokautisen hoidon muotona. Vanhainkoti- ja terveyskeskushoitoon verrattuna tehostettu palveluasuminen nähdään vähemmän laitospäivähoitona, joka mahdollistaa vanhoille ihmisille yksilöllisemmän ja autonomisemman elämän. Samalla asiakaslähtöisyydestä on tullut hoidon laadun kriteeri asumispalveluyksiköissä Suomessa aivan samoin kuin muuallakin länsimaissa. Asiakaslähtöisyys tarkoittaa, että palvelut räätälöidään yksilön arvojen ja tarpeiden mukaisesti eli hänen itsemääräämisenänsä turvaten. Koska itsemääräämisen korostaminen haavoittuvassa asemassa olevien ihmisten kohdalla ei ole ongelmallista, tämän tutkimuksen tarkoituksena oli määrittellä asiakaslähtöisyys uudelleen tehostetun palveluasumisen kontekstissa.

Tutkimustehtäväksi muotoutui näin ollen se, kuinka vanhat ihmiset onnistuvat toteuttamaan persoonuuttaan tehostetussa palveluasumisessa. Toimintamahdollisuusteorian pohjalta tutkimuskysymykseksi tarkentui, mitä asukkaat voivat tehdä ja olla eläessään tehostetussa palveluasumisessa. Asukkaiden tekemisen mahdollisuuksia lähestyttiin heidän autonomiansa ja toimijuutensa näkökannalta ja heidän olemistaan tarkasteltiin mahdollisuutena tulla persoonana tunnustetuksi ja säilyttää osallisuuden kokemus tehostetun palveluasumisen ympäristössä.

Tutkimuksessa asukkaiden autonomiaa, toimijuutta, tunnustetuksi tuleamista ja osallisuutta tarkasteltiin etnografisella tutkimusmetodologialla. Osallistuvaa havainnointia tehtiin kahdessa etelä-suomalaisessa ympärivuorokautisen hoidon yksikössä vuonna 2013 ja sen lisäksi tehostetun palveluasumisen asukkaita haastateltiin vuonna 2014.

Asukkaiden autonomia oli luonteeltaan varsin relationaalista eli monista ihmisen itsensä ulkopuolisista asioista riippuvaista. Asukkaiden oma jäljellä oleva toimintakyky tuki heidän autonomisuuttaan, mutta ei määrittänyt sitä. Toimintakykyään menettäneiden asukkaiden autonomian tunnetta tukivat sukulaiset ja ystävät palvelutalon ulkopuolella. He myös kompensoivat toimintakykymentyksiään monin tavoin ja korostivat tekemisen mahdollisuuksia itse tekemisen sijaan.

Heikkenevän toimintakyvyn vuoksi asukkaiden toimijuus ei ollut selkeästi toimintakeskeistä, vaan toimijuuteen sisältyi yhä enemmän olemisen piirteitä tekemisen lisäksi. Päälöytönä toimijuuden osalta voidaan pitää sitä, että asukkaiden kohdalla ei ehkä kannattaisikaan puhua toimijuudesta sanan perinteisessä merkityksessä, vaan pikemminkin toimijuustilasta. Toimijuustila syntyi, kun ympäristön tarjoumat (affordances) tukivat asukkaiden omaa kompetenssia ja motivaatiota.

Asukkaat tulivat tai eivät tulleet persoonina tunnustetuiksi monista hoidon resursointiin, asumisyksikön rutiineihin ja henkilöstön asenteisiin liittyvistä syistä. Tunnustetuksi tulemista vaikeuttivat asukkaiden tietynlainen näkymättömyys henkilöstön silmissä, henkilöstön kiireinen aikataulu, asukkaiden standardikohtelu, dokumentaation roolin korostuminen ja liiallinen vastuun siirto henkilökunnan toimesta asukkaiden suuntaan. Toisaalta asukkaiden persoonan tunnustamista tukivat yksityisyyden suojaaminen ja aiempien tapojen ja harrastusten tukeminen. Henkilökunta edesauttoi tunnustamista myös tukemalla asukkaiden tunnelmaisua esimerkiksi laskemalla yhdessä leikkiä tai väittelemällä heidän kanssaan sekä heidän toiveitaan huomioimalla.

Asukkaiden osallisuutta tutkittiin osallisuuden tunnetta estävien eli tässä tapauksessa eristyneisyyttä tuottavien tekijöiden kautta. Eristyneisyyden tunne perustui monenlaisille tekijöille asukkaiden elämänhistoriasta ja persoonallisuudesta aina hoidon resursointiin ja henkilöstön työkuultuuriin asti. Osallisuuden tunteen kannalta oli tärkeää sekä pystyä luomaan mielekkäitä suhteita ihmisiin palvelutalossa että kyetä säilyttämään suhteita ihmisiin palvelutalon ulkopuolella.

Empiirisen tutkimuksen perusteella autonomia, toimijuus, tunnustetuksi tuleminen ja osallisuus määrittyivät keskeisiksi persoonuuteen liittyviksi toimintamahdollisuuksiksi, sillä niiden kautta ihmiset toteuttivat persoonuuttaan. Kun painotus siirtyy persoonana olemisesta persoonuuden toteuttamiseen, voimme määritellä persoonan suhteellisen autonomiseksi, toimijuustiloja hyödyntäväksi yksilöksi, jonka toiset ihmiset tunnustavat persoonaksi ja hyväksyvät hänet sellaisena kuin hän on. Persoonassa on näin määritellen sekä yksilöllinen että yhteisöllinen puolensa, mikä edesauttaa ihmisarvoisen hoidon toteutumista silloinkin, kun ihminen itse ei enää ole kompetentti muodostamaan käsitystä hyvästä elämästä tai kommunikoidaan käsitystään toisille. Empiirisen tutkimuksen pohjalta muotoillun tunnustavan hoitofilosofian ainoan varsinaisen maksimin mukaan haavoittuvien vanhojen ihmisten hoidossa tulee painottaa yleisinhimillistä persoonuutta yksilöllisen persoonan rinnalla. Siten tunnustava hoitofilosofia turvaa nykyistä paremmin heidän hyvän elämänsä toteutumisen.

1 Introduction

Let us imagine John. John is an 85 year-old man. He is a former engineer who has been retired for 23 years. John has never been much of a people-person. The company of his wife, Millie, and his three children has more or less taken care of his social needs. In addition, his seven grandchildren have always been close to him, especially the oldest, Lisa, whom John has missed very much since she moved to the US.

When John was younger, he used to hike in Lapland with Millie every summer. When the couple got older, the trails got shorter, and the hikes ended when John was 75. After that they satisfied their desire for nature by living in a summer cottage every year from May to October. John also loved all kinds of motors, and motorbikes were his passion. He owned several bikes and took long trips alone every summer until his eyesight prevented him from biking at the age of 70. However, John kept his bikes and spent a lot of time in the garage with them.

When John was 75 and the hiking stopped, there were some signs of John's incipient memory disorder, but the couple managed fine alone until John was 83, and with the help of the home care service after that. John's diagnosis was Alzheimer's, and the disease had advanced so that John needed help in all his daily activities and Millie could not manage any longer, even with the home care service. Millie had been John's official family carer for several years. The municipality offered John a place in a sheltered home with round-the-clock care. The facility had just been converted from a nursing home to a sheltered home according to new national policies. Millie discussed this with John and they decided that they should see the place, although she was dubious about all care facilities since they had quite a negative reputation.

John and Millie visited the facility in advance and Millie was convinced that it was a good place for John. During the visit, John had one of his deeply disorientated moments so his opinion was not heard. Millie had had many conversations with John about moving, and she knew John was nervous about the strange people that would surround him. But Millie trusted that having his own room and privacy would eventually calm John down and she made the decision of the move together with the authorities. The manager of the facility had told Millie and John that they provided

individual care supporting John's own functional abilities. John could participate in many kinds of activities if he wanted to and he could enjoy the privacy of his own room, too. Self-determination was the most commonly used word in the conversation, and Millie trusted that John could remain John, although living in a care facility. John moved in and Millie visited every day during lunch time to help John eat.

This imaginary story about John and Millie could be a true story from Finland today, and we will return to it in the end. The number of older couples where one is the other's caregiver is growing, and frequently the caregiver is the woman (Tikkanen 2016). Older people are staying in their private homes in worse condition than before with help from the home care service (Ala-Nikkola 2003). This is partly due to national elderly policies, which have resulted in the closure of geriatric hospital wards, the conversion of nursing homes to sheltered homes and highlighting home and family care (Ala-Nikkola 2003; Anttonen 2009; Finlex 2012a). People also stay in private homes as long as they can because of their desire to manage on their own for as long as possible (Jolanki 2009a) and because care facilities have a poor reputation (Pirhonen *et al.* 2016).

The promise the manager gave to John and Millie is consistent with Finnish national policy and recommendations regarding the quality of elderly care (ETENE 2008; Finlex 2012a; 2014; Ministry of Social Affairs and Health 2008). Individuality and self-determination are widely accepted as the cornerstones of good care, which can be seen in the written care philosophies of elderly care facilities too. However, as both international (Eyers *et al.* 2012; Petriwskyj, Gibson & Webby 2014) and Finnish (Järnström 2011a; Lämsä 2013) research point out, the rhetoric may be at odds with reality in elderly care, giving rise to constant tension between the ideals of care and practice. There seems to be a gap between the two; we know how to give good care in theory, but the theory does not meet practice for one reason or another.

I started working on the missing link between theory and practice on Martha Nussbaum's (2007; 2011) thoughts of capabilities being the cornerstone of dignified human life. Just as policies should actualize in practice, dignified life is not just a theoretical idea but it is also ordinary life. Care policies and national recommendations acknowledged good, dignified life at a universal level, but failed to acknowledge the people they were talking about. Marx's and Engels' (1978) critique against contemporary philosophers seemed plausible when transferred to this modern day dilemma. Marx and Engels accused philosophers "of representing not true requirements, but the requirements of truth; not the interests of the proletariat, but the interests of human nature, of man in general, who belongs to no

class, has no reality, who exists only in the misty realm of philosophical fantasy” (Marx & Engels, 1978, p. 75). Older people in need of care did not exist in the misty realm of political fantasy but in concrete care facilities affected by diminishing functional abilities, scarce resourcing of care and other reminders of reality. Therefore older people and their situation needed to be made visible so that care policies that can meet their needs could be developed.

A plausible way to make older people in care facilities visible can be found on Axel Honneth’s (2005) theory of the recognition of persons. According to Honneth (*ibid.*), individuals need to feel loved, appreciated, and respected in order to be fully recognized as persons. I transferred this idea to care surroundings and studied whether older people were recognized as persons in the way Honneth had stipulated. Nussbaum’s ideas of capabilities and Honneth’s philosophy of recognition seemed to have a strong affinity – they both concerned the relation between human dignity and personhood. Nussbaum was interested in how individuals may perform their personhood through the choices available, while Honneth studied the social aspect of how persons become persons and maintain personhood during their lives. Personhood seemed then to become the missing link between policies and practice. I began to anticipate that “the misty realm of political fantasy” connected to older people’s ordinary lives through the philosophy of recognition.

Based on this theoretical background, the empirical task became to study how older people could maintain and perform their personhood while residing in care facilities. Capabilities, recognition, dignity, and good life intermingle with each other, and this dissertation presents one way to study these issues based on empirical research conducted in elderly care surroundings. The terminology regarding care for older persons is numerous and confusing, even in Finland. My research is not about long-term care since long-term care covers both home and institutional care. By definition institutional care covers care in geriatric hospitals, health centers, and traditional nursing homes, but many include sheltered housing with round-the-clock assistance to this definition, too. On the other hand, the idea of the latter has been to make round-the-clock care less institutional and more homelike, and therefore sheltered housing with round-the-clock assistance should be separated from institutional care. In this research I chose to use the term assisted living to refer to sheltered housing with round-the-clock assistance for clarity and to make international comparisons possible.

I will introduce the political and ethical frameworks for elderly care, the Finnish elderly care system, and the concept of person centered care in chapter 2. Chapter 3 concentrates on the concept of good life and introduces the question that is the

common thread through the dissertation: “What are older persons able to do and be while residing in assisted living?” (cf. Nussbaum 2007, p. 20). After this the specific research questions will be presented in chapter 4 and the methodology of the research and the research site in chapter 5. The research results will be presented in chapter 6 based on the four original articles enclosed in the dissertation. Each subsection 6.1–6.4 is based on an original article. The four constituents of good life in assisted living based on this research are autonomy (article 1), agency (article 2), recognition (article 3), and affiliation (article 4). Since most of the people residing in assisted living suffer from dementia illnesses (Noro & Alastalo 2014), subsection 6.5 presents a summary of dementia-related issues in relation to the findings. In chapter 7, a novel care philosophy will be sketched based on the results and a short conclusion will be presented in chapter 8.

2 The framework for elderly care

“Over the next few decades, the Finnish nation will be ageing fast. Municipal councils and managers, particularly, must recognize this trend in their operating environment and ponder ways of providing high-quality services for older people that demonstrate dignity and respect for individual clients while being both effective and financially sustainable... ..The key fundamental value is *respect for human dignity*. Everyone must be ensured the right to a dignified old age and good treatment, irrespective of where they live or are cared for and of what their requirements for services may be. The ethical principles safeguarding a life of human dignity are: self-determination, acknowledging clients’ resources, equality, participation, individuality, and security.” (Ministry of Social Affairs and Health 2008, my emphasis)

This quote from *National Framework for High-Quality Services for Older People* represents Finland’s highest health authority’s perception of high quality services for older people. The short quote is worth a closer look. Due to demographic ageing, the Ministry sets the goal of providing high-quality services in an effective and financially sustainable way. The fulfilment of this difficult task is left to municipalities, which are responsible for the concrete provision of care for citizens living in the municipality¹. Regardless of how the municipalities fulfil the task, their actions should demonstrate dignity and respect for individual clients. Dignity and respect then seem to be the core values of high-quality services. The Ministry holds that dignity is secured when services are based on six principles: self-determination, acknowledging the clients’ own resources, equality, participation, individuality, and security.

ETENE (The National Advisory Board on Social Welfare and Health Care Ethics) (2008) holds that

¹ The provision of social and health services is changing in Finland. From the beginning of 2019 the duty of providing citizens with social and health services will be transferred from municipalities to larger provinces. Now there are over 300 municipalities producing the services, after the reform there will be 18 areas responsible for the provision. The reform has been justified with both economic and consumer-friendly reasons.

“Treating elderly persons as individuals forms the basis of ethically sustainable eldercare. Care should be tailored to the needs and wishes of the elderly, respecting their values and taking their opinions into account. Care planning should take into consideration each person’s state of health and functional capacity, support provided by people close to him or her, and his or her social network in its entirety”. (ETENE 2008)

The highest ethical board for social and health services in Finland also emphasizes individuality as a basis of good quality care - for a good reason. Our Western culture and lifestyle today is based on the notion of free individuals making free choices based on their best knowledge, and legislation and guidelines for care reflect the spirit of the times. However, prior research has shown that individuality, emphasizing autonomy and freedom of choice, is not necessarily a good value to have in elderly care, especially in institutional care and assisted living (Järnström 2011a; 2011b; Lidz, Fischer & Arnold 1992; Pirhonen 2015b; Pirhonen & Pulkki 2016; Sherwin & Winsby 2010). As George Agich (2003) remarks, autonomy is a desirable political value, but we may have made a mistake when adopting it uncritically in care provision. There are multiple reasons for the inconsistency between policies and practice. In order to understand the current situation, we need to take a look at the development of elderly care. In subsection 2.1 I will concentrate on the Finnish elderly care system. Subsection 2.2 presents the international rise of assisted living as the desired form of care, and subsection 2.3 presents the triumph of person-centered care as the main ideology of assisted living. The critique that has arisen regarding person-centered care will be discussed in subsection 2.4.

2.1 Finnish elderly care

According to Anttonen (2009), taking care of vulnerable people has always been seen as a task for the family, yet there have always been people outside this safety net. During industrialization and urbanization in the 19th century, many people cut their family connections and the need for a system to take care of them emerged. The first attempt of solving the situation was to “sell” vulnerable people to private households one year at a time. Municipalities held auctions where vulnerable people were given to those households that asked for the least amount of money for taking care of them. The history of institutional long-term care in Finland starts from the common almshouses (that took care of orphans, handicapped persons, and older people under

the same roof) in the 19th century. By the middle of the 20th century almshouses had vanished and different groups of vulnerable people were taken care of separately, older people in need of constant care in nursing homes, health centers, and geriatric hospitals. Alongside the construction of the welfare state from the 1950s onwards, elderly care became a task for the welfare state and the role of families decreased. In the 1970s children's responsibility to take care of their elderly parents was removed from legislation. Now, in the 2010s, the circle is closing and family care appears to be the most desirable form of care due to its affordability. (Anttonen 2009.)

Today, the municipalities still have a duty to provide elderly care. They may provide it themselves or in collaboration with other municipalities, or purchase services from private providers. Round-the-clock care is provided in geriatric hospitals, health-centers, nursing homes, and in assisted living. (Aaltonen 2015.) Assisted living has increased and other forms of round-the-clock care have decreased in the 2000's (National Institute of Health and Welfare 2016). The proportion of assisted living provided by private enterprises has grown rapidly over the last few years and this growth is expected to continue.

Thus, a long tradition of favoring institutional elderly care is breaking, and current emphasis is on assisted living (Anttonen 2009; Kröger 2009; Kuronen 2015). The reasons are the same as in the rest of the West: demographic change resulting in deteriorating maintenance ratios and austerity in public health and social services. Currently, the whole health and social services sector is in unparalleled change aiming to equalize private, public, and the third sector service providers and increase individuals' freedom of choice. Although the Finnish elderly care policy today emphasizes strongly home care and family care as primary options for older people (Ala-Nikkola 2003; Finlex 2012a; 2014; Noro & Alastalo 2014), the number of people living in assisted living has grown due to demographic aging (National Institute of Health and Welfare 2016).

A new law concerning social and health care services for older people urges municipalities to provide care services in people's private homes (Finlex 2012a). The bill regarding the Act by the Government of Finland states that assisted living facilities are also perceived as homes (Finlex 2012b), and care providers are keen to share this perception. However, even the most enthusiastic social constructivist would not think that calling a place a home would make it a home. What makes a home in a facility would be a good research question for a whole different dissertation, but I will approach the issue through documents describing good care, since those do say something about the ideals of dignified life (as the ministry put it in the first quote) during old age in Finnish society.

The Act on Supporting the Functional Capacity of the Older Population and on Social and Health Care Services for Older Persons (Finlex 2012a, 14§) states that “long-term care and attention must be provided so that the older person can feel that he or she is living a safe, meaningful and dignified life and can maintain social contacts and participate in meaningful activities promoting and maintaining his or her wellbeing, health and functional capacity.” The first part of the quote acknowledges that good human life is partly a matter of experience: people need to feel that their lives are dignified and that there is meaning to life. The latter part of the quote concentrates on how to put the good life in practice: there needs to be social contacts and meaningful activities through which people actually may feel that they are living a good, dignified life. According to the quote, good human life seems to be about accomplishing meaningful things together with other people.

Care providers seem to share the lawmakers’ perception about good human life. The organization that runs the facility I studied, states in its web pages: “Every resident is entitled to a privacy-securing, unrestricted room and bathroom or an apartment. In addition, a resident may take part in communal life. A resident has opportunities to exercise safely in the outdoors, to have hobbies, and to take part in common activities in her own community... . . . a resident of the group-home may move around in safe, common areas and take part in daily chores.” Residents seem to be entitled to privacy and they “have opportunities” and “may move around”, which emphasizes their self-determination. They may take part in communal life and take part in common activities, which acknowledges their social needs and needs for meaningful activities. Elderly care has gone through a cultural change since the 1980’s when medical models and disease-centeredness were substituted with models that increasingly emphasize individuals (Brownie & Nancarrow 2013; Koren 2010), resulting in the rise of assisted living defined in the next chapter.

2.2 The promise of assisted living

The number of facilities providing residential care for older people has increased rapidly in Finland and throughout the Western world (Ball *et al.* 2004; National Institute for Health and Welfare 2016; Street *et al.* 2007; Zimmerman *et al.* 2003). The reasons for the growth have been both economic and humane, since residential care has been depicted as a low-cost form of care in surroundings that are less institutional than others (Chapin & Dobbs-Keppler 2001). The diversity of

residential care is vast, since these facilities have nearly 20 different names in the United States alone (Mitchell & Kemp 2000). The term assisted living has become a widely used concept to capture this wide range of settings that vary in size, service provision, regulatory standards, funding, fees, and resident characteristics (Kemp *et al.* 2012). Ideologically, assisted living strives for combining the best parts of both institutional care and home care; and combining provision of housing with basic care round-the-clock (Cutchin, Owen & Chang 2003).

Although assisted living covers such a large variety of settings, researchers have made efforts to define it. According to Roth and Eckert (2011, p. 216), assisted living “emphasizes a home-like environment that fosters respect for an individual’s sense of autonomy, privacy, and freedom of choice”. Zimmerman *et al.* (2005, p. 195) hold that the core idea of assisted living is to “provide a choice of services and lifestyles to avoid the typical characteristics of an institutional setting”. The resident should decide on care and all other residence-related activities as much as possible (Koren 2010). The key words regarding assisted living seem to be autonomy and individuality (Ball *et al.* 2004; Roth & Eckert 2011; Zimmerman *et al.* 2003), which have been depicted as cornerstones of person-centered care.

2.3 Person-centered care

Person-centered care has become a new watchword for both good practice (Nolan *et al.* 2004) and quality of care (Brooker 2004; Brownie & Nancarrow 2013; Edvardsson & Innes 2010; Koren 2010). The new paradigm was launched by Carl Rogers (1961), who used it in psychotherapy as “person-centered counselling”. In the 1980’s, Tom Kitwood (1988) started to use the concept as a critique of approaches that emphasized the medical and behavioral management of dementia. Kitwood was a pioneer in the endeavor to see persons, instead of diseases, as a cornerstone of good care. After Kitwood, person-centered care was adopted to encompass all clinical and informal care and especially all long-term care for older people (Brooker 2004).

Similarly to every attempt to capture the definition of good care, person-centered care is also slippery and open to various interpretations. There are numerous synonyms of person-centered care in literature such as patient-, client-, family-, and relationship-centered care (Entwistle & Watt 2013; Morgan & Yoder 2012). From this point on, I will use person-centered care to cover all the synonyms for the idea of person-centeredness. The common idea in person-centered care is to criticize the

traditional clinician-centered and disease-focused medical models and to emphasize the importance of client-customized care (Morgan & Yoder 2012). Leplege *et al.* (2007, p. 1564) distinguished four elements of person-centered care: it should i) address the person's specific and holistic properties, ii) address the person's difficulties in everyday life, iii) consider the person as an expert on their own condition and put the emphasis on participation and empowerment, and iv) respect the person 'behind' the impairment or the disease. Donald M. Berwick (2009, p. 560) defines person-centered care as "the experience (to the extent the informed, individual patient desires it) of transparency, individualization, recognition, respect, dignity, and choice in all matters, without exception, related to one's person, circumstances, and relationships in health care".

These days, the claim of person-centered care is written in western legislations and national recommendations of care. The Institute of Medicine in the U.S. defines person-centered care as "care that is respectful and responsive to individual patient preferences, needs, and values, and ensuring that patient's values guide all clinical decisions" (Institute of Medicine 2001 according to Morgan & Yoder 2012, p. 8). The Department of Health for England & Wales defines that the aim for person-centered care is to "treat people as individuals and provide them with packages of care that meet their individual need" (Department of Health for England & Wales 2001 according to Brooker 2004, p. 217). The close communion between assisted living and person-centered care is obvious in a recommendation from Canada stating that "the philosophy of assisted living is to provide housing with supports that enable tenants to maintain an optimal level of independence. Services are responsive to tenants' preferences, needs, and values, and promote maximum dignity, independence, and individuality" (Government of British Columbia, web pages). These ideals from the U.S., U.K., and Canada match perfectly with the Finnish legislation described previously. Dignity, self-determination, and individuality are core values, which are protected by an emphasis on care home residents' preferences, needs, and values.

The idea of person-centered care has matched well with the culture change in elderly care from the 1980's onwards (Brownie & Nancarrow 2013; Koren 2010). Self-determination and individuality were appropriate values when elderly care provision shifted from institutional care to more "homely" solutions. In addition to promoting the individual's role in their care, those values have also matched well with the rise of consumerism and the shift of responsibility from the welfare state to individuals (Gilleard 1996; Jolanki 2009b). However, critical voices have also awoken.

2.4 The critique of person-centered care

Person-centered care has become such a paradigmatic refrain regarding good care that some researchers are worried about the loss of the concept's empirical connotations and about person-centered care being turned to evangelism without practical application and a body of knowledge (Brooker 2004; Katz & Calasanti 2014; Nolan *et al.* 2004; Packer 2000). It may be that the wide use of the concept has resulted in an inflation of its value. In addition to inflation, person-centered care has been criticized particularly for the uncritical usage of its main values: autonomy (read: self-determination) and individuality. According to Nolan *et al.* (2004), the focus on individuality reflects wider trends of promoting liberal societal values that have resulted in emphasizing the independence and autonomy of older people. As for independence and autonomy, they are central concepts in "successful ageing" (Baltes & Carstensen 1996; Rowe & Kahn 1997), which has shifted responsibility for the good life in old age from societies to individuals. In addition, the emergence of consumerism has boosted individualism in social and health care, since people using services have become consumers with consumer rights (Gilleard 1996).

Putting too much weight on individuals making autonomous choices has raised worries regarding social responsibility (Entwistle & Watt 2013; Nolan *et al.* 2004; Pirhonen & Pulkki 2016). In health-care, clients often have to make difficult choices in challenging conditions. Professionals are expected to give understandable information about the clients' situation and then leave the decisions to them (Entwistle & Watt 2013). This is a dubious situation especially in assisted living, where older people reside because they have lost their ability to live independently (Agich 2003). When person-centered care is based on individual choices, it demands a high level of rationality from the person. Putting too much weight on individual choices may also lead to a situation where those people, who are incapable of articulating their preferences, are marginalized. Putting emphasis on individual choices may result also in seeing good care simply as fulfilling individual desires.

The increased number of immigrants in the West from Far-Eastern cultures has also resulted in a reconsideration of the Western reading of person-centeredness (Geertz 1984; Perkins *et al.* 2012). The Western perception seems egocentric when compared to the Eastern sociocentric models of self. When the former tends to distinguish the individual from the social context, the latter emphasizes the role of

the family and community. The dichotomy is not that strong in reality, and both views are heterogeneous. However, growing ethnic minorities have increased discussion on what person-centeredness in elderly care is (Perkins *et al.* 2012).

These worries have resulted in adding social components into person-centered care. People do not live and make choices in a vacuum, their environment and the people around them are a significant part of who they are. Entwistle and Watt (2013, p. 33) hold that “to treat others as persons we must be sensitive and responsive to their specific characteristics in the particular situations in which we encounter them”. Nolan *et al.* (2004) shift the emphasis from an individual person to personhood. If we want to deliver good care, we need a perception of what it takes to be a person. Nolan *et al.* (*ibid.*) shares Kitwood’s (1997b, p. 8) stance that personhood is “the standing or status bestowed upon one human being by others in the context of a relationship”. The term personhood acknowledges both the individual and the objective nature of being a person.

The critique of the current reading of person-centered care returns us to Kitwood’s (1997b) original idea. The concept of a person needs to be widened to personhood in person-centered care in order to develop ethically sustainable care policies and practices for older people in assisted living. Acknowledging individual preferences is important as long as residents’ values and preferences are communicable. When it is not possible to determine an individual’s values and preferences, as in the case of people with severe dementia, it is safer to concentrate on the universal traits of being a person. In situations beyond communication it’s of no use to ask what an individual wants, but it is plausible to ask how may this individual perform her personhood. Answering the latter question requires ongoing ethical evaluation of the preconditions of good human life.

3 Human flourishing

Since preserving older people's self-determination and person-centeredness of care have become the core values of assisted living today, they might reflect our perception of good human life. Law texts, recommendations, and care philosophies regarding the provision of elderly care in the previous chapters discussed dignity. As Claassen (2014, p. 244) remarks, "ascriptions of dignity always need a grounding in one or more features of the dignity-bearing creature; there must be something about that creature that makes it dignified". Philosophers have connected dignity to various features such as rank, virtue, religious status and individuality of human beings (Düwell 2014). Regarding provision of assisted living, there seems to be an understanding that dignity is connected with possibilities to live a good human life. Good human life is the goal in assisted living, yet it is the technique to achieve the goal at the same time; to reach a good human life is to live a good human life. For Aristotle, the goal (*telos*) for a human being was flourishing (*Eudaimonia*). Philosopher Juha Sihvola (1998) has summarized what Aristotle meant by *Eudaimonia* in the *Nicomachean Ethics* (Aristotle 1962):

“*Eudaimonia* requires preparedness for living a full human life without unfair risks, being healthy, satisfying the basic needs for nourishment, shelter and sexuality, using and developing one's senses and capacities to imagine and think, studying an extensive cognitive world view, bonding with other people, participating in the planning of one's own life and life of one's community, and living in well-balanced relation to nature.” (Sihvola 1998, p. 32, my translation in Pirhonen 2015a, p. 30)

If we changed the words “*Eudaimonia* requires preparedness” from the beginning of the quote to “Our residents are provided with opportunities,” we would have a perfect written care philosophy for any assisted living facility in the Western world. A good human life is achieved when residents live their everyday life according to Sihvola's (1998) summary. The economist Amartya Sen (e.g. 2009) and philosopher Martha Nussbaum (2007; 2011) have approached human flourishing through human capabilities, which may be reached through different functionings (Claassen 2014).

For Sen, functionings are the various things a person manages to do or be in life. Functionings are thus doings and beings; both eating and being nourished are functionings. Functionings are a value-laden issue since they are doings and beings that a person has reason to value, and capabilities are desired sets of functionings. However, Nussbaum, as a philosopher and legal scholar, holds that whether a functioning is valuable is not decided by the person herself. A functioning's value is objective and may be revealed by a process of ethical evaluation, in which the perception of a good life is important. (Claassen 2014, pp. 240–241.)

Nussbaum's standpoint appears more plausible when the task is to deliberate over criteria for assisted living that supports a good life for residents. For example, in Sihvola's summary above, living in a well-balanced relation to nature is a prerequisite for human flourishing, i.e. good human life. Nussbaum (2007, p. 77; 2011, p. 34) also emphasizes relation to other species and to nature as a whole as a central human capability. An assisted living resident's capability of being in connection to nature actualizes when she reaches relevant functionings, for example when she has actual access to outdoors and there are opportunities to have plants and animals inside the facility. As Claassen (2014, p. 241) puts it, capabilities are freedoms to achieve something and functionings are the achievements. Maintaining one's relation to nature in assisted living is a capability that actualizes as a functioning when residents have real access to plants and animals.

For Nussbaum, capabilities are similar to human rights. She has elaborated a ten-point list of central human capabilities, which may be applied differently across political-cultural-local contexts (Nussbaum 2007, pp. 76–78; 2011, pp. 33–34). The list includes 1) life, 2) bodily health, 3) bodily integrity, 4) senses, imagination, and thought, 5) emotions, 6) practical reason, 7) affiliation, 8) other species, 9) play, and 10) control over one's environment. As we can see, the list is directly based on Aristotle's perception of human flourishing as Sihvola summarized it. I have studied the capabilities approach in connection to assisted living elsewhere (Pirhonen 2015a), and Nussbaum's list proved to be a plausible framework for the delivery of long-term elderly care that supports dignity.

In this study, my focus is on deliberating over the connection between residents' good human life and self-determination and person-centeredness, which both previous research and documents qualifying good care seem to emphasize. Nussbaum offers her helping hand again by defining a capability in an interesting way. She states that capabilities may be seen as an answer to a question "What is this person able to do and be" (Nussbaum 2011, p. 20). Those valued doings and beings should be objective features of good human life stipulated by public ethical

deliberation. Therefore, Nussbaum's approach justifies asking what older people residing in assisted living *should* be able to do and be, which makes Nussbaum's question normative in some way.

To answer Nussbaum's question for persons in assisted living, I will divide it into two separate questions. The question "what is this older person able to do when residing in assisted living" directs the attention towards her possibilities to maintain both decisional and executive control over her life. To answer the question, then, we need to consider her possibilities to maintain autonomy and agency. The question "what is this older person able to be when residing in assisted living" intertwines with her possibilities to get treated as a person and to maintain affiliation despite the transfer from a private home to a care facility. Residents need to feel that their life continues, in the sense that they are the same persons after moving into a care facility as they were before that. It is also important that they may keep the social basis of self-respect after moving into a care facility. In the next two subsections 3.1 and 3.2 I will present the theoretical background for answering Nussbaum's question in assisted living surroundings.

3.1 Doing

To understand what residents are able to do, we need to scrutinize their decisional and executive control over their lives in assisted living surroundings, i.e. their autonomy and agency. As we have seen, national guidelines for the care of older people in Finland, such as *The National Framework for High-quality Services for Older People* (Ministry of Social Affairs and Health 2008), stress autonomy, the right to self-determination, and making choices. Based on the previous chapter, the right to self-determination seems to be accepted as a major component of quality in elderly care. As good as this maxim is regarding service production altogether, it is problematic as a guiding principle for delivering assisted living for older people, where they are most vulnerable (Agich 2003; Pirhonen & Pulkki 2016). As Agich (2003) put it, autonomy and freedom are the dominant and plausible values of liberal political perceptions, but we may have made a serious mistake when expanding their sphere to cover nursing and caring, too.

3.1.1 Autonomy

The autonomy of older people who receive care may be restricted by several factors related to their surroundings and themselves. People's actions never take place in a vacuum, but human life is intertwined with facticity and connections and interactions with other people (Atkins 2006; Christman 2014; Sherwin & Winsby 2010). Human existence is intersectional and embodied by nature, as the feminist tradition emphasizes (Ells, Hunt & Chambers-Evans 2011; Käll & Zeiler 2014). This is especially true for older people residing in assisted living, since the facilities, even today, have some features of Goffman's (1968, p. 17) total institutions: all aspects of life are conducted in the same place, many daily activities are carried out in the immediate company of others, activities are scheduled from above by a system of formal rulings, and the purpose of these activities is at least partly to fulfil the official aims of the institution. In addition, resident autonomy may also be reduced by paternalistic attitudes of the staff (Sherwin & Winsby 2010) and sometimes care-related decisions are judged by the motivations and goals of the helpers instead of the helped (Collopy 1988).

The preconditions for autonomous life in assisted living are also restricted by the residents' diminishing functional abilities. According to Agich (2003, p. 1), "individuals need long-term care because they suffer illnesses and incapacities that compromise their ability to function independently and choose rationally." Emphasizing rationality is especially dubious in an assisted living context since we know that cognitive illnesses, such as dementia, are the number one reason for older people to end up in residential care (Matthews & Denning 2002; Noro & Alastalo 2014; Wolinsky *et al.* 1993). Residents execute their diminishing functional abilities in situations which are *de facto* out of their control in many ways. This makes their autonomy highly relational.

The concept of *relational autonomy* (Atkins 2006; Christman 2014; Sherwin & Winsby 2010) would fit assisted living better than other concepts, since it takes into account that individuals' actions are inevitably connected to multiple relational factors, such as social relationships, personal characteristics, and the chances and restrictions of the agent's environment. Prior research indicates that autonomy in assisted living is constant balancing between independence and dependence (Ball *et al.* 2004) and adjusting to changes in the residents' abilities (Morgan *et al.* 2014).

Baltes and Baltes (1990) discussed a lifelong process of maximizing gains and minimizing losses by means of three processes: selection, optimization, and compensation (SOC). According to the SOC-theory, older people use multiple coping strategies, such as lowering standards and using aids, to maintain a feeling of control in their lives despite diminishing functional abilities (Freund & Baltes 1998;

Rothermund & Brandstädter 2003). In an earlier study on autonomy of community-dwelling nonagenarians (Pirhonen *et al.* 2016), we introduced the concept *ability others* to describe how nonagenarians highlighted their autonomy by checking it against the situation of those peers who had transferred into a care facility. Institutionalized people were seen as ability others since they had lost their independence due to diminishing abilities. The concept of relational autonomy has a strong affinity with the SOC-theory; they both acknowledge the importance of negotiation when an older person uses her remaining resources to maintain a good life.

3.1.2 Agency

Relational autonomy acknowledges that the environment always influences our decision making in one way or another. In sociological tradition, this individual-environment interaction has been discussed in theorizations about human agency (Giddens 1984; Jyrkämä 2008; Ritzer 2000). The classical, Giddensian interpretation of agency entails that on the one hand, social structures direct individual action, which then, on the other hand, reshapes the structures. Elder and Johnson (2003) define agency by stating that individuals construct their own life course through the choices they make and the actions they take within the opportunities and constraints of history and social circumstances. Defined like this, a close communion between agency and relational autonomy exists.

Although autonomy and agency operate in the same field of self-determination, there is a difference that challenges us to study them separately as elements of good human life. Autonomy and agency carry features of each other. As we saw, the concept relational autonomy acknowledges the influence of environment regarding our decision making (Atkins 2006; Christman 2014; Sherwin & Winsby 2010). Agency focuses more on our opportunities to execute decisions within the limits of social or other structures around us than relational autonomy (Giddens 1984; Jyrkämä 2008). The basic difference is that autonomy incorporates primarily decision making whereas agency deals with action taking. People make more or less autonomous decisions, while their success in the execution of those decisions dictates how agentic they are.

Once again, suspicion arises when we consider agency and older people with diminishing functional abilities residing in assisted living. Elder and Johnson above described agency as the “choices they make and actions they take”. As Wray (2004, p. 24) expresses it, “dominant Western conceptualizations of agency are often used

uncritically; individualistic notions of choice, autonomy, and in/dependence often pervade accounts of agency.” Frail older people seem to be at risk of becoming “have-nots” in terms of agency. Indeed, Gilleard and Higgs (2010, p. 122) hold that residents of assisted living facilities have lost their cultural frame of reference regarding individual agency due to failure in self-management and transfer into round-the-clock care. These readings of agency are problematic when considering people with limited functional abilities, since they presuppose certain competences (Atkins 2006; Morgan *et al.* 2006) which frail older people often lack.

An obvious factor that has so far influenced our perceptions of agency is the triumph of activity regarding gerontological research. Both physical and social activity has become the major component of successful ageing (Baltes & Carstensen 1996; Rowe & Kahn 1997). According to Tulle (2008), physical activity is advocated as prevention against falls and the reduction of functional abilities, and it carries the potential of improving quality of life in old age, which produces cultural capital that older people gain by “staying fit”. Katz (2000) holds that activity has become such a paradigm of well-being in old age that questioning it would be considered unprofessional or even heretical. As important as activity is regarding both quality of life in old age and the economic resilience of society, we need to acknowledge again the vulnerability of human life. Agency is not necessarily active trade or reciprocity between the individual and structures. Agency is more about both an actor’s individual characteristics and her environment influencing chances to fulfill her aims. Therefore, it answers Nussbaum’s (2011) question “What is this person able to do?” for its part.

3.2 Being

Since the latter part of Nussbaum’s (2011) question incorporates residents’ possibilities to *be*, it deals with their possibilities to maintain a social basis of self-respect. Therefore we need to consider their recognition as persons and chances for affiliation in assisted living surroundings.

3.2.1 Recognition

According to the philosopher Axel Honneth (2005), the whole social world may be seen as a struggle for recognition. The struggle occurs in three separate fields since

there are three fundamental elements in our positive identity: self-confidence, self-esteem, and self-respect. Honneth (*ibid.*) holds that we need to feel loved by our significant others (self-confidence), appreciated by our community (self-esteem), and respected by society (self-respect) to build and maintain a positive identity throughout our lives. Needs for love, appreciation, and respect do not vanish in old age. On the contrary, they might become more urgent when older people lose their functional abilities due to ageing and become more dependent on other people to be recognized as persons. This is particularly true for those older people residing in assisted living facilities, since in addition to diminishing functional abilities, they have left behind their familiar surroundings when transferring into the facility. They have also entered a new, perhaps frightening, social world and with new rules.

Culturally, moving to a facility may bring feelings of otherness, since our culture emphasizes successful ageing, where success is defined as activity, autonomy, and anti-ageing (Bowling & Dieppe 2005; Katz 2000). Also, moving to a facility has been described as a major event in older people's lives (Gubrium 1997; Powers 1995). According to Grenade and Boldy (2008, p. 472), becoming an assisted living resident means leaving behind a private home, family and friends (and pets), local communities and previous lifestyles. The routinized life in the facility may also endanger older people's control over their lives and their ability to express their identity (article 3). Thus, older people's recognition as persons, their chances to feel loved, appreciated, and respected, need to be thoroughly considered in assisted living surroundings. The transfer from a private home to a care facility may also be a relief to an older person and it may impact positively on their quality of life. However, encountering residents as persons affirms their continuity of self in any case.

Philosopher Arto Laitinen (2002; 2009) has elaborated on two features of recognition that are particularly fruitful when applied to assisted living: 1) recognition possessing the two powers of creating and maintaining objects and 2) the practicality of recognition. The two powers of recognition become apparent when we consider an older person transferring from a private home to an assisted living facility. The first power of recognition is to create; through the attitude of the staff and the nature of everyday practices, the facility may create an identity of an inmate or even a patient for the person moving in. According to previous literature, this is a regrettably common procedure, although probably not intentional (Collopy 1988; Lidz, Fischer & Arnold 1992). As I pointed out previously, care facilities today have been noted still to have some features of Goffman's (1968, p. 17) total institutions, where frail older people are at risk of losing their identity. However, the second power of recognition is to maintain; through staff attitudes and the nature of everyday

practices, the facility may support older persons' life-long identities even after they have transferred into assisted living.

Laitinen (2002) also holds that due recognition is practical, which means that recognition is not just a cognitive procedure but it is action as well. Recognizing is acknowledging features and treating accordingly, i.e. recognizing a person requires one to treat her as a person. To return to Honneth's (2005) idea of tripartite recognition, everyday life in an assisted living facility should be organized so that residents' needs to be loved, appreciated, and respected are both acknowledged and actualized. Recognition from others is particularly important for frail older people and their continuity of self. The maxim of person-centeredness shows that care providers are already on the right track.

3.2.2 Affiliation

As Honneth (2005) points out, the recognition of a person actualizes in relation to other people and society (institutions). The transfer from a private home is therefore a significant transition in older peoples' lives with regard to recognition. Gubrium (1997, pp. 84–90) describes the transfer from a private home to a care facility as a process of “breaking up a home,” when older people reluctantly give up their former lifestyle. Older people are still attached to people, places, belongings, and memorable events from the past although they understand that life cannot continue as it did before the move. According to Bethel Ann Powers (1995, p. 180), residents perceive a care facility as “the end of the line” where they become separated from the familiarities of home and life outside the walls. Jorun Drageset (2004) emphasizes the loss of social ties, especially relatives and close friends, which may result in loneliness in assisted living. People can indeed feel lonely although they are surrounded by others around the clock (Jylhä & Saarenheimo 2010; Uotila 2011). When residents long for their previous life circumstances very much, their sense of belonging is directed to somewhere else, which may result in ruptures regarding their affiliation.

Nussbaum (2011, pp. 39–40) finds that affiliation is one of the most important human capabilities together with practical reasoning. For her, affiliation is a twofold capability. *Firstly*, affiliation denotes “being able to live with and toward others, to recognize and show concern for other human beings, to engage in various form of social interaction, and to be able to imagine the situation of another (Nussbaum 2011, p. 34).” *Secondly*, affiliation is about “having the social bases of self-respect and

non-humiliation and being able to be treated as a dignified being whose worth is equal to that of others (Nussbaum, *ibid.*)” Based on these definitions, affiliation encompasses the social bases of self-respect, and has a close connection with Honneth’s (2005) concept of recognition as elaborated previously. Residents should be able to live among, and connected to, others, and be treated as dignified beings whose worth is equal to that of others. We also could say that residents should be able to bond with people inside the facility and maintain their previous connections with people outside.

Previous research has largely compared these social worlds, providing conflicting results of their importance to residents (Burge & Street 2010; Fessman & Lester 2000), yet Nussbaum’s perception of affiliation as a twofold capability emphasizes the importance of both social worlds. This study approaches affiliation in assisted living through ruptures in it, i.e. residents’ experiences of social isolation. Due affiliation may not be reached when residents feel that they cannot reach people on site or that their bonds with people outside are weakening, which results in social isolation, which in turn may result in loneliness (Weiss 1973; Victor, Scambler & Bond 2009). Social isolation is usually seen as an objective and quantifiable reflection of one’s lack of social interaction and the reduced size of one’s social network (e.g. Nicholson 2012; Steptoe *et al.* 2013), yet it can also be understood and addressed as a subjective experience. Victor, Scambler and Bond (2009) define social isolation as lack of communion between individuals and detachment from the socio-spatial context of daily life, highlighting the spatial elements of social isolation (see also Sinclair, Swan & Pearson 2007).

Social isolation might have specific features in the assisted living context where one is physically close to others, yet at risk of feeling separated from the everyday social environment along with prior social relationships. We need to know how the experiences of social isolation are embedded in the social context and structure of the assisted living environment, and examine the opportunities of conceptualizing and addressing social isolation as ruptures in affiliation. Thus, to understand what older persons are able to be in assisted living, we need to study whether they are recognized as persons and whether they are able to reach affiliation.

The theoretical background of this research was framed in this chapter on human flourishing. The Aristotelian perception of *Eudaimonia* (flourishing) was converted into Nussbaum’s capabilities, which were then conceptualized as residents’ possibilities to do and be i.e. their autonomy, agency, recognition, and affiliation. In the next chapter (4), I will present the detailed research questions. Chapter 5 presents how and where my empirical research was conducted.

4 Aims of the study

The aim of the study is to reassess the substance of person-centeredness regarding assisted living for older people. As we have seen, assisted living is not necessarily a surrounding where competent agents make reasonable choices based on their best knowledge, which is at least an implicit assumption in the current reading of person-centered care that highlights individuality. We need to revive Kitwood's (1997b) original idea and widen the concept of person to personhood (cf. Foster 2011). Personhood-centered care would encompass individual persons and protect those that are incapable of expressing themselves from marginalization. In addition to listening to individuals, the criteria for personhood-centered care are formulated in a process of ethical deliberation, which shifts responsibility from vulnerable individuals to communities. In this study, I will try to formulate the substance of personhood-centeredness by answering Nussbaum's (2011, p. 20) question "What is this person able to do and be?" in an assisted living setting.

The question "What this older person is able to *do* when residing in assisted living?" is further divided into two research questions:

1. What is the nature of residents' autonomy in assisted living surroundings?
2. How is residents' agency shaped in assisted living surroundings?

In addition, the question "What is this older person able to *be* when residing in assisted living?" is further divided into two research questions:

3. What kinds of factors in daily life affect residents' recognition as persons in an assisted living facility?
4. What kind of issues affect residents' affiliation in assisted living surroundings?

5 Methodology

5.1 Ethnographical research frame

Since the aim of the study was to reassess the substance of person-centeredness in assisted living for older people, an ethnographical research frame suited this research well (cf. Geertz 1973; Hammersley & Atkinson 1995). I needed to understand assisted living surroundings and residents' experiences of it to understand what residents were able to do and be in their living surroundings. Based on my own background as a practical nurse I knew the world I was entering, which had both advantages and drawbacks. I had to "make the familiar strange and the strange familiar", like Riikka Lämsä (2013), a former hospital nurse who studied hospital wards or Bethel Ann Powers (1995), who worked as a gerontological nurse while studying an institutionalized care setting. My background made it easy to enter the setting and I did not have to use my observation time to understand the basic structures of daily life in the home. However, my background also highlighted the need to make the familiar strange to understand it in a different way. I had previously seen care settings largely through the eyes of a practical nurse, although I conducted participant observation in a care facility already in my master's thesis (Pirhonen 2015a). The familiar became strange when I studied the setting from different perspectives, concentrating on the residents' view.

Ethnography may be described both as a method and a methodology (Hammersley & Atkinson 1995; Ojajärvi 2015). As a method it aims to deepen the understanding of social phenomena in a social setting and to explore how people make sense of the world in everyday life and how they act on the basis of that understanding (Agar 1986; Gubrium 1995; Hammersley & Atkinson 1995; Lämsä 2013). I studied the phenomena in question in one setting but from different perspectives, aiming to reach "thick" descriptions on which to base the new understanding (cf. Geertz 1973; 1984; Honkasalo 2008). Ethnography as a methodology refers to the entirety of data collection, analysis, interpretations, and writing the reports (Hammersley & Atkinson 1995; Honkasalo 2008; Ojajärvi 2015). There are probably as many ways to conduct an ethnographical study as there are ethnographers, but there are some common features, which make ethnography a

specific research orientation. These are fieldwork, the position of the researcher, and the purpose of the study.

The first ethnographers were European anthropologists who usually spent years among unfamiliar cultures in other continents in the late 19th and early 20th century, trying to understand how human cultures develop (Grönfors 1982; Roper & Shapira 1999). The idea was that by observing “primitive” cultures researchers could discover the “laws” that guide the evolution of cultures from the primitive to modern Western ones. Ethnography was thus perceived as part of positivist science. The First World War wrecked the perception of the nobility of Western culture and ethnography lost its genuine purpose. Following this, ethnographers in the US found the subcultures inside the US society, and ever since ethnographers have largely studied segments of their own societies and cultures. However, the importance of fieldwork as a method remained.

The importance of fieldwork emphasizes the position of the researcher in ethnography. The researcher herself is the most important research “device”. Being in the field personally among the participants makes ethnography embodied and inevitably emotional, too. What seems to be the weakness of ethnography in a scientific, objective sense, becomes the strength of the methodology when we consider the purpose: to deepen insights of the studied phenomenon. Ethnography is not about providing new information but new understanding (Gubrium 1995). Tom Kitwood (1997a) has gone even further, defining the aim of ethnography as “from understanding to standing under”. Kitwood conducted studies among older people with dementia illnesses to try to understand the experience of dementia (Kitwood 1997a; 1997b). By “from understanding to standing under” he means that the researcher may even go beyond understanding and touch the participants’ experiences by standing in the same circumstances with them. Although other individual’s experience is beyond the researcher’s reach as such, she may reach a similar experience when “standing under”.

Nursing homes became the scenes of ethnography in the 1970’s in the US and developed into a distinctive genre during the 1990’s (Henderson & Vesperi 1995). The rise of nursing ethnography was parallel with the rise of other institutional ethnography and the study of different subcultures inside the US society (Smith 2005; Roper & Shapira 1999). The catalysts that pushed me towards ethnographic research were two books written by sociologists Jaber Gubrium (1997, originally 1975) and Timothy Diamond (1992). These two nursing home ethnographies inspired my methodology in my master’s thesis (Pirhonen 2015a) and encouraged me to continue with this study. Gubrium (1997), who spent time in a nursing home

without any prior experiences of them or the people connected to them wrote a thick description of daily life in a care facility. As Gubrium says in the introduction to the second edition of *Living and dying in Murray Manor* (1997, p. xii), “The research opened my eyes to a sad world, but also one that revealed the complicated meanings of living and dying in an institution. My aim in writing the book was to bring those complicated meanings to light, to document that from the participants’ perspectives”. Diamond conducted his study unconventionally. He first took a course for six months to become an assistant nurse and then worked in several care facilities to understand the growing nursing home business from inside. His book, *Making Gray Gold, narratives of nursing home care* (1992), presents a deep insight of how seeing elderly care as a business affects the lives of those working and living in care facilities. Diamond’s book shows how numbers in profit and loss accounts, balance sheets, and GDPs transfer into the lives of people occupying nursing homes. Both studies highlight the strength of ethnography in seeing how people (have to) make sense of their current lives in their current physical-social-cultural living surroundings.

In Finland, some recent ethnographical studies have been conducted in care settings (Järnström 2011a; 2011b; Koivula 2013; Lämsä 2013). Riitta Koivula (2013) interviewed and observed the relatives of people with dementia to understand how the relatives’ agency was constructed in long-term care facilities. The relatives’ agency seemed to construct randomly depending on various issues such as their and their close ones’ life histories, physical structures and spaces of the facility, interaction with other people on site, and expectations regarding their roles as set by themselves and the staff. She discovered that although relatives affected older people’s quality of life positively when being cared for in inpatient wards, there were no explicit plans or instructions to affirm the relatives’ agentic role in care settings. Koivula’s ethnographic research inspired me to keep an eye on the role of relatives in many issues related to assisted living residents’ good life.

Riikka Lämsä (2013) conducted an ethnographic study in three hospital wards to understand how patienthood was constructed in everyday life. She made interesting observations of how the ideal and the actual patient were two different categories. The ideal patient was either an active decision maker on her treatments or a consumer exactly as the laws and recommendations presented in chapter 2 presume. However, hospital practices, such as patient clothing, time management by the organization, or discussing patients’ issues publicly during doctor’s rounds objectified patients, which is interesting with regard to their recognition as persons. Lämsä discovered, through spending time in patient rooms, for example how

patients' agency was passive by nature and how patients learned to understand what was happening in the ward just by listening to its sounds. These findings highlight the core idea of ethnography – the contradictions between the ideal and actual patienthood, the nature of patients' agency, and the importance of sounds were revealed by spending time in the field observing everyday life.

Sanna Järnström (2011a) studied how customer orientation was fulfilled in a geriatric hospital by taking part in ten doctor's rounds. Customer orientation is one of the guiding values of person-centered care, which highlights self-determination and individuality, yet in everyday life in a geriatric hospital it seemed to be an ideal that was rarely reached. At worst, decisions about older patients' follow-up treatments and even transfers to nursing homes were made in the absence of the patient herself. Sometimes, when the patient was present, a doctor would ask a nurse if there was something to consider in the case of the patient in question. Written documents and other professionals got emphasized instead of the older people themselves, which again makes one wonder about patients' recognition as persons. We will return to this issue in assisted living surroundings later in chapter 6.3 on recognition.

5.2 The research site

The facility I studied was run by a municipality. Therefore, in addition to contacting the ethics committee of the local Hospital District, which approved the research plan, I contacted an authority who was in charge of elderly care in the municipality, which was in Southern Finland. The authority approved my research plan and we added an observational period in a geriatric hospital since she was interested in seeing what the biggest differences between a hospital and an assisted living facility were from older persons' view, and that begun to interest me too. I started the field work by observing in a geriatric hospital for two months in the autumn of 2013. I used this hospital data in my first original article (article 3 in this dissertation). However, after the first article was complete, I decided to exclude the hospital data from this study. Although the hospital data added to my understanding of older people's life in a care facility, the context of the data (a hospital) did not meet the aim of this research. I wanted to concentrate on assisted living where older people live for the rest of their days and which is both nationally and internationally “the new paradigm” of long-term elderly care (Ball *et al.* 2004; National Institute for Health and Welfare 2016; Street *et al.* 2007; Zimmerman *et al.* 2003). Therefore, the

comparison between a hospital and an assisted living facility remains to be done in the future. I observed one assisted living facility for two months (165 hours) at the end of the year 2013 and conducted ten interviews there in May-October 2014. Next I will present you with the site, the people in it, the data collection and the analysis.

The facility consisted of two separate five-storied buildings connected with passages. It was occupied by 114 residents divided into nine group homes. The facility was brand-new and I observed the first two months of the action. Both the staff and the residents transferred there mainly from hospital wards that were going to close. The home was located next to a lake and the area was quite park-like and peaceful. I decided to focus my observations on one group home of 15 residents to get to know their daily lives as thoroughly as possible. Some of the residents were familiar to me from the hospital ward I had observed earlier.

Most residents had their own rooms in the home, but there were also some double rooms for couples in the building. Some couples lived in these rooms together, but usually the double rooms were occupied by two separate residents. The rooms were furnished with the residents' own belongings and furniture except for the hospital beds, which were provided by the facility. The residents usually wore their own clothes, though there were hospital clothes available and many used those as a nightgown. The general idea was to make the surroundings as homely as possible. The variety of furnishings was as diverse as the residents and their relatives. Some rooms were austere and included only the bed, a table, a chair, and a TV set (these were usually occupied by men), while some were filled with bookshelves, ornaments, and pictures of family members.

In every group home there was a spacious common room that served as a dining room (with a small kitchen aside) and smaller common spaces with TV sets, DVD players, X-BOX game sets, equipment for physical exercise, and recreational materials such as board games and equipment for pottering. There were large glazed balconies with electric barbeques. There was also a sauna in every group home. The main entrance into the building was open during the day but the doors to group homes were always locked and opened with a five-number code. The procedure intended to protect residents with dementia from wandering off on their own. Since the building was five-storied, there was a spacious lift to reach the group homes, and no stairs inside, which made it easy to move around. There was also a small office for the staff that had computers and a separate space for pharmaceuticals and a storage room for nursing equipment, hospital and bed clothes, and other materials needed in daily life.

The staff were mostly recruited from the closing hospital wards around the municipality. Management considered this a risk, since it was not self-evident that the staff would understand the shift from a hospital to assisted living and that they would be able to adjust their thinking and working methods accordingly. The ideological shift between a hospital where older people were patients and assisted living where older people were residents was large, and the management understood this. The shift was constantly discussed with the staff who also participated in training given by a professional artist, aiming to help the staff to encounter the clientele as individuals. Most of the staff were practical nurses. There were also registered nurses to take care of demanding nursing work, two physiotherapists, two recreational instructors, and some kitchen assistants in the home. All daily work was run by three managers. The staff wore uniform clothing that was provided by the employer. During my observation, there were usually two staff members in both morning and evening shifts and one during the night shift, but sometimes there were three staff members at work in the morning.

I focused my observation on one group home of 15 residents to understand their everyday life as deeply as possible. Since the original research plan included a comparison between the hospital and the assisted living facility, I chose a group home with several residents that I had already met during observations at the hospital. The clientele at all the group homes was quite similar. There were eleven female and four male residents in the group home during my observation. All except three suffered from a dementia illness to some degree. Their physical abilities varied from acting independently to being bed-ridden. Martha (all the names except for mine are pseudonyms), for example suffered from severe memory problems but she was physically the most fit resident in the group home. Eva was cognitively sharp, but was bed-ridden for somatic reasons. Ella had largely lost both her cognitive and physical abilities and needed help in all her daily functions. People enter assisted living in ever more poorer condition (Ala-Nikkola 2003), which was evident in my research site. Now, three years after the observation, four of the original fifteen residents remain. I still miss the deceased today. Especially Eva, who humorously called me “the doctor of technique” referring to my PhD study, and Ella whom I spent hours and hours feeding.

In addition to residents and the staff, relatives, friends, and volunteer workers become familiar to me during my stay. Some residents had a relative (usually a daughter) who visited on a daily basis, some had hardly any visitors during my two months. Volunteers were provided by an organization that was managed by local parish, and they usually came to visit once a week. Relatives, friends, and volunteers

kept residents company, took them outside, and relatives also brought them goods that the facility did not provide, such as electronics and alcohol.

Everyday life was organized around meals and the staff shifts. The morning shift began at 7 a.m., which launched the morning routines. Residents were helped to wash and get dressed and they were then brought to the dining room for breakfast and their morning medication. This was done by 9 a.m., after which the staff had a break, following which the routines continued. People were showered, their bed clothes changed, bowel movements charted, some wounds taken care of and whatever else there was scheduled for the day was done. Sometime around noon lunch was served and most of people were brought into the dining room for lunch. Usually, this was the only time the bed-ridden residents were helped out of beds. The morning shift lifted them up and the evening shift laid them down again. Residents were offered a napping time after lunch, and coffee around two o'clock. The morning shift gave reports to the evening shift and recorded their activities in the electronic system. Since both morning and evening shifts were present for a while, the storage room was kept in order and the supplies in residential rooms were restocked. The morning shift was over at around 3 p.m. and the evening shift carried on the tasks left over from the morning shift and started to prepare the dinner that was served around 4 p.m. Many residents had their dinners in their rooms. After dinner, the staff had their own break and then scheduled the evening routines including washing, putting on nightgowns, and serving supper and night medication. Everything needed to be finished by 8 p.m. since the night shift arrived at 9.p.m. and everything needed to be recorded in the computers before that.

This was the basic rhythm of everyday life. Sometimes there were recreational activities for residents during the day, but not on weekends. Whenever I entered the group home, it seemed at first sight that there was not much going on. If there were residents sitting in the common dining room, they seemed to be quietly waiting for something. Diamond (1992, p. 129) wrote almost poetically about residents waiting for breakfast as “they waited quietly, with a wild patience, practicing patienthood, actively practicing the skills of silence”. Diamond’s description revealed aptly the unique nature of daily life in elderly care facilities. What seemed to be doing nothing, was actually *practicing* patienthood and *actively practicing* the skills of silence. Wild patience was a skill that did not easily meet the eye. Since my aim was to see the surroundings with the residents’ eyes, I will let them describe their experiences of daily life in the results chapter 6.

5.3 Data collection

Ethnography as a method usually consists of participant observation, interviewing people, and gathering all kinds of documentary available on the research subject (Hammersley & Atkinson 1995; Järnström 2011b; Roper & Shapira 1999). Participant observation is its most characteristic method inasmuch that without observation we cannot speak of ethnography. The intensity of participation varies from full participation (for example being a nurse and conducting a study at the same time) to mere observing (researcher sitting alone in the corner making notes) (Roper & Shapira 2000). Usually the intensity is somewhere between these, such as in my case, when I was an outsider in the group home but participated in daily life.

I started to connect with study participants before the actual observation in the assisted living facility. I met some of the residents in the hospital I observed previously. I also participated in sessions in which an artist (an actor) coached the staff in encountering residents as individuals, and introduced myself and my research at the same time. In addition, I introduced myself and the study to everyone on site in the beginning of the study and placed notes about the study written in plain language on group home notice boards.

I spent 165 hours in two months on-site during late 2013. I talked to people and participated in tasks that were available for volunteer workers. I fed residents, moved them with the staff, took part in recreational activities, and took residents outdoors. I visited the group home every day of the week, usually between 7 a.m. and 9 p.m. when there was something to observe. Once in the beginning I slept in an empty resident room for two consecutive nights, and I also spent days in the common rooms and took my meals with residents to get an insider's view regarding the site.

I do not think that my presence annoyed people on-site. The staff knew that I was a former practical nurse and that I had done the same kind of work they were doing, and they appreciated that. The residents' relatives considered it important that someone was interested in their close ones' quality of life, and residents treated me as a visitor and sometimes as a staff member.

I used a method called jotting (Emerson, Fretz & Shaw 1995), writing short descriptions of events in a notebook I always had with me. I used keywords and self-made abbreviations when I needed to get something on paper in a hurry. After every observation, I went straight home and wrote down wider descriptions using my notes and fresh memories. The final observational data included 79 pages of text.

In addition to observation, I conducted ten interviews with the residents. Since it was not possible to conduct all the interviews in the observed group home due to

residents' dementia illnesses, I asked staff to nominate ten interviewees from the total 114 residents from all the group homes. There was a risk in this procedure that the staff would nominate residents who were most positive towards the facility. However, I needed ten people cognitively fit enough to give an informed consent for the interview to meet the ethical criteria in the study, and I did not know the residents from other group homes that well. A group of two head nurses and a practical nurse nominated the ten whom they considered to be cognitively fit enough, and who all gave an informed consent. Regarding the risk of residents being the most positive ones, we will see in the results section (6) that they were quite critical.

The interviews were conducted in the residents' rooms during the day. In one interview, there was a resident's friend present and her son also arrived at the end of the session. The others were conducted in private. I conducted thematic, semi-structured interviews (Britten 1995; Fylan 2005) since my idea was to give the interviewees a chance to describe their experiences in the home. I had prepared a battery of questions in case residents would not talk much on their own initiative. The themes broadly connected to residents' capabilities, in order to enable the data to be used in studying various topics. We talked about the residents' background, their perception of the home as a place for living, their notions of the care they received, the content of their daily lives, issues connected to control over their lives in the facility, and their perceptions of their overall situation. I let the residents include other topics as they wished, ensuring that they said something on my prepared themes. Referring to Hughes (1992, p. 444), "I did not simply ask the questions; the questions were asked when they were appropriate and when there was something to ask about". The interviews lasted from 25 to 65 minutes and the verbatim transcription totaled 281 pages.

Although the interviews were eventually emphasized in the analysis, the field work was crucial for the research for several reasons. As I stated in the beginning of this chapter, the aim of the study was to reassess the substance of person-centeredness of care with regard to older people in a particular kind of setting. The residents' interviews would not have opened to me in the same sense if I had not known their surroundings. In addition, knowing the surroundings steered my development of the interview themes. For example, I had seen different kinds of interactions between the residents and between the staff and residents, which helped me to discuss the variety of residents' experiences on the issue. Being in the group home and seeing the everyday life in the home also enabled a more critical reading of the interviews. For example, a resident told me that they could go outdoors

whenever they wanted, but on basis of what I had witnessed, I knew it was not that simple. Finally, my insight on life on site steered the data analysis. Diamond's (1992) "actively practicing the skills of silence"- kind of inner knowledge from the field helped me to isolate phenomena connected to residents' autonomy, agency, recognition, and affiliation in the data.

In addition to observing and interviewing, ethnographers usually gather all kinds of information on the research subject available in the field (Hammersley & Atkinson 1995; Roper & Shapira 1999). I read all the information available in the care provider's web pages. I also asked for some documents from the management, such as information on how residential fees were constructed, and I investigated what kind of income transfers residents were entitled to. And of course I always followed and still closely follow public discussion on elderly care.

5.4 Data analysis

According to Morse (1994, p. 174), ethnographic analysis, like all scientific analysis, is about "searching for patterns in data and for ideas that help explain the existence of those patterns". Bernard (1988) differentiates between two meanings for the term analysis: describing and theorizing. The former aims to make complicated things understandable by taking them back to their component parts. The latter is about making complicated things understandable by showing how the component parts fit together according to some rules. Both forms of analysis were used in this research.

At first, the concept of good human life was taken back to Nussbaum's (2011) question "What is this person able to do and be", which was then reduced to doing and being, which were then conceptualized as autonomy and agency (doing), and recognition and affiliation (being). In this phase of analysis, the data were involved and the empirical analysis started. I first went through all the observational notes and transcribed interviews by myself, utilizing my knowledge accumulated in the field to isolate all the excerpts dealing with the four topics of the articles (one article at a time). In the second phase of the empirical descriptive analysis, other researchers (Ilkka Pietilä in all original articles and Elisa Tiilikainen in the fourth) were involved to find the component parts of the four topics. According to Atkinson (1992), our techniques could have been anything from using qualitative analysis software to cardboard shoe boxes, yet we chose to categorize the excerpts by transferring them to new Word-documents several times. When analyzing the first article (article 3 in

this dissertation), we printed the isolated excerpts and cut them, and collated them manually to different themes over and over again, but we found the technique slightly too laborious and moved to Word documents.

We categorized and re-categorized the excerpts making new Word-documents until we reached an agreement that we had captured the basic components of the four phenomena. For example, residents seemed to base their perception of their autonomy mainly on three things: people outside the facility, their remaining functional abilities, and the existence of opportunities. Referring to Bernard (1988), these three were the basic components of residents' perceived autonomy. Naturally, there were excerpts that could have been included in more than one article. For example, some excerpts were found to capture residents' autonomy as well as their agency, but we chose to use each excerpt in connection to one phenomenon for clarity. In these cases, we used my insider's view. Observing the site previously provided me with understanding on the specific nature of residents' life in the particular facility, which helped us to decide which phenomenon was relevant in conflicting situations.

After conducting descriptive analysis, we had the findings of the four original articles, i.e. we had made complicated things (residents' autonomy, agency, recognition, and affiliation) understandable by reducing them to their component parts in an assisted living (cf. Bernard 1988). Then, there was Bernard's (ibid.) theorizing left; to make complicated things understandable by showing how the component parts fit together according to some rules. This was partly done in the four original articles. Let the example now be the second original article on residents' agency, which was found to be constructed from the residents' competence, motivations, and affordances of the assisted living surroundings. These parts were then tied together by introducing the concept *agentic space* in the discussion of the article. In this dissertation, Bernard's (ibid.) idea of theorizing will once again be used when I suggest a care philosophy that joins together autonomy, agency, recognition, and affiliation in the discussion section (7).

The analysis was both deductive and inductive making it abductive (Karisto 2008). Deduction was utilized when prior concepts and theories were used to understand what the empirical data had to say about residents' autonomy, agency, recognition, and affiliation. On the other hand, induction was involved when we categorized data excerpts and found new patterns and rules explaining how the separate excerpts fit together. Thus, the analysis was abductive since it contained elements of both deductive and inductive analysis.

5.5 Writing the ethnography

As Karisto (2008) points out, academic dissertations are written particularly carefully, avoiding making mistakes, almost holding one's breath. Formality is justifiable, since dissertations are written to prove that the researcher masters the practices and procedures of conducting and reporting academic research. However, Karisto (*ibid.*) talks about doing "cheerful sociology" when he refers to the writing process – the text needs to breathe. Especially qualitative research reports and particularly ethnographies are narratives of the research process, and the writer's creativity and writing skills inevitably impact on the final study result. The "poetic nature" of ethnography (Clifford & Marcus 1986) does not vitiate the scientific substance but makes it more comprehensible. In my work, the formality rules, such as the structure of the dissertation and referring conventions, come from the discipline of health sciences, yet the text follows the art of ethnography. Writing this dissertation is writing a story that is coherent with facts, yet this final ethnographical report is a constructive narrative about a creative process called life.

Some ethnographers might deny that my study is pure ethnography because I involved other researchers. Although I was the one in the field, participating, and alone in collecting all the data, others were involved in the analysis after the fieldwork and while writing the original articles. Ethnography has traditionally been seen as a methodology of a sole researcher from planning to reporting. However, my research is traditional ethnography in the sense of data collection. This view is also supported by Hammersley and Atkinson (1995), who see the term ethnography as preferring primarily to a particular set of methods. They perceive the preconditions for ethnography as involving the ethnographer participating in people's lives for an extended period of time, watching what happens, listening and asking questions and collecting whatever data available for enlightening the issues under research. (*ibid.*, p 1.) That is what I did. Involving other researchers in data analysis and the writing process of the original articles helped me to crystallize my insider's view regarding the topics at hand. Ilkka Pietilä and Elisa Tiilikainen worked as my sparring partners, challenging me to concentrate on what was genuine in my data compared to what was already known about the topics. My insight was used in all analyses in addition to traditional qualitative content analysis.

6 Results

In this chapter I will answer Nussbaum's (2011) question "What is this person able to do and be" with empirical research among residents in a Finnish assisted living facility. I will study what the residents are able to do through exploring their chances to have control over their lives and to act according to their values. What the residents are able to be will be studied through exploring their chances to become recognized as persons and their possibilities for affiliation in assisted living surroundings. Subsections 6.1–6.4 are summaries from the results of the four original articles included in the dissertation. I will summarize dementia-related issues in the results in subsection 6.5. I will illustrate the results with highlights from the data. All the names of people and places in the interview excerpts, except for mine, are pseudonyms.

6.1 Autonomy as resident-facility fit (article 1)

The residents' autonomy seemed to be highly relational, insomuch that I approached it through the concept of resident-facility fit (e.g. Ball *et al.* 2004). I used resident-facility fit as a philosophical value judgment where the fit was good when residents felt that they had control over the environment, i.e. a good resident-facility fit entailed that the environment offered positive opportunities for autonomous living. Whereas previous research had seen the fit as a goal for a process aiming to avoid resident transfers from one facility to another due to diminishing health and functional abilities (Ball *et al.* 2004; Roth & Eckert 2011; Zimmerman *et al.* 2003), I comprehended the fit more as a result of a process that aimed for residents to have control over their lives. Thus, the resident-facility fit was neither an objectively measurable phenomenon nor a subjective feeling, but rather a combination of the two; the resident-facility fit was the residents' perception of their ability to manage in their new surroundings with their current capability. Therefore, I changed the concept of resident-facility fit to *perceived* resident-facility fit in the original article.

The residents' autonomy when perceived as resident-facility fit was mainly based on three factors: i) the social, functional, and physical features of the facility, ii) the residents' individual traits, and iii) the residents' potential to act.

6.1.1 Surroundings

Although the residents' everyday social world consisted mostly of the staff and other residents, people outside the facility seemed to be very important with regard to the residents' control over their lives. The role of the staff and peers was emphasized more with regard to the residents' social fit with their surroundings. I will study this issue in more detail in subsection 6.4 concerning affiliation. The residents often seemed to base their autonomy feelings on relatives and friends, who took them out to run errands and brought them the goods they needed. In the first excerpt, Paul gave the words for the importance of "outsiders."

Jari: Can you easily get stuff here that the house won't provide, the bottle of cognac for instance or...

Paul: I only need to give my nephew a ring, say that we'll make a trip to the market and it's settled.

Jari: Right. So, whatever you'll need, you'll just go over and ...

Paul: Yeah. Likewise all this equipment. I can't even bring that stuff myself or go and get it anywhere, so ...

Jari: Yeah, you mean the TVs and...

Paul: Yeah, my son-in-law will bring them to me with my daughter. (Excerpt 1, male resident, 82, moved independently with walker)

Visitors and phone calls from the outside were emphasized by the residents' own initiative during the interviews, which is a sign of their importance. In addition to taking residents outside and bringing desired goods, friends and relatives served as psychosocial resources, which reduced the residents' dependence on official care, in line with previous research (Lloyd *et al.* 2014). Highlighting visitors may also indicate their importance with regard to the residents' social status among peers and the staff and it certainly boosted the residents' self-esteem. Anita seemed proud to share in the interview that even her son's parents-in-law visited her regularly, which meant

that she still was a significant family member, even after she had transferred into the facility.

In addition to social factors, the environment encompassed functional and physical features that affected the residents' autonomy. The functional features were practices and procedures necessary for the care organization to fulfill its purpose and I will open them up in more detail when scrutinizing residents' recognition in subsection 6.3. Here it is sufficient to conclude that daily routines had both positive and negative effects on autonomy feelings, depending on whether they matched the residents' own preferences or not. Being woken up by the staff in the mornings was not necessarily desirable but mealtimes regular as clockwork were appreciated.

An obvious autonomy-influencing feature of the physical environment was that the front doors of group homes were always locked and opened with a five-number code, which restricted residents' freedom of movement. An excerpt from the observational notes is clear about this.

When I arrived at the group home, some people were sitting at the table in the dining room. I sat down at one of the tables with three female residents. One of them asked me what ailment was preventing me from opening the door out. She said she can't go out and it feels like being in prison here. I told her that people probably get to go out only with an escort. The lady kept on talking to herself for a while still, about being a prisoner, but I couldn't quite make out what she said. (Excerpt 2, observation notes)

Feeling imprisoned could be the worst situation when considering the perceived resident-facility fit. Keeping the doors locked was a procedure to keep people with dementia illnesses safe, but it was just these people who did not understand why the doors were locked. Some of the cognitively capable residents knew the code and moved in and out freely. In addition to locked doors, some residents were tied to their wheelchairs with a lap belt to prevent them from falling and hurting themselves, although prior research has found that physical restraint use agitates older people in care facilities (Werner *et al.* 1989) and there is no strong evidence of the efficacy of restraints for safeguarding residents (Evans & Strumpf 1989). Physical restrictions in elderly care have raised vivid public discussion for a reason. People with dementia need to be protected, but interfering with basic rights, such as freedom of movement, is an extremely delicate matter. I will return to the issue of self-determination in subsection 6.5 on dementia-related issues.

6.1.2 Individual traits

All of the residents lived in a sheltered home due to diminishing functional abilities, which inevitably affected their chances to lead an autonomous life. However, residents had their ways of feeling autonomous regardless of this, especially by lowering standards of autonomy, highlighting their remaining abilities, adjusting their activities to their functional level, and comparing their situation with co-residents with a lower level of functional abilities. Sarah expressed how standards of autonomy were lowered in practice. She suffered from a somatic illness that had taken away her ability to walk, and was asked whether she could move around independently in the home with her wheelchair.

Sarah: Yes I can. I can wheel myself around a bit. They usually take me to the dining room for lunch, for example, but then I sometimes end up waiting at my door for someone to let me in, because I always keep my door locked because of that person (a resident who wandered around). So if I want to get away from the dining room, I'll wait there for someone to open the door. (Excerpt 3, female resident, 86, could move only aided)

Sarah answered the question about whether she was able to move around independently with a straightforward “yes I can”, but her account reveals the phenomenon that Street *et al.* (2007) called miniaturization of autonomy. Sarah was not able to pass through the door on her own, but she considered herself autonomous since she could roll herself to the door. At the same time, she highlighted her remaining abilities, which may be interpreted as a coping strategy. Coping strategies (SOC) (selection, optimization, compensation) are used to compensate functional losses in old age (see. e.g. Freund & Baltes 1998). Another coping strategy was to adjust one’s doings to one’s diminishing abilities. Sarah had switched knitting to cryptic crosswords due to her aching wrists, whereas Harry sat on a bench outside instead of walking due to shortness of breath.

Previously I introduced the concept *ability others*, which we found earlier to describe how community-dwelling nonagenarians highlighted their autonomy by checking it against the situation of those peers who had transferred into a care facility (Pirhonen *et al.* 2016). Institutionalized people were seen as ability others since they had lost their independence due to diminishing abilities that forced them to transfer into a facility. According to this study, the phenomenon still prevails in assisted

living. Joanna said it herself when she was asked whether the help from the staff was sufficient.

Joanna: The help's been enough for me, but I don't know if you'll get the necessary care if you're in worse shape than I am. (Excerpt 4, female resident, 85, moved independently with walker)

Like Joanna did here, residents boosted their own autonomy feelings by comparing their situation to co-residents with a lower level of functional abilities.

6.1.3 Potential to act

One significant finding was that having the potential to do something seemed sometimes to be even more important than actualizing the potential. The next two excerpts highlight how having potential to act may affirm the perceived resident-facility fit by enabling the feeling of control over one's life. In the first excerpt, Paul was asked whether he felt connected to people outside the home. In the latter, Sarah differentiates between life in a sheltered home and a geriatric hospital.

Paul: I do. I can get a ride in a car. My daughters or buddies will pick me up and take me places if I want to go somewhere.

Jari: Okay.

Paul: So I don't have any problems with that. The other thing is that I can go for a walk any time, or catch a bus and go to the city center, but I don't like to do that, go there on my own. (Excerpt 5, male resident, 82, moved independently with walker)

Sarah: It's a good thing this is different, but better in the sense that, of course, I prefer to be alone in my own home and be free to go where I want. I could take a wheelchair-accessible taxi to go visit my friends, but I haven't gotten around to it yet... (Excerpt 6, female resident, 86, could move only aided)

Similarly to these excerpts, residents talked about things they could do *if* they wanted. They could go to recreational area nearby, could pick a phone and call their relatives, or get some fresh air in a balcony although they never had done those

things. Apart from enabling a feeling of control over one's life, potential to act provided people with positive expectations of the future. Saving enjoyable activities for later expressed positive prospects regarding the residents' remaining functional abilities still available in the future. Potential to act is also important for hope, which has been found a key factor in residents' ability to maintain their feeling of autonomy in assisted living settings (Perkins *et al.* 2012).

6.2 Agency in assisted living (article 2)

In this subsection I will describe what the residents' agency looked like in an assisted living setting. Agency was sometimes hidden in the sense that it was not active doing or interacting, but it was more like being. In addition to residents' personal characteristics and motivations, affordances of the surroundings affected their agency.

6.2.1 Competence

In this study, the concept of competence was used to incorporate the personal qualities the residents needed to accomplish their aspirations, such as their skills and knowledge and creativity in applying those skills. Being able to do things, i.e. functional ability, was an important yet not vital component of competence. For the residents, competence was about using other people's functional abilities to accomplish one's own aspirations. Residents outsourced their actions to the staff, relatives, and friends voluntarily. Sarah, who was unable to move around by herself, kept her closets in order by a frequently visiting friend. Many residents had outsourced their finances to a daughter or son, and Harry said he could not care less about what pills he was taking because the doctor was a better expert on those. Delegating one's agency voluntarily to other people was agentic.

The situation was different if residents felt that their agency was taken away unwillingly, as Anita described in the next excerpt. She was asked what the biggest differences were between living in a private home and an assisted living facility.

Anita: Well, at home I could of course wake up whenever I wanted to, although I can do that here, too. I had to go grocery shopping and cook. That's a difference right there.

Jari: Yeah. Do you miss things like that, going to the store or cooking your own meals?

Anita: (laughs) Why not...

Jari: Uh-huh. And do you think you could still do it?

Anita: Huh?

Jari: Could you still do it?

Anita: Sure, I could still do it. (Excerpt 7, female resident, 78, moved independently with walker)

Anita missed the domestic work part of living in a private home. She still felt competent enough to carry on with such activities, but the facility did not encourage her to take part in daily chores. The kitchens of the group homes were restricted areas for residents due to hygiene reasons. Earlier in the interview, Anita explicitly stated that her "children began to say 'you can't manage at home on your own'. And I could still manage if I were there". She seemed to consider herself too competent to live in a facility and therefore seemed to feel that her agency was restricted by her children. Based on this kind of finding, decisional agency got separated from delegated agency. One can delegate the "action part of agency" to other people and hang on to decisional agency at the same time when the delegation is voluntary.

Another way to compensate lowering functional abilities in agency was simply to use aids as we all constantly do. The residents used wheelchairs and walkers to move around, and they had cell phones to keep in touch with people outside the facility. Usually, the devices were appreciated simply as aids, but sometimes they enabled deeper agentic feelings, as in the case of Ida.

Ida: And I can go to the bathroom, that's a big deal.

Jari: You can go on your own?

Ida: I can go on my own, and then I've got this walker, I can use it to go to the bathroom.

Jari: Yeah, that's important.

Ida: (laughs) yeah, I never had any accidents on the bed, I can get to the bathroom before... and I don't have to go that often, I never have had that kind of issues.

Jari: And you don't need help when you go there...

Ida: No I don't. I don't need any help at all. (Excerpt 8, female resident, 94, moved independently with walker)

It is notable here that Ida emphasized the walker in connection to the bathroom. The walker was not just a moving aid, but enabled her to feel agentic. The aid made her competent enough to deal with "bathroom business" without other people and thus supported her agency (and autonomy).

Sarah gave an example on how competence actually is much more than functional abilities. As we remember, she had lost most of her physical abilities to a somatic illness. In the excerpt, she looked back to days when she lost her ability to walk, now sitting in a wheelchair in her room.

Sarah: But then I came to (mentions the hospital ward she was in before the assisted living facility) and the first time two nurses, pretty strong, strong-looking ones, tried to get me into a wheelchair, and my legs went all... one crossed under the other. Then they said we'd all been close to taking a tumble. So that's when they said this isn't going to work, off to the bed with you. And after that it's been bed rest for me. I like to sit there, too (points to the bed). I don't lie down unless I'm sleeping. (Excerpt 9, female resident, 86, could move only aided)

The more residents had lost their functional abilities, the subtler their agency got. Sarah shared how other people had made the decision of her becoming bedridden on her behalf, which inevitably had affected her agency negatively. When Sarah was not able to move around independently, she found the difference between active doing and passive being in issues such as sitting on the bed: "I don't lie down unless I'm sleeping." Sarah had her ways of feeling agentic after all.

6.2.2 Motivation

There were two interesting findings regarding residents' motivation in the study. Firstly, it seemed that expressing one's wishes or desires called for an account about the speaker's resources to fulfill the aspiration in question. When residents talked about things they did not want, an account was not needed. They simply stated "I refused to take that medicine", "I denied the night nurse permission to enter my

room”, “I don’t want to wear make-up,” and so on. But when there were positive expectations, accounts were presented as Paul did in the next excerpt.

Jari: What expectations do you have for the future now that you’ve moved in here and lived here for three months?

Paul: Well, I’d of course want to take a short trip abroad at some point. I need an assistant, though, and I can’t afford to pay for two people. (Excerpt 10, male resident, 82, moved independently with walker)

Paul had traveled a lot before, with his late wife, and still dreamed of a trip abroad. However, it seemed that when people’s functional abilities had lowered so that they resided in assisted living, there was a kind of accountability for agentic feelings. Agency was being constantly re-negotiated.

The second and more important finding regarding residents’ motivation concerns theories of action. Hans Joas (2005) holds that traditional theories of action are teleological, i.e. the *primus motor* of action is the actor’s goal-oriented motivation. An actor has a goal in mind and she then chooses an action most suitable to her situation to achieve the goal. Joas, however, thought differently. He assumed that an actor’s motivation is based on her situation. At first there is the actor’s situation, which defines the actions available, which then define the goal. Joas’ (ibid.) theory of action is thus non-teleological. Our findings lent support to Joas’ theory. Ida’s occasional dizziness and constant exhaustion motivated her to stay in her room all the time although she explicitly stated that she was lonely. People with dementia could be seen as a living argument for Joas’ non-teleological theory – the more the rationality diminishes, the more the situation directs the action. Once, when conducting the fieldwork for my master’s thesis (Pirhonen 2015a), I observed a conversation between four people with dementia (Pirhonen & Laitinen, article manuscript). The situation seemed like a normal conversation; people talked in turns, nodded and made supportive sounds when someone else was talking. But when I listened to what the discussion was about, there was no logic at all. They talked about different things and probably did not understand each other, but sitting together around a table made them talk together. The situation motivated their action.

Aging itself lends support to Joas’ (2005) non-teleological theory of action. Age-related losses in functional abilities reveal how actions are bound to situations. Joas’ (ibid.) theory has a strong affinity with the SOC (selection, optimization, compensation) theory (e.g. Freund & Baltes 1998) of coping with age-based changes, but there is one fundamental difference. According to the SOC theory people *adjust*

their actions to reduced functional abilities, but interpreting Joas we could say that people *create* their actions based on the situation. Thus, Joas' theory is relevant to the agency of people with severe functional declines.

6.2.3 The affordance of the surroundings

The assisted living facility, as a living surrounding, both encouraged the residents' agency by providing opportunities and discouraged it by setting limitations. These two may be combined as the affordance of the surroundings. Kytta (2002, 109) describes affordances as the functionally significant properties of the environment that are perceived through the active detection of information. Both the environment and the acting individual generate affordances together. For example, when a resident sees another resident sitting alone in a common room, she may choose or not choose to join her.

Similarly to the case of autonomy previously, agency was influenced by several factors connected to the social, functional, and physical features of the facility. When I asked Joanna what constitutes a home, she shared how living in a facility restricted her agency.

Jari: If you think of home as a concept, do you have some kind of idea of what home consists of? What kinds of things make a home?

Johanna: It's the living itself. The things that you do. You don't do them here. There's no cooking or baking here. (Excerpt 11, female resident, 85, moved independently with walker)

Joanna missed the domestic work of private home just like Anita previously. Assisted living providers tend to emphasize that sheltered homes are *homes*, where people carry on living more or less the same way as they did earlier in their private homes. Paul sometimes helped other residents, although the staff had tried to prevent him from doing so by appealing to safety regulations. Another female resident once wondered why there were no duties available for her in the home. The written business idea of the home I studied stated that residents could take part in domestic work if they wished, but those were empty words. Fulfilling that promise would affirm the agency of many older people in a simple way.

The surroundings naturally provided support for agency as well. The residents were quite happy with the help they got from the staff, friends, and relatives.

Sometimes living in a facility was indeed an expansion of a resident's agency compared to a private home, highlighting the core idea of assisted living. For example, Ida said that she was no longer able to cope in her private home.

As Giddens (1984) points out, social structures affect individuals and vice versa. In assisted living this means that in addition to coping with the setting, residents shape it as well, as Sarah reflected in the next excerpt.

Sarah: But then, little by little... The other residents wouldn't say anything to anyone. I just went on and asked questions and now I've got four people at the table that I can talk to. And who talk to me, and listen, and answer questions. (Excerpt 12, female resident, aged 86, could move only aided)

The excerpt shows that the residents were not just passive recipients of care but could influence their surroundings. Sarah was a very social person and was annoyed because other residents would not chat with her during meals. She decided to change this and kept talking to others until they started to answer. She made her surroundings more social herself, proving to be highly agentic in spite of losing her physical abilities. Sarah utilized the affordance of dining together.

6.3 Recognition of persons (article 3)

As we saw in the theoretical background of this research, assisted living as a form of care emphasizes the person-centeredness of care as its core idea. One plausible way to see whether a care facility lives up to the principle is to study whether or not the daily practices of the facility support the residents' recognition as persons. The empirical study revealed several practices that both discouraged and encouraged recognition.

6.3.1 Practices discouraging recognition

There were five main features of daily practices that hampered residents' being seen as persons: residents' invisibility, staff timetables, standard treatment, the dominant role of documents, and shifting responsibility. The residents' invisibility meant that

residents were not *de facto* encountered during interaction with the staff. An excerpt from observational notes illustrates this. Anna could not move around independently, and was asking for help.

After lunch Anna asked the staff several times whether she could leave and go back to her room. A practical nurse replied that it's better you sit there a bit longer, so that you're not in your room all the time. Next, Anna got dismissive replies. Then one of the practical nurses said she will take her once she's cleared the table. She never did, but went on to do other tasks. (Excerpt 13, observational notes)

Often when residents sought attention staff members replied with repeated, automatic 'in a minute' answers. Sometimes people's requests were ignored altogether, almost as if residents were invisible. This kind of practice hardly affirmed residents' recognition as persons. One obvious reason for residents becoming invisible was the staff's timetables, as the next excerpt reveals.

Ella had been put to bed as early as 4.30 p.m., which was really sad. Her daughter went straightaway to the nurses to ask why her mother was in bed so early. The answer was that staff had arranged their work so that they could be sure everything was done by the end of their shift. So Ella was tucked in, wearing her nightdress, even though she had not yet had dinner. (Excerpt 14, observational notes)

Evening routines in the group home begun just after dinner and occasionally even earlier (as in Ella's case above) to make sure that the staff fulfilled their tasks and had time to record everything electronically before the end of their shift. I once asked a nurse why the common spaces were usually empty of residents at 6 p.m. and she said that according to research, older people want to retire early in the evening. Even if that were the case, it highlights the next way in which practices may discourage residents' recognition as persons; standard treatment. The next excerpt illuminates the issue.

During lunch one resident was unhappy with having been given too big a portion and rye bread, which she could not eat. I overheard her talking to herself or to someone else at the table about how she loses her appetite when the portion

is too big. The staff always tell her to eat what she can and leave the rest. (Excerpt 15, observational notes)

I overheard several times how this resident asked for a little portion and half a slice of white bread, yet often she got a large portion accompanied with dark bread. One possible reason for this was the procedure where one staff member portioned the food and another served it to tables. This was not always the case since some staff members did portion the food according to residents' wishes. However, standard treatment occurred when residents were treated as a group of similar people instead of recognizing them as persons.

Sometimes the residents' individuality was overruled by emphasizing documents. Toby shared an extreme example from the hospital ward where he awaited a placement to assisted living.

Toby: I was given a single room there and I moved in and then on the first Monday a doctor came in to see me and said: Good morning. So you're the so-called end-of-life-care patient.

Jari: Aha!

Toby: I looked the doctor straight in the eye and if I'd been in a different mood I would have punched him in the face. I said to him I'm sorry doctor but it seems you've got the wrong patient, I'm definitely not yet at the stage of being an end-of-life-care patient. And the doctor just nodded and said: "Well, we'll talk about this some other time," and off he went. The next morning, he came back to my room and shook my hand and apologized, saying that you were right all along, I'd been reading another patient's papers. (Excerpt 16, male resident, 60, moved independently with walker)

We might say that Toby was seen but not heard. Even though the doctor was seeing him for the first time, he chose to believe the (wrong) documents he had read rather than an older person who insisted that there had been a mistake. Toby was seen through documents, not recognized as an individual. On another occasion, Mary's daughter asked a nurse if she could see her mother's list of medication. The nurse replied that she should check the computer to see if Mary had forbidden her information to be given to other people. However, since Mary was present, they asked Mary who said it is ok to give the list to her daughter. In spite of this, the nurse checked the computer and found no remarks about giving Mary's details to relatives

and decided not to give the list without checking with the doctor first. Documents overruled Mary's direct wish.

There probably was a logical reason for the nurse's conduct above, such as dealing with confidentiality, patient rights, and Mary's cognitive competence, yet there was an ethical problem involved. In this particular case Mary's self-determination got overruled, yet sometimes residents' self-determination seemed to get over-emphasized. According to my observations, emphasizing self-determination sometimes resulted in the misrecognition of persons. What I mean is that the staff sometimes appealed to the principle of the residents' self-determination to ease their own workload. Responsibility was placed in incompetent hands which I called shifting responsibility. I will give an example.

When feeding people who were unable to eat by themselves, I noticed that some residents were very slow eaters. It took me 30–45 minutes to feed Ella. Often, when Ella was fed by the staff, the staff member tried to feed her for some minutes and then claimed that Ella did not want to eat this time/anymore and took her meal away. Ella was unable to speak for herself. Responsibility for Ella's nutrition was shifted to an incompetent person and Ella's basic needs were misrecognized. I understand that the time constrained staff cannot take 45 minutes to feed one person, but Ella was the one to pay the price for the economic efficacy of the care provider. Appealing to self-determination may result in abandonment in the case of cognitively incompetent people.

6.3.2 Practices encouraging recognition

Life in the facility was not as much doom and gloom as the practices illustrated in the previous subsection could imply. There were practices that affirmed the residents' recognition as persons, too. The residents were recognized through offering them privacy, giving them opportunities to continue life-long habits, joking and debating with them, and by putting an active emphasis on their wishes.

As we have seen, the core idea of assisted living is to make residents feel at home in the facility. There is an old phrase "oma tupa, oma lupa" in Finnish which means that "I am my own boss in my own home." Assisted living provides residents primarily with their own rooms, which they furnish with their own belongings. This was a practice that the interviewees obviously appreciated, as Sarah said in the next excerpt.

Sarah: It was just wonderful when I moved in from there (hospital) and I could be all on my own, just as I pleased here in my room, by myself, even though I had a nice room-mate there (in hospital). (Excerpt 17, female resident, 86, could move only aided)

The room-mate Sarah mentioned became her friend in that she visited Sarah in the sheltered home frequently. Yet, Sarah was happier to live in her room all alone than she would be sharing it with a good friend. Sarah's account manifests the residents' appreciation for privacy. Paul had forbidden the staff from checking in on him during the night since he appreciated privacy, too. He stated that "I pay a rent for my room and since I live here alone, I don't want anybody to barge in on their own", emphasizing his consumer rights as a tenant. Many cognitively capable residents kept their doors locked to prevent people with dementia from entering their rooms. Thus, supporting privacy affirmed residents' recognition as autonomous persons.

Continuing life-long habits seemed to affirm recognition, as the next observational note shows.

Residents had taken sauna yesterday and today. Hanna was very pleased that she had been able to go to sauna after such a long time. She happily enjoyed a small beer afterwards. (Excerpt 18, observational notes)

Finns and sauna may already be a cliché, but some residents very much appreciated that there was a sauna in every group home. Hanna actually cried of joy after a sauna. Violet and Martha enjoyed the sauna together, since a sauna is more than a means to clean oneself in Finland; it is a place for relaxation and socialization (Edelsward 1991; Hänninen 1986). When residing in assisted living, people were able to pick up many of their earlier customs: to visit their children's homes and summer cottages, to enjoy a glass of cognac, to smoke a cigar on a balcony, to do handicrafts, and so on. Providing residents with opportunities to do things they had always done was a way to recognize them as persons.

The staff making personal contact with the residents obviously affirmed their recognition. Debating and joking with the residents seemed to equalize the carer and the cared for. A debate entails both parties considering the other as a person; it takes two to tango as they say. The same goes for humor when people joke together. Joking functions as recognition when the jokers are interacting as equals, otherwise it would be mockery, irony or something mean.

Finally, I will share an excerpt that shows how putting emphasis on the residents' wishes highlights their personhood. I was playing a game called Fortuna with residents one evening.

When we were playing, one of the practical nurses from the night shift made us milk shakes. He also said that in the future, he could order some popcorn for when we were playing. That's a good idea. We really enjoyed ourselves, playing in a large group, while having our shakes. At one stage I asked the practical nurse if we still had time for one more round before their evening duties. He replied: "Absolutely, the game on Saturday night is much more important than anything else". (Excerpt 19, observational notes)

In this short extract the nurse recognized the residents in several ways. He offered them a special treat indicating that he appreciated the residents. He understood that a Saturday night game is just as important to residents as it is for the rest of us. And he explicitly expressed that the residents' enjoyable moment was more important than hanging on to evening routines. The residents were recognized as a group of persons whose wishes overruled the institutional order.

6.4 Ruptures of affiliation (article 4)

As we saw in section 6.1, the staff, other residents, friends, and relatives affected the residents' perceived resident-facility fit. The resident-facility fit was a broader concept encompassing a variety of issues relating to the residents' possibilities to feel that they had control over their environment. Other people had an impact on the residents' autonomy, and in this section I will examine how they affect the residents' affiliation. Affiliation, as Nussbaum (2011) defined it in subsection 3.2, deals with residents' possibilities to maintain their identity and preserve the social bases of self-respect. Affiliation might, thus, be defined as the social aspect of resident-facility fit. The residents' affiliation within assisted living surroundings seemed to employ two distinct social worlds: one inside the facility and another outside. In this chapter I will examine affiliation through residents' difficulties in reaching it, i.e. their social isolation.

6.4.1 Detachment inside the facility

When older people transfer into assisted living, they enter a new social surrounding that is given to them i.e. they cannot choose who the other people present are. These other people make up the residents' primary social world. Inability to bond within the primary social world may result in social isolation which then may result in feeling lonely (Brownie and Horstmanshof 2011).

Other residents' qualities both affirmed and impaired the residents' affiliation. Living together in a group home enabled people to choose their company inside the home although they could not influence who the other residents were. Sally explained how resident heterogeneity enabled affiliation in a group home.

Sally: Well I choose who is suitable for me.

Jari: Okay. So you can like choose who you want to hang around with.

Sally: Yes. That's it. And so to speak I prefer them to be men.

Jari: Oo-kay.

Sally: Most women are just, you know, full of themselves and clothes and stuff, but they don't like, care...men think more broadly about things, at least the ones I know. (Excerpt 20, female resident, 82, moving independently with walker)

Living in a group home for both sexes suited Sally perfectly since she preferred the company of men. Violet and Martha become close friends in the home, and as we saw, Sarah had her ways to make her primary social world more suitable for her regarding discussions during meals. However, since our interviewees were those with the best cognitive capabilities, they often found the co-residents impossible to socialize with due to their dementia illnesses. Paul's account was revealing when I asked if he could bond with other residents.

Paul: Some of them just stare out in space. Can't really connect with them.

Jari: You mean some guys have some kind of memory disorders?

Paul: Memory disorders.

Jari: Yeah, then it's kind of difficult to make contact.

Paul: No, it won't work. Even when we were in the sauna with a couple of these guys, you can't really have a decent conversation with them. (Excerpt 21, male resident, 82, moved independently with walker)

For the residents with the best cognitive capacities, peers to bond with were few and far between. Paul and some others kept their door locked to prevent people with dementia from entering their rooms. Ida, who previously said that she stayed alone in her room due to dizziness, considered the quality of peers another reason to stay put.

Jari: Okay. Well, do you feel that you belong to a certain group living here?

Ida: I'm terribly lonely. But I don't miss anything that much. They are all like me.

Jari: Right. So you mean that being alone works well for you.

Ida: It works out fine. It's okay, everybody's just as old and silly as me.

(Excerpt 22, female resident, 94, moved independently with walker)

In the interview, Ida explicitly stated that she was terribly lonely, yet she chose to be alone in her room since other residents were “just as old and silly as me”. Harry gave a straightforward account regarding other residents when I asked if he took part in the recreational activities available.

Harry: Well they do have activities. I could attend many of those but I don't feel like it.

Jari: Yeah okay.

Harry: Doing activities with damn bitches like that, bitches who are a hundred years old, there's nothing to talk about you know, and we have nothing in common, so I feel like a hairy troll, fuck it. (Excerpt 23, male resident, 73, could move only aided)

Harry could be seen as a socially double marginalized resident since he was a relatively young man surrounded by older women, which made it difficult for him to bond with the others. Actually Paul, Ida, and Harry each seemed to choose to be alone rather than interacting with other residents, an interesting aspect related to social isolation in assisted living. On the one hand, they could have chosen the company of co-residents, which then would have made them feel different and disconnected from them even while spending time with them. Instead, they chose being alone in their rooms.

Difficulties in bonding with co-residents highlights the role of the staff in affiliation with primary social world, yet that was also not a simple issue, as Harry expressed.

Jari: Do they (nurses) know what your individual needs are, what kind of things Harry wants?

Harry: I don't know what they ...no I don't think they know.

Jari: Do they have time to chit-chat with you?

Harry: Not really, we only talk about work related stuff.

Jari: Alright. So you talk about things that have to do with living here, like when it's dinner time or when you can have a smoke...

Harry: Yeah, that's it. We don't talk about other stuff.

Jari: No personal stuff.

Harry: Yeah, no nothing like that. (Excerpt 24, male resident, 73, could move only aided)

Older people residing in assisted living are as colorful a group of people as any group of individuals. In addition, residents' illnesses and medications can bring on negative characteristics and conduct disorders. The staff may find some residents challenging, which easily leads to avoidance and keeping interactions with certain residents to a minimum. Harry seemed to be such a straightforward person that the staff avoided contact with him. When we conducted the interview, it was past lunch time and he was still waiting for a nurse to help him with his morning routines. He was a smoker and he said that sometimes he had to wait until 4 or 5 p.m. to get to a balcony for a smoke. The staff seemed to keep their interaction with Harry to a minimum. Joanna also said that there were staff members who showed no personal interest in her whatsoever.

The staff's personal characteristics were only one side of the story, the other was, once again, the staffing ratio and the staff's workload. Eight out of ten interviewees said there were too few helpers available. One commented that there was enough aid for her, but not for those who were in worse shape than she was, and only one interviewee said that the situation was good. The staff said that their resources covered only basic care, which my observations supported, as seen in the next excerpt.

There were three people in Ella's room; the daughter, nurse and Ella who was in bed. The nurse was explaining that there were only two nurses on duty, and that they were going to give Ella a shower today. They hadn't had time to do that before lunch even though they should have. The daughter had asked why her mother was still in bed after noon in her night-diaper and without her teeth. The

nurse was a little upset and explained that one shouldn't be mad at the nurses, but to direct any complaints to their superiors. (Excerpt 25, observational notes)

The small number of staff reduced residents' affiliation inside the facility, since many residents, like Ella here, could not independently get out of bed and the insufficient staffing ratio resulted in these people being helped out of bed only once a day, usually for lunch. It was self-evident that this staff procedure reduced social contacts since the residents usually had to stay alone in their room all evening. Also, many nurses said that they felt sorry about this policy, because they would have preferred to spend more time personally with residents, time that would have prevented social isolation. The rule of keeping the staffing ratio to a minimum came from the economics of staffing, yet Ella paid the price once again.

Affiliation inside the home seemed to be difficult, yet not impossible, to reach. As mentioned previously, friends were made among peers, and most of the interviewees also had good relations with some staff members.

6.4.2 Separateness from the social world outside the facility

Bethel Ann Powers (1995, p. 180) described how residents perceived a care facility as “the end of the line” where they became separated from the familiarities of home and life that exists outside the facility walls. This is a perfect description of social isolation in connection to the world outside the walls; people become isolated when they lose connection with their significant others, or when the connection weakens radically. In our case, we are talking about the residents' connections with their past before transferring to the facility. Disturbances of the connection between the past and present hampered the residents' sense of continuity and resulted in longing for people, places, and familiarities of their previous life and thus emotional isolation. Toby longed for his sons.

Toby: I would like my sons to visit me more often. Both of them could come here more often.

Jari: I get it. You miss your sons.

Toby: (moved) yes.

Jari: Have you told them this?

Toby: I have told them. In an e-mail.

Jari: Yeah.

Toby: And they are both so bitter about their childhood years, when I was drinking a lot and I never raised a hand against my children nor my wife, but I had a foul mouth. That's why they are hurt, still, even if it was such a long time ago, they are still hurt, so... (Excerpt 26, male resident, 60, moved independently with walker)

Toby's wife had divorced him and the relationship with his two sons was now problematic. The older son visited him rarely, and the younger one had broken relations with him altogether because of Toby's prior drinking problem. Toby was a "young man" (60) who was already living in a sheltered home, as his rough life had taken its toll, hampering his abilities to function so that he needed round-the-clock attention. However, Toby did not feel socially isolated all the time. He was connected to the world outside via his laptop and Internet connection, and he talked on the phone with some of his friends. He told me that he socialized with some members of the staff and he also said that there was one peer he spent time with. Toby's isolation was related to missing his children. Toby's personal history (drinking problem) resulted in feelings of isolation and loneliness in old age.

Personal history isolated Harry as well, yet through a different mechanism. Just over a year before the interview, Harry had played up to five gigs per week in a dance band as a drummer. Then a somatic disease broke his health down quickly and considerably, and he moved into the sheltered home. Now Harry needed help in all his daily functions except for eating. During the interview, Harry did refer to himself as a drummer, emphasizing his life-long identity as a musician. Although Harry was 73, he referred to the other residents as oldsters and "a hundred-years-old bitches", drawing a clear distinction between other residents and himself as a professional musician, as we see in the next excerpt.

Jari: Well, so do you spend time anywhere else than in your room? Do you go to the common room to watch tv?

Harry: Well I really can't, you know I'm a musician, so normal people's stuff just don't work, you know...

Jari: Okay.

Harry: It just doesn't work. They can't deal with my stuff.

Jari: Okay. So do you miss the company of other people in here?

Harry: Well I do miss someone to talk to, but there's no one on my wavelength here except for me, there's no one like that.

Jari: Okay. I get it.

Harry: So it's like talking to a wall. It's really different for musicians than for normal people. (Excerpt 27, male resident, 73, could move only aided)

This time Harry calls his peers normal people and pictures himself as different, as a musician. Harry's sense of belonging was still turned toward his prior musical circles, thus making him feel isolated. He talked about the famous Finnish singers he had accompanied. By hanging on to his former lifestyle, Harry preserved his continuity of self but, at the same time, isolated himself from the others although he explicitly said he did miss someone to talk to at the home.

Ida's social isolation was partly connected with her son's current phase of life.

Ida: When my husband died a long time ago, he died in a car accident. And I only have one son and he's got his own family and they've got their own lives, so I'm really lonely. But I'm used to it somehow. (Excerpt 28, female resident, 94, moved independently with walker)

Once again Ida said that she was lonely. She also said in the interview that she had a cell phone to call her son. She had lived in the home for over six months, but had never called, although she obviously missed her son in the excerpt. According to Zimmerman *et al.* (2005), older people tend to avoid becoming a burden to others, especially their close family members. Ida understood her son's situation with his own family and did not seek his attention for herself. It seems that Ida chose social isolation over the risk of becoming a burden to her son.

Anita was the one who previously proudly stated that his daughter, son, and even son's parents-in-law visited her regularly. Yet, longing was familiar to her, too.

Jari: Have you made any new friends or other important relationships at the sheltered home?

Anita: Well, no. My own family are those things. But I used to have friends when I was home, but none of them have been over to visit me, even though my daughter asked them to come. (Excerpt 29, female resident, 78, moved independently with walker)

Anita missed her friends from those earlier days when she still lived at her private home. Sarah also said that her husband had encouraged their common friends to visit her, yet nobody had ever come. It might well be that older people who are still living in private homes find care facilities a bit frightening and avoid visiting them,

as a staff member once contemplated. In another study (Pirhonen *et al.* 2016), we reported how Finnish community-dwelling nonagenarians feared their own transfer into a nursing institution, sometimes even more than dying. In addition to people, the residents longed for other aspects of the past as well. Anita and Joanna missed the daily chores in their private homes and Violet longed for her beautiful summer cottage. In addition, people with dementia illnesses sometimes seemed to long for their former homes or people from their past. One resident in the research site longed for her mother, often loudly and desolately crying for her in the evenings.

As a conclusion, social isolation was found to be a multifaceted phenomenon in assisted living surroundings. Sometimes social isolation resulted in loneliness, like when Ida kept repeating how she was terribly lonely. Sometimes residents isolated themselves from others to avoid feeling awkward in their company. Even Ida herself justified being alone with the qualities of co-residents available. Harry hung on to his prior identity as a musician, probably due to difficulties in accepting his current situation where he was vulnerable and needy. Hanging onto the past affirmed his continuity of self, yet it isolated him from the people on site at the same time. In addition, the qualities of the people available compared to his preferences made Harry stay in his room alone. Toby did not feel socially isolated on site but felt isolated from his own sons. Paul's daughters and friends visited him regularly, but the qualities of co-residents made him feel socially isolated on site. Due affiliation seemed to demand satisfaction with two separate social worlds: the one inside the facility and the one outside.

6.5 The influence of dementia illnesses (articles 1–4)

The results presented here in chapter 6 would be incomplete without scrutinizing the effect of dementia illnesses on the presented elements of a good human life: autonomy, agency, recognition, and affiliation. The residents interviewed were those with the best cognitive capabilities although the majority of assisted living residents both in Finland (Noro & Alastalo 2014) and globally (Matthews & Denning 2002; Wolinsky *et al.* 1993) suffer from dementia illnesses. In this subsection I will study the effects of dementia based on my data.

Regarding autonomy, people with dementia illnesses were unable to use coping strategies (SOC) since they were not able to consider their situation. It is impossible to adjust to one's environment if one does not comprehend it at all. The resident-facility fit for people with dementia could be evaluated based on their behavior. Poor

fit was expressed as a constant effort to be somewhere else. When Mary moved into the home, she constantly asked her daughters to take her away. When she was brought into the dining room, she constantly asked to be taken back to her room. When the chances to cope cognitively had diminished, people seemed to solve poor fit with the situation by striving for escape. Good resident-facility fit, on the other hand, was expressed through being calm. Violet and Martha demonstrated this.

Violet and Martha were keenly watching the Olympics, seemingly almost out of habit. The important thing seemed to be the actual act of watching and rooting for the athletes, even though the residents immediately forgot everything, including how well the athletes did. For example, when the nurse asked how the Finnish ski jumper Ahonen did right after he had jumped, the residents could not tell her. (Excerpt 30, observation notes)

Although Violet's and Martha's cognitive capacities had declined to the point where they could not keep track of the overall situation in the ongoing ski jump contest, it still seemed to be a pleasant moment for them. Watching the games seemed to be an act that was in harmony with their continuity of self, which Lidz, Fischer and Arnold (1992, pp. 12–16) perceive as one definition of autonomy. They hold that people act autonomously when the action is in accordance with their authentic selves. In Violet's and Martha's case, the resident-facility fit was affirmed by enabling them to continue with an old habit (watching the Winter Games).

Regarding agency, it may seem that our results are not compatible with people with dementia since a person's competence and motivation were highlighted in addition to the affordances of the surroundings. People with dementia are indeed in trouble regarding agency when we note Wray's (2004, p. 24) words saying "dominant Western conceptualizations of agency are often used uncritically; individualistic notions of choice, autonomy, and in/dependence often pervade accounts of agency". If we add the traditional perception of goal-setting being the *primus motor* of action, people with dementia seem to become "have-nots" regarding agency. However, if we accept Joas' (2005) idea that goals do not always motivate our action but the goals may derive from the actor's situation, people with dementia may be recognized as possessors of agency, and their agency may be studied and affirmed. People with dementia could be seen as a living argument supporting Joas' non-teleological approach to action. One plausible approach to the agency of people with dementia could be joining Joas' (ibid.) ideas with Pia Kontos' (2004; 2005) work on embodied selfhood. Kontos urges researchers to abandon the Cartesian dualism of

mind and body in which the mind leads and the body follows. Embracing the notion that the person is her body, its gestures, movements, and habits, would provide new insight and direction for the future investigation of the agency of people with dementia. I often observed how people with severe dementia fiddled with available objects, such as tablecloths, their own clothing, or plants. Although it looked irrational, they were performing their remaining agency based on situational affordances.

Even people with severe dementia may be recognized as persons. As Laitinen (2009) points out, recognition is not just a cognitive act of giving recognition to someone but a practical task, too. This idea combined with Laitinen's (ibid.) another notion encloses people with dementia in the theory of recognition. Laitinen distinguishes two different types of recognition: there are strict and broad definitions. According to the strict philosophical definition, due recognition entails reciprocity. Recognition actualizes only when the recognized acknowledges the recognizer as a qualified recognizer and appreciates the given recognition. This kind of definition demands advanced rationality, which automatically rules out the majority of people residing in assisted living due to dementia illnesses. However, according to Laitinen's broad definition, recognition may be unrequited. Recognition is adequate when the recognizer recognizes another's normatively relevant features and treats her accordingly. A recognizes B as C when A treats B according to C's normatively relevant features. This means that a nurse recognizes a resident as person when she treats the resident in a way that persons ought to be treated. This does not require residents to have higher cognitive capacities in order to be recognized as persons.

Cognitive disorders affected the residents' affiliation differently depending on the nature and seriousness of the illness. For people in the early stages of cognitive disorders, relatives and friends seemed to bring comfort and safety, and they were able to make new friends in the facility, like Violet and Martha above. In previous research (Marventano *et al.* 2015), being surrounded by familiar faces has been found to be good for people with dementia and it probably affirms their affiliation too. But how could we support the affiliation of those people with severe dementia, for example the one resident who cried for her mother in the evenings? One solution could be to utilize what was said about the agency of people with dementia above, i.e. to observe how they respond to their surroundings and what makes them peaceful, and then affirm the positive affordances. In addition, as Kitwood (1997a) and Clare (2002) point out, even people with severe dementia illnesses may give

accurate information about their feelings and one can always talk to their relatives and nurses to find out what they enjoy.

The liberal values of self-determination and freedom of choice that originate from politics have penetrated the provision of health- and social services, which raises ethical problems since these services are often used by the most vulnerable people (Agich 2003; Pirhonen & Pulkki 2016). In previous studies (Pirhonen 2015b; Pirhonen & Laitinen, article manuscript) I have used the case of taking medication to picture the difference between affirming self-determination and abandoning older people in assisted living. Is it acceptable, in any circumstances, to mix medicine with food if an older person will not take them otherwise? If this person refuses to take her medicine referring to any logical or justifiable reason, she should be entitled to do so. If she refuses to take her pills referring to an obviously wrong or false reason, it is acceptable to try and persuade her to take the pills, but then again, she has got a right to make her own mistakes. This presupposes that she has the competence to consider things and occasionally to make mistakes. If she is obviously not competent to make up her own mind, and cannot express herself, other people should take responsible over her. If she spits out the pills, this is not necessarily a sign of deliberation as the reason might be the taste or size of the pills. To make an older person, no longer able to deliberate, to take her pills can be a form of taking responsibility over her. (Pirhonen & Laitinen, article manuscript.) As we remember, adequate recognition entails recognizing the normatively relevant features of a person and treating her according to those features. When we recognize that someone is not capable of taking care of herself, it is our duty to take care of them.

7 Discussion

7.1 Concluding the results

There are numerous factors affecting what older persons residing in assisted living are able to do and be, i.e. to lead a good human life based on this research. *Firstly*, there are factors depending on the residents themselves: their functional abilities, motivation, life histories, and personalities. *Secondly*, other people around them make a difference: the co-residents, the staff available, and social ties outside the home. *Thirdly*, the physical and functional structures of a facility create the frameworks for the residents' self-fulfillment. *Fourthly*, there are differences in the extent that the daily practices in a facility acknowledge the residents as persons. *Fifthly*, connected to the latter, both resourcing and attitudes of the staff create the space for the residents to perform their personhood inside the facility. And *sixthly*, the residents' chances for dignified life begin from public representations of old age, older people, and elderly care.

All these factors are connected to the residents' autonomy, agency, recognition, and affiliation in different ways. Older people's diminishing functional abilities emphasized the relational nature of *autonomy* in assisted living (cf. Agich 2003). The residents compensated their diminishing abilities by adjusting both goals and actions, and by comparing their competence with those of co-residents with a lower level of functional ability. The residents affirmed their autonomy feelings also through their connections to people outside the facility in two ways: on the one hand, people outside fulfilled the residents' concrete wishes and thus reduced their dependence on formal care, and on the other hand the people outside acted as a psychosocial resource. The residents' autonomy was relational in relation to their functional abilities and it was literally relational in relation to relatives. In addition to being relational, it was also partly hypothetical; the residents highlighted their potential to act if they chose to.

As a conclusion regarding the residents' *agency* I will now introduce the concept *agentic space*. Agency in assisted living seems to be neither a quality of the residents nor pure interaction with the surroundings. With regard to people with a low level of functional ability, agency consists of being as well as doing – it is a space that is

created when a person's competence and motivation meet the right affordance of the surrounding. For example, Sarah executed her agency when sitting on her bed instead of lying down. Her agentic space was created from her competence (ability to use her mechanical bed), motivation (preferred sitting over lying down during the day), and the affordance of the surroundings (the facility provided her with the mechanical bed). Compared to the prevailing SOC theory (Baltes & Carstensen 1996), agentic space is creative by nature. Older people *adapt* to age-based changes according to SOC, but they *create* their agency in agentic space.

The findings regarding the residents' *recognition* may be summarized with Laitnen's (2002) thought about two distinct powers of recognition. Firstly, recognition may create things. When a resident moves into a facility, the staff and institutional practices may start to create a new identity for her as an inmate or even a patient. The second power of recognition is to maintain, i.e. the staff and daily practices may support the residents' life-long identities and treat them as individual persons. There were practices serving both powers of recognition, i.e. the residents were sometimes treated as persons, sometimes as "standardized elderly" or even as objects. Recognition and especially misrecognition were not intentional, but were indirectly caused by under-resourcing and lack of consideration. The residents' invisibility, staff timetables, standard treatment, the dominant role of documents, and shifting responsibility to vulnerable people could be overcome with adequate resourcing and especially thinking through for whom the entire service is meant.

The residents' *affiliation* was studied based on Nussbaum's (2007; 2011) definition of the concept, i.e. being able to live in connection to others while simultaneously preserving the social bases of self-respect. Affiliation was ruptured by feelings of social isolation, which were connected to two separate social worlds: the one inside the facility and the other one outside. The quality of relations to peers and interaction with the staff were found to be the cornerstones of affiliation inside. Our cognitively fit interviewees tended to isolate themselves from co-residents who reminded them of the contradiction between their actual and desired social worlds (cf. Brownie & Horstmannshof 2011). Resourcing played once again a significant role in the interaction between the residents and the staff, but the residents also pointed out some attitudinal issues regarding the staff. Affiliation was also ruptured when social relationships with people outside the home, such as friends and relatives, reduced or were missing altogether.

7.2 Re-framing the central capabilities

I introduced Nussbaum's (2007; 2011) list of ten central capabilities² in chapter 3. Nussbaum stipulated the list to cover the entire range of decent human life, from nutrition and proper shelter to capabilities to imagine and reason. One item in Nussbaum's list was included in this study unchanged, since the definition of affiliation was taken from her. Furthermore, Nussbaum (2011, p. 39) found affiliation to be one of the most important capabilities. Together with practical reasoning, affiliation is an *architectonic* capability for her – it organizes and pervades the others.

Nussbaum defined affiliation as being able to live in connection to others while preserving the social bases of self-respect at the same time, and practical reasoning as being able to form a conception of the good and to engage in critical reflection about planning one's own life (Nussbaum 2011, p. 34). We have already seen that Nussbaum's definition of affiliation is plausible in assisted living, but her definition for practical reasoning seems problematic especially with regard to people with dementia. Forming conceptions and making critical reflections are out of range for many people residing in assisted living. However, Nussbaum (2009) holds that the interests of people with severe cognitive disabilities are generally better ensured when other people take responsibility over their interests instead of the disabled themselves. She appreciates that speaking on someone's behalf involves both ethical and juridical issues and that there is a risk of malpractice, but it would be a bigger offence to make the vulnerable responsible for themselves. For example, Ella was malnourished because time-constrained staff claimed that she did not want to eat anymore, although the reason to stop feeding emerged from the resources available.

Ella's case brings us back to my aim to revive Kitwood's (1997b) original perception of personhood regarding person-centered care and Nussbaum's ethical procedure of evaluating the constituents of dignified life (Claassen 2014, pp. 240–241). To form an ethically sustainable care philosophy for the most vulnerable people, who often are incapable of forming and communicating perceptions of a good life, we need to deliberate what it takes to be a person. By care philosophy I mean a holistic perception of good care incorporating both the aims and methods of care and the perception of a human being. We started off with Nussbaum's (2011, p. 20) perception that capabilities are those things persons are able to do and be. While all the ten capabilities in Nussbaum's (2007, pp. 76–78; 2011, pp. 33–34) list

² 1. life, 2. bodily health, 3. bodily integrity, 4. senses, imagination, and thought, 5. emotions, 6. practical reason, 7. affiliation, 8. other species, 9. play, and 10. control over one's environment.

are important, in this research doings were studied through the residents' autonomy and agency, and beings were studied through the residents' recognition and affiliation. I suggest that these four could work as a list of central *personhood-related* capabilities. These four capabilities are important when we perform our personhood. Inspired by Nussbaum (2007; 2011), I will try to conceptualize the personhood-related capabilities.

Autonomy; being able to execute one's self-determination as long as there are prerequisites for it. Being able to receive help in executing one's decisions and to trust that others will ensure one's good human life when the prerequisites of self-determination have deteriorated or when there are no ways to form and/or communicate one's preferences.

Agency; being able to lead one's life despite the level of one's functional abilities. Being able to trust that one is allowed to express herself in ways arising from her situation without humiliation.

Recognition; being able to get recognition as a person in spite of the level of one's communication abilities or other individual features. Being able to trust that other people treat one as a dignified human being until the end of one's days.

Affiliation; being able to live with and towards others just the way one is and maintain the social basis of self-respect at the same time (applied from Nussbaum 2007; 2011).

Based on this study, we could define a person as a relationally autonomous individual utilizing agentic spaces and who is recognized and accepted by others. Being a person is thus a matter of both individuality and community, which joins together traditional Western and Eastern conceptions of self (Geertz 1984; Perkins *et al.* 2012). People with dementia are included in this definition of person since we have seen that they possess relational autonomy and at least affordance-based and bodily agency. Their recognition is not dependent on their competences but is based on their normative human characters. Although I cannot say much about the affiliation of people with dementia, my sophisticated guess based on this study is that the people around them have a huge impact on it. To avoid the accusation of evangelism presented by the critics of person-centered care (Brooker 2004; Nolan *et*

al. 2004; Packer 2000), I will open up this new definition of a person in assisted living surroundings and sketch a care philosophy to be built on it.

7.3 Recognition-oriented care philosophy

I suggest that we need a care philosophy that is based on the theory of recognition (Honneth 2005; Laitinen 2002; 2009; Ringmar 2012; Taylor 1991). Recognition is one of the four personhood-related capabilities that I have introduced, but referring to Nussbaum (2011, p. 39), I would call recognition an architectonic capability – it organizes and pervades the others. Recognition is an essential precondition for being a person, which is an essential precondition for autonomy, agency, and affiliation.

Recognition-oriented care is based on Charles Taylor's (1991) ethics of authenticity. Taylor makes a difference between authenticity and individuality as we understand it today. Authenticity concerns an individual's faithfulness to her authentic self, whereas modern individuality has become a cover for instant fulfillment of needs and egoism. We have learned to see both the world and people occupying it as resources and means, not as values. Kant (2011) warned us about this already in the 18th century. Marketization and consumerism have turned individuals to consumers, which can be also seen in the provision and delivery of social and health care services (Gilleard 1996; Jolanki 2009b; Pirhonen & Pulkki 2016). Individualism has lost its original connection to authenticity, and this new version of individualism has become the core value of person-centered care. However, throughout this dissertation, we have been dealing with the fact that people reside in assisted living because they are losing their abilities to meet the criteria of modern individualism (Agich 2003; Sherwin & Winsby 2012). Recognition-oriented care admits that people should be able to age authentically, while simultaneously preserving their social basis of self-respect.

The basis of recognition-oriented care philosophy comes from Honneth (2005), Laitinen (2002; 2009), and Taylor (1991), yet Erik Ringmar (2012), who discussed the recognition of states, also makes an important contribution. I have brought Ringmar's thoughts to bear on assisted living elsewhere (Pirhonen 2015b), but I will summarize his contribution to recognition-oriented care here with a little help of the imaginary John from the introduction. Rephrasing Ringmar (2012), due recognition of a person demands that John's existence, humanity, singularity, and significant others get recognized. Residents' *existence* in assisted living is always recognized at a symbolic level; they are signed in as residents, they are given a room or some other

space in the facility, plans for their care are written etc. However, Laitinen (2002) holds that symbolic recognition is not adequate, but persons need to be recognized practically as well. Previously I reported how the residents seemed to be socially invisible at times (c.f. Honneth 2001), for example, the residents who sought the staff's attention were ignored. At worst, the residents get treated as objects. I have often witnessed (and admit of being guilty of this myself as a practical nurse) how bedridden residents get treated as though they were not present as persons. Two members of the staff may turn them in bed while changing diapers and chat at the same time as though there were only two people in the room. To practically recognize John's existence is to encounter him as a person.

Recognizing John's *humanity* is partly a matter of cultural values. Today, there is a cultural tendency to see older people as "others" (Calasanti 2003, Gilleard & Higgs 2013), maybe even as devalued. The Finnish *Act on Supporting the Functional Capacity of the Older Population and on Social and Health Care Services for Older Persons* (Finlex 2012a) took effect in 2013 but was partly amended in 1.1.2015. One of the changes made was that securing a dignified life for an older person ceased to be a reason to be granted long-term institutional care. After the change, only medical reasons and reasons related to patient security justify long-term institutional care. One may wonder how this change reflects the lawmaker's perception of older people's humanity. Another sign of devaluing the old is the repeated intention to lower the recommendation regarding the staffing-ratio in assisted living and also to lower the standards of the staff's occupational education in elderly care.

Recognizing residents' humanity in practice necessitates that they are treated as human beings. Laitinen's (2009) broad definition of recognition may work as a guideline: recognition is adequate when A recognizes B as a carrier of feature C and treats her accordingly. Feature C may be any normatively relevant feature of a human being: being a sentient being, being an individual, having a personal life history, being someone else's significant other, being a possessor of merits and achievements and so on. Being vulnerable and not being able to take care of oneself are normatively relevant features as well. John gets recognized when his disabilities caused by Alzheimer's get recognized and the staff has courage to take responsibility over him. As we saw, over-emphasizing self-determination may result in abandonment in assisted living surroundings.

Recognizing residents' *singularity* fails when they get standard treatment or are first and foremost encountered as the old, inmates or even patients. The residents are particular kinds of persons with various particularities, merits, talents and achievements. They have lived unique lives that made them unique characters. The

residents' singularity could be recognized by supporting their previous lifestyles and life-long habits, finding out and fulfilling their wishes, and supporting their privacy and self-expression. In John's case, he could be taken outdoors as often as possible because he had always loved nature. Visiting motorcyclists would be easily arranged or maybe John could even get a ride in a sidecar from time to time? Could there be a corner in the facility to store one of John's bikes so he could see and touch his past at a concrete level? Life is for the living - assisted or not. Even severe dementia does not reset one's life history, the history remains as long as the individual is alive.

The fourth prerequisite for recognition inspired by Ringmar (2012) was recognizing residents' *significant others*. As Honneth (2005) and Laitinen (2002) emphasize, feedback from our significant others make us who we are. Based on this study, friends and relatives had positive impacts on the residents' control over their environment, supported their agency and continuity of self, and were critical regarding the residents' due affiliation in assisted living surroundings. These findings underline the importance of making the residents' significant others a part of the care community in case they want to be involved. However, previous research has found ordinary interaction between nursing staff and residents' close ones problematic (Foner 1994; 1995; Gubrium 1997) and I have to agree based on my own experiences. The staff easily think annoying those relatives who are keen on the resident's affairs. Questions are easily interpreted as criticisms. Reasons for the problematic relationship are probably multiple; public pressure regarding the quality of care, the historical load of institutionalized care practices, and moral distress (cf. Corley 2002) of the staff when they know that they could do a better job with adequate resources. However, recognition-oriented care cherishes all the residents' relationships. In John's case, it would be very important to make Millie feel welcome in the facility. Since Millie visits every day during lunch, could the facility serve her a lunch as well, at cost? It would be helping Millie to help John and ensuring that Millie stays fit since her existence is so important to John. Recognizing John also entails acknowledging his children and grandchildren. For example, could the staff arrange John skype calls with Lisa who moved to the US?

These four subjects for recognition – existence, humanity, singularity, and significant others – become the core values of a recognition-oriented care philosophy in assisted living. This philosophy may be put into practice by sticking to the two prerequisites of adequate recognition defined by Laitinen (2002; 2009); recognition must be practical and it may be unidirectional instead of bilateral by nature. The residents' *treatment* should be *based on* their normatively relevant *human*

features. In addition to this maxim, recognition-oriented care philosophy is not a package of instructions but a constant process of ethical deliberation.

7.4 Ethical considerations

Research ethics in ethnographical studies is a multidimensional and delicate issue. There are always moral and ethical considerations, and in my case, the participants' cognitive abilities are also an issue of juridical deliberation. Juridical acceptability for the research was found in the *Medical research act* (Finlex 1999), which states that incompetent persons are justified to take part in research when: i) research results are expected to benefit them or people in similar situations and ii) the study causes no harm to them. These preconditions were filled, yet juridical acceptability is not enough. In fact, a referee of the third original article advised that we remove the reference to *Medical research act* since justifying a research through legislation might sound suspect in readers' minds. We took out the reference from the article, but I mention the Act here to show that juridical aspects were taken into account from the beginning of the study. Although my intention was not to specifically study incompetent persons, it is a fact that most assisted living residents in Finland suffer from dementia illnesses (Noro & Alastalo 2014). Thus it is practically impossible to observe assisted living facilities without observing people with dementia at the same time. Also, as Kuula (2006) points out, excluding marginal groups (such as people with dementia) from research would exclude essential spheres of human life. I have examined the influence of dementia illnesses regarding the constituents of a good life in chapter 6.5, and the data has the potential to benefit people with dementia in the future.

Moral dilemmas in this study concerned the voluntariness of individuals at the research site. Although assisted living facilities are not total institutions like the army or prison, there still are some features of totality to take into consideration (Goffman 1968). Ojajärvi (2015), who studied conscripts' health conceptions in a Finnish military regiment, discussed the relation between official research permits and participants' voluntariness in research inside institutions. Referring to Mäkelä (2008), when an organization has permitted the research, the members of the organization have no actual choice but accept being studied. Therefore, compared to collecting signed consents from each individual in site, it is more important to inform the

participants as thoroughly as possible before and during conducting the research. In my case, participant observation concerned numerous people living, working, and visiting the site. Since collecting signed consents is not obligatory in an observational study (Kuula 2006) and it would have been extremely difficult, I shared Ojajärvi's (2015) and Mäkelä's (2008) perception that thoroughly informing participants was more important than hunting for signatures.

The ethical committee of the local hospital district approved my research, and the highest authority of elderly long-term care in the municipality gave a signed research permission to conduct the observations and interviews at a hospital and in an assisted living facility. She also allowed the use of the data not only for the PhD research but also for my other research. Official preconditions were thus met, and at the site I informed people as thoroughly as I could. At the hospital I first contacted the head nurse and visited her explaining my research and together we chose the wards to observe. We agreed on a date when I could explain my research in a staff meeting, and I also placed information notes written in plain language on the noticeboards of the wards I planned to observe. When the observation begun, I introduced myself when addressing them for the first time. The procedure was much the same when I transferred to the assisted living facility with the exception that I did not meet the local manager in advance. I introduced myself and the research when taking part in sessions where an artist trained the personnel to encounter residents as individuals just before the facility was opened. This way I met all the three managers and the nursing staff of the facility.

To affirm the ethicality, the interviewees were selected by the staff since I knew residents from only the one group home I had observed. I asked the staff to nominate both men and women, and got the names of four men and six women. Before the interviews, I gave them written information of the study and also told them about the interview. I explained that participation is voluntary and that they could decide not to answer all the questions and that they had the right to stop the interview at any point without sharing the reason. I explained the anonymity issues and explained that I would possibly use the data in my other research in addition to the PhD study. I considered verbal agreements adequate, since according to Kuula (2006), written consents are needed in interviews only if the researcher plans to connect the interview data with data provided by authorities or if the data will be kept for future research as without anonymization. I used only data I collected myself and I anonymized the interviews when transcribing them.

Further ethical considerations of the study were connected to the researcher's role in the site. I needed to reflect between being a researcher, a human being, and a

former practical nurse. All these overlapping roles affected what I saw and heard and my interpretations of it. As Ojajärvi (2015) remarks, an ethnographer has learned good scientific and ethnographical practices from books before the fieldwork, yet her own feelings need to be processed too. Like Ojajärvi (ibid.), I also utilized my feelings in the fieldwork. I learned to appreciate the overlapping roles since the different views caused conflicting interpretations, which kept me ethically alert from the beginning of the study to finalizing this dissertation. As Ojajärvi (ibid.) points out, it seems that the researcher's conscience is eventually a part of research ethics in ethnographies.

7.5 Validity of the results

Most ethnographies are written in a narrative format and presented as natural histories or chronologies (Morse 1994). The textual outcome, the report, is a vital part of the project called an ethnographical study. I agree in a sense that the report is a retrospective layout of the research and it is the basis of the validity of the research as well. According to Vesperi (1995), Sanjek (1990) has presented three criteria for evaluating the validity of ethnographical texts: an ethnographer should i) make the theoretical decisions and other influences explicit to the reader, ii) provide the reader with a multidimensional view of how the fieldwork was actually conducted by an individual person moving in time and space with other individuals, and iii) make the relationship between the finished ethnographic text and field work clear. I have expressed what my theoretical framework has been with regard to the research. I also described the field and the participants when describing the methodology and in the results too, and described my journey from the beginning of the study to this discussion. The relation between the written ethnography and fieldwork is highlighted in this discussion, where I have sketched a novel care philosophy based on the research. In the beginning I presented “the state of the art” regarding person-centered care and suggested that Nussbaum's (2007; 2011) perception of capabilities could make it more suitable for vulnerable people residing in assisted living. I then tested my hypothesis in “the wild”, concentrating on the residents' autonomy, agency, recognition, and affiliation, and eventually presented a novel care philosophy. Sanjek's (1990) validity criteria of making the theory explicit, picturing the field work, and distinguishing between written ethnography and field work were thus met.

Like any other researcher, ethnographers plan their studies in advance, but they understand what they did only afterwards. Being in the field and conducting interviews is totally different from going back there through the data afterwards. While in the field, ethnographers are more or less participants, and they may be true observers only retrospectively through the data they gather. That is why multileveled reflexivity is an important part of the validity of the study (Burawoy 1998; Hammersley & Atkinson 1995; Morse 1994). When I was choosing my research topic, I reflected on my personal history as a practical nurse. I reflected on the care world that I knew against Nussbaum's (2007; 2011) capabilities approach. I reflected on what I had done and seen as a practical nurse against my later understanding of the constituents of good human life. Building a research plan and forming the research questions were highly reflexive processes, and the plan changed reflexively over time after meeting people, seeing changes in the care field, and, for example, after participating in a course on Axel Honneth's philosophy or taking part in a workshop on loneliness in Finland. I also had to be reflective when comparing the participants' views with each other and against mine, i.e. reading the interviews against each other and the observational data and vice versa (cf. Roper & Shapira 2000). Throughout the process I had to reflect on the connection between my methodology and my research aims, and between the data and the research questions. Karisto (2008) holds that reflexivity has turned into an empty word in both research and work life after being overused, and he is probably right. However, I reflected much, for want of a better word.

Since the most relevant fieldwork was done in a single assisted living facility in Finland, I cannot suggest that the results could be generalized as such. Assisted living includes a wide range of facilities that are operating according to different policies and principles and are occupied by different older people who are cared for by nursing staff with diverse educational backgrounds. However, an ethnographic study is not basically designed to provide information, but to deepen understanding about the daily life of its research subjects (Gubrium 1995). The phenomena which were found in one research site, may be tracked as well in other facilities that are providing round-the-clock care for older people. Thus, our results can be generalized theoretically. Care providers may utilize our results to understand and affirm the prerequisites of residents' good human life in their own facilities.

8 Conclusion

An empirical study in an assisted living surroundings showed that one plausible way to evaluate whether residents are able to lead a good human life is to base the evaluation on philosophy. Nussbaum's (2007; 2011) version of the Capabilities Approach guided us to ask what the residents were actually able to do and be. The question led us to the residents' possibilities to perform their personhood through their autonomy and agency, and their possibilities to get recognized as persons and maintain affiliation in assisted living surroundings. Nussbaum (ibid.) guided us to Honneth's (2005) philosophy of recognition and to the refinement of the four personhood-related capabilities. The Capabilities Approach and philosophy of recognition led to the recognition-oriented care philosophy.

During the process we have covered both ontology and epistemology regarding good human life. Drawing from the Aristotelian-Nussbaumian tradition, the substance of good life may be seen as objective by nature and may be revealed by a process of ethical evaluation (Claassen 2014, pp. 240–241). The evaluation process went into two directions simultaneously. *Firstly*, we needed to deliberate on the constituents of good life in our society and *secondly*, we needed to make these universal goals accessible to special groups and individuals. Defining the central doings and beings was the “objective” part of the process, and applying the idea of autonomy, agency, recognition, and affiliation in assisted living equaled taking the universal back to particular.

The research has potential for prominent practical implications regarding the quality of life in assisted living. Being in the field and talking with people gave new insights regarding daily life that providers of assisted living may utilize. The development of future assisted living needs to be based on a comprehensive care philosophy. However, since we are talking about authentic aging processes and endless variation of the assisted living surroundings, it is impossible to construct a strict “one size fits all” theory. Recognition-oriented care philosophy is not a package of instructions but a constant process of ethical deliberation. What makes it a comprehensive care philosophy is the maxim that residents' *treatment* should always be based on their normatively relevant *human features*.

To operationalize the idea of recognition-oriented care philosophy, I wrote a declaration which – hopefully – every staff member in every assisted living facility is able to sign one day.

“Older people living in this facility are encouraged and supported to live an authentic life. They are recognized as human beings and persons, and their significant others are just as important to us as the residents themselves. The residents’ self-determination is cherished to the fullest possible, yet we have the courage to take responsibility over the vulnerable. Our work is based on the idea that by caring about other people, we simultaneously cherish our own humanity”.

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Perceived resident–facility fit and sense of control in assisted living

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ABSTRACT

The concept of resident–facility fit has largely been used to illustrate whether a residential care facility and a resident are together able to meet requirements set by only the hampering functional abilities of the latter. The purpose of this paper is to study how assisted living residents perceive resident–facility fit. The data were gathered ethnographically from both observations and resident interviews in a sheltered home in Finland during 2013–2014. Perceived resident–facility fit is based on several relational factors that connect to both the residents as individuals and their surroundings. This fit seems also to be partly conditional and indeed depends on residents' trust in having their own potential to act. Good resident–facility fit results in feeling at home in a facility, whereas poor fit can even result in residents' feeling imprisoned. Care providers can thus utilize our results to affirm residents' quality of life in residential facilities.

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Introduction

During the last few decades, different forms of residential care have become the fastest growing form of long-term care for those growing older (Ball et al., 2004; Street, Burge, Quadagno, and Barrett, 2007; Zimmerman et al., 2003) for both economical and humane reasons (Chapin and Dobbs-Kepper, 2001). The diversity of these forms of care is vast, since residential care facilities for older people are known by nearly 20 different names in the United States alone (Mitchell and Kemp, 2000, p. 117). Indeed, the term *assisted living* (AL) has become a widely used label since it captures both the nature of residential care facilities and the philosophy of residential care (Mitchell and Kemp, 2000). According to Cutchin, Owen, and Chang (2003) AL attempts to offer a middle ground between independent living arrangements and nursing homes by combining elements of both; provision of housing combined with basic care round-the-clock. Kemp, Ball, Hollingsworth,

and Perkins (2012, p. 491) hold that AL encompasses a range of settings that vary in size, service provision, regulatory standards, funding, fees, and resident characteristics.

AL does not easily surrender to strict definitions, but there are some common features regarding the policies and nature of AL care. According to Roth and Eckert (2011, p. 216), AL “emphasizes home-like environment that fosters respect for an individual's sense of autonomy, privacy, and freedom of choice”. Zimmerman et al. (2005, p. 195) hold that the core idea of AL is to provide a choice of services and lifestyles to avoid the typical characteristics of an institutional setting. Key words related to AL are autonomy and choice (Ball et al., 2004; Roth and Eckert, 2011; Zimmerman et al., 2003), which refer to the goal of enabling as good a quality of life as possible for these older individuals, regardless of any hampering functional abilities. In addition to affirming the quality of life, a growing number of older people and the increasing costs of nursing care have directed the evolution of care towards AL (Zimmerman et al., 2003, p. 107). According to Chapin and Dobbs-Kepper (2001), AL is perceived as an economical way to care for low-income, frail older people in contrast to care given in the more traditional nursing homes.

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There is yet another factor behind the success of AL, namely, the promise of aging in place (Zimmerman et al., 2005, p. 196). The concept aging in place originally referred to older people's possibilities to grow old in private homes without transferring to care facilities, but today it may be taken to encompass AL as well (Ball et al., 2004; Mitchell and Kemp, 2000; Roth and Eckert, 2011; Zimmerman et al., 2005). According to this philosophy, a facility adjusts its service provisions and care criteria to meet their residents' changing needs to postpone or even erase the need of high-level nursing care (Chapin and Dobbs-Kepper, 2001, p. 43). Simply put, the idea is that AL becomes the last home for older people, a home where they can spend their last years and where eventually they pass away. Indeed, as Ball et al. (2004, p. 202) remark, today AL residents are increasingly older, more functionally impaired, and have greater care needs than before, which in *de facto* terms paradoxically prevents people from aging in place. Chapin and Dobbs-Kepper (2001) reported how in particular, incontinence, behavioral problems, and lowering cognition still easily can result in a transfer from AL to a higher-level nursing facility. Service-directing policies and the business goals of care facilities may also either promote or prevent the nature of desired aging in place (Ball et al., 2004; Roth and Eckert, 2011).

Resident–facility fit

For successful aging in place, it is highly important that a person's and the environment's capabilities meet in AL. This idea can be tracked back to Lawton's (1980) pioneering work on the person–environment relationship, which gave rise to environmental gerontology (Wahl, Iwarsson, and Oswald, 2012). The concept known as *person–environment fit* was thus generated to study the possibilities for aging in place in general, including the broader phenomena that range from housing to community infrastructure. *Resident–facility fit* can thus be seen as a sub-concept of person–environment fit by focusing on factors that influence the possibilities of older persons to live in a given facility without any transfer to a higher-level care facility (Ball et al., 2004; Roth and Eckert, 2011; Zimmerman et al., 2003).

According to Morgan et al. (2014), prior research on resident–facility fit has largely focused on changes in the aging person, i.e. the challenges posed by functional decline, although resident–facility fit is also influenced by constant changes in the resident, the facility, and community factors. In addition to residents' functional decline, staff, procedures, policies, ownership of facilities, and other factors are contingent by their very nature (Ibid.). Only focusing on the hampering functional abilities of the residents, however, easily leads to just a “one way model” in AL where the environment is designed to match the individuals' competence levels (cf. Roth and Eckert, 2011, p. 216). On the other hand, focusing on the individual may result in overemphasizing residents' capabilities, such as their autonomy competences (Atkins, 2006). Ball et al. (2004) indeed hold that resident–facility fit is both an outcome and an influence on the management process of decline in which both the resident and the facility try to manage expected resident decline.

In this article, we see resident–facility fit as the resident's perception of his/her fit in the facility. We use resident–facility fit as a philosophical value judgment where the fit is good when residents feel that they have control over the environment.

Thus, good resident–facility fit entails that the environment meets residents' needs and offers positive opportunities for autonomous living. The fit does not have to be constantly good or poor to have sense of control but it may differ from time to time and situation to situation. Our notion entails that resident–facility fit can be affirmed or impaired by multiple factors that relate to the residents, other people, and the surroundings. Resident–facility fit may then be seen as an outcome of the residents' chances to maintain continuity in their lives despite have moved into a care facility. Whereas the previous research sees this fit as a goal for process that aims to avoid transfers in residential care, we see fit more as a result of process that aims to achieve a residents' control over their surroundings. In this article, resident–facility fit is neither an objectively measurable phenomenon nor a subjective feeling, but rather a combination of the two; resident–facility fit is the residents' perception of their ability to manage in their new surroundings with their current capability. Thus, the idea of resident fit can be best studied by interviewing people and observing them in their daily lives.

Relational autonomy

AL and resident–facility fit both carry a promise of affirming resident autonomy. National guidelines for the care of older people in Finland, such as *The National Framework for High-quality Services for Older People* (Ministry of Social Affairs and Health, 2008), stress autonomy and the right to self-determination and making choices. It is recommended that older people be treated on the basis of informed choice and should be given both the information and other help they need to make their decisions (Ibid., p. 13). In reality, AL seems to be rather difficult surroundings in which older people can execute their right to choose, since usually these “individuals need long-term care because they suffer illnesses and incapacities that compromise their ability to function independently and choose rationally” (Agich, 2003, p. 1). According to Sherwin and Winsby (2010), resident autonomy may also be reduced by the paternalistic attitudes of staff, other people's self-interests (such as relatives), and residents' personal fear that disobedience could result in abandonment. Collopy (1988) holds that helping interventions are often judged by the motivations and goals of the helpers instead of the helped, which easily reduces the autonomy of the latter. Daily routines are still another issue that influences residents' opportunities to act freely (Eyers, Arber, Luff, Young, and Ellmers, 2012). Traditional conceptualizations of autonomy as self-determination or the right to choose seem to exclude a large group of people, namely, those older people who are residing in AL due to their hampered functional abilities.

The perception of *relational autonomy* acknowledges the situated nature of human life intertwined with facticity and connections and interactions with other people (Atkins, 2006; Christman, 2014; Sherwin and Winsby, 2010). Relational approaches to autonomy grant that individuals' actions are inevitably linked to several relational factors, such as social relationships, personal characteristics, and the affordances of the agent's environment. Human will is not free, but rather governed by reality or, in Kant's (2012, p. 486) words, human will can only be free when governed by reason. Especially, the feminist research tradition, which highlights the intersectional

and embodied nature of human existence (Käll and Zeiler, 2014), has interesting implications for both autonomy and resident–facility fit. As Ells, Hunt, and Chambers–Evans (2011) point out, promoting relational autonomy aids in a greater critical understanding of the impact of care settings on residents' dependence and autonomy and thus their opportunities over time to maintain control over their lives and their identities.

Our goal in this article is to shed light on factors that influence residents' perceived fit in an AL facility. The notion of relational autonomy channeled our observations to the subtle distinctions residents make when they deliberate on their situation in AL. What kind of relational factors influence resident–facility fit for daily life of residents? How can we affirm the fit of the most vulnerable residents, such as those with dementia? Based on an ethnographic study conducted in Finland, we determined that residents' quality of life might be improved by providing them with more chances to maintain sense of control while residing in AL.

Methods

We gathered the data by undertaking participant observation and thematic interviews at a single care facility for older people in Southern Finland in 2013–2014. The research site was a sheltered home where 114 residents lived in eight group homes and between nine and fifteen residents in each home. In Finland, sheltered housing as care is an option that falls between nursing homes and home care, thus a form of AL. It has become the major and a growing type of residential care for older people over the past few decades (National Institute for Health and Welfare, 2014). At our research site, the concept was to provide as homelike an environment as possible. People had their own rooms, which they furnished with their own belongings, and they wore their own clothes. In addition to residential rooms, there were common rooms, large balconies, and a sauna in every group home. Staff members were available round the clock. Residents paid rent for their rooms, and they paid separately for food, medication, and care.

Some of the residents lived in AL for some degree of cognitive disorders, some were there for somatic or physical reasons, and some suffered from both cognitive and physical illnesses. John, for example, was an 82-year-old man, who was cognitively very fit, but could not live alone due to dizziness and several chronic diseases. Martha (79), on the other hand, was physically extremely capable, but suffered from severe dementia. About 70% of the residents were female, and their ages ranged from 60 to 100+ years.

One researcher observed life at the facility for 165 h over the course of two months. We considered two months to be long enough since there would be thematic interviews of residents that followed. The researcher also visited the site irregularly ever since these scheduled two months to keep in touch with the people he had gotten know during the study. We chose a single group home of 15 residents as the main research site to become as familiar as possible with the residents and their daily lives. Participant observation involved the researcher talking to people and taking part in recreational activities at the home. He also performed typical tasks carried out by voluntary workers, such as feeding people and helping the staff move them. Most of the observations took place between 7 a.m. and 9 p.m. every day of the week. Once, during the beginning, the

researcher stayed for two nights in an empty resident room at the home, eating the same food with the residents to become very familiar with the settings, as resident would do.

Participant observation is an appropriate method when a researcher wants to understand as much as possible about a research subject (Geertz, 1973; Hammersley and Atkinson, 2007). The daily life of a resident in a care facility includes a vast number of encounters with different people, and it has many facility routines and practices where a researcher who is observing the community can see nuances that would likely not come to light in interviews only (cf. Clark and Bowling, 1990). Since most of the residents at the chosen research site were cognitively disordered to some degree, observing their daily lives provided information that would not have been obtainable from either interviewing or questionnaires. The researcher used a method called “jotting” (Emerson, Fretz, and Shaw, 1995), which entails making short notes in a notebook while in the field and then writing more detailed descriptions on a computer immediately after the observation sessions.

In addition to the observation, we held ten thematic interviews at the sheltered home. Themes were organized around interviewees' backgrounds (education, work–life balance, family ties, etc.), the home as a living environment, the care residents received, the content of their daily lives, and their perception of their life situation in general. We framed the themes broadly to enable data use on multiple research topics, and there were no specific questions asked about residents' perceptions of their autonomy. Since most of these residents had cognitive disorders, we asked the staff to nominate 10 candidates out of the total of 114 residents who were most capable of granting informed consent and an interview. The advantages of the procedure were that the staff knew best residents' cognitive capacities and also it added to ethical aspects of the study when professionals defined individuals' capability to give an informed consent. The risk was that the staff would choose residents with most positive view regarding the facility. Two head nurses and a practical nurse nominated the interviewees, and all gave their informed consent. And, as we will see, the interviewees were quite critical about the surroundings. The interviews were recorded and lasted from 25 to 65 min and then transcribed verbatim.

Due to the vulnerability of the participants in this study, a thorough consideration of research ethics and scientific practices was required before data collection (cf. Hubbard, Tester, and Downs, 2003; Wilkinson, 2002). We personally informed the staff and residents about the study, and posted information letters on notice boards at the facility. We also gained permission from the manager of the facility and ethical approval from the local hospital district's ethics committee. Regardless of these actions, however, some of the residents did not understand that a study was being conducted due to their personal cognitive disorders. However, we did share with them our perception that incapable people have the right to participate in research that is aimed at improving their situation (Bond and Corner, 2001; Finlex, 1999).

We analyzed the data using directed content analysis (Hsieh and Shannon, 2005). We employed triangulation (Thurmond, 2001) in the analysis, since two kinds of qualitative data and two researchers were involved. In our case, directed content analysis meant that prior theorizations served as a starting point in the analysis. First, we categorized the data manually by

focusing on excerpts that referred to situations related to older people's autonomy, as previous research had explicated that autonomy (e.g. Agich, 2003; Atkins, 2006; Meyers, 2004). A common feature seen in these excerpts was that the residents' will, wishes, or preferences were somehow involved. For example, residents talked about their wishes and factors, which either stood in their way or enabled them to fulfill those desires. In the observational data, there were descriptions of situations where other people or the setting itself seemed to influence these residents' actions.

In the second phase of the analysis, we categorized the excerpts based on their connections to the concept of resident–facility fit. During the analysis, we discovered that two kind of factors seemed to be influencing resident–facility fit. On the one hand, there were factors influencing the fit that depended on residents' social, physical, and functional surroundings, such as help from people outside or daily routines of the facility. On the other hand, there were factors that depended on the residents themselves, such as their functional abilities and coping strategies. We also discovered that some excerpts did not fit either category, but instead dealt with the residents' hypothetical chances regarding their control over surroundings in AL.

Results

In this section, we present our findings, highlighting them with excerpts from the gathered data. We first examine how the social, functional, and physical characteristics of the facility create the conditions for residents to fit into their environment. Secondly, we describe those factors that are influencing residents' fit with the facility that depend on the residents themselves. At the end of this section, we suggest that, regardless of the real fit between a person and his/her environment, residents do strive to have control over their lives, a finding that emphasizes the importance of individuals having potentials to act. All names in the excerpts are pseudonyms, and in the interview excerpts, R stands for the Researcher.

Social relations outside the home

Social relationship outside the home apparently affirmed the residents' fit inside the home. Outside relations provided residents with access to items and goods and thus affirmed a resident–facility fit, making the residents rooms in the AL home feel more like home.

R: Can you easily get stuff here that the house won't provide, the bottle of cognac for instance or...Paul: I only need to give my nephew a ring, say that we'll make a trip to the market and it's settled.R: Right. So, whatever you'll need, you'll just go over and ...Paul: Yeah. Likewise all this equipment. I can't even bring that stuff myself or go and get it anywhere, so ...R: Yeah, you mean the TVs and...Paul: Yeah, my son-in-law will bring them to me with my daughter. (Excerpt 1, male resident, aged 82)

Lloyd, Calnan, Cameron, Seymour, and Smith (2014) noticed how some older people paradoxically based their feelings of autonomy on help from their relatives. Relatives, on the other hand, considered their help as supporting the older person to

maintain a bit of independence and not so dependent on official care. Relations outside the home seemed to support our interviewees' resident–facility fit specifically by providing the residents with things they needed in the home and taking them out without an attendant from the staff accompanying them. Having relationships outside the home was psychologically and psychosocially important as well. Visitors and phone calls from outside were highlighted in these interviews on the residents' own initiative, suggesting that outside relationships also supported the residents' self-esteem. One interviewee even asked the interviewer during their conversation whether he was going to ask her about her personal visitors. She was visibly proud to tell him that even her son's parents-in-law visited her regularly, which meant that she still was a significant family member, even after she had moved into AL.

Social relations with the staff

When residents had no regular connections outside the home, other people inside the home naturally became more important. Harry was the youngest resident (60) and he lived in the home due to multiple somatic illnesses caused by an unhealthy way of life. He was divorced and had two sons. One visited rarely, and the other had broken up with him altogether. He had friends outside, but they kept in touch only by phone. Harry talked about his plans to buy a bigger TV.

Harry: So the nurse will then come and give me a hand. At first I was like, Jake will come, but Jake had that thing so he can't make it.R: Yeah.Harry: Then Jenny promised to come, though.R: Fine. The nurse will help you to get the TV here. Very good. (Excerpt 2, male resident, aged 60)

Jake and Jenny were Harry's named nurses, who filled the gap with Harry's relations outside. They affirmed Harry's resident–facility fit by helping him execute his decisions. The poorer the functional abilities of the residents were, the more important was the role of the staff regarding resident–facility fit, emphasizing that such fit fundamentally is a matter of autonomy or dependence (cf. Ball et al., 2004). When residents felt, as Harry did, that they could rely on the staff, the feeling affirmed their fit with the facility. Others, like Sam, Annie, and Laura thought that the staff was not interested in them as persons, but talked only about details connected to their encounters as a helper and a helped person. Feeling that one is not being encountered as a person in that individual's daily life hardly affirms a positive resident–facility fit. Both residents and the staff told us that there were too few nurses per shift although staffing ratio was in accordance with national recommendations. Some nurses considered that bed-and-body work took all their time, leaving no space for socializing with residents and getting to know them personally. Still, some nurses had time to encounter residents as persons. We will get back to this in the end.

Social relations with peers

Together with the staff, it was found that other residents created the everyday social world of residents and thus had an impact on their fit with the facility. Laura felt lucky since she appreciated the company of men more than women, and living

in a group home made it possible for her to choose her company. Paul often helped other residents when they were lost and helped them manage in the facility this way. John sometimes pushed other residents outside in a wheelchair. Violet and Martha became personal friends after meeting in the home. Other residents affirmed resident–facility fit in many ways, but also sometimes impaired it. Paul's account gave us a clearer picture. He was asked whether he had ever had any problems with other residents.

Paul: Well, it does bother you a bit to have some of those here that wander about. They are a bit annoying, but my door here can be locked so they can't get in any more. In the beginning they came, once there was that man suddenly in the middle of the room, just standing there, so I took him away. Several times I took him to the nurses and I had had enough of it when the same man was standing in my bathroom meddling about with my buckets and washing stuff, so I took him away and after that they set my door so that I have the key so that I can move about. The door is always locked. (Excerpt 3, male resident, aged 82)

Other residents with dementia illnesses had violated Paul's privacy by entering his room on their own time, thus impairing Paul's perceived resident–facility fit. However, facility practices kept Paul's door locked and thus counterbalanced his fit. Another resident, Jim, felt that he did not fit into his social surroundings at all, calling the other residents geriatrics and “hundred-year-old bags”. He solved this dilemma by keeping to himself own in his room.

Routines and procedures of the facility

In the previous excerpt, the undesirable visits of other residents to Paul's room were stopped by locking this door, but this technique did not work with the staff. Paul said that he had forbidden the staff from checking on him during the nights, but for some reason (probably due to routines, turnover of staff, and a bad flow of information altogether) a night nurse often entered anyway. In a previous study (blinded for review), we reported on how staff timetables, the dominant role of documents, and standard treatments prevented residents from being seen as persons. In Paul's case, ignoring his wish had such a negative effect on resident–facility fit that he was thinking about moving into another home. As stated in the Introduction here, the idea of AL is to diminish the institutional features of care and make older people feel at home. Feeling at home in a facility can be seen as the perfect resident–facility fit.

Paul was annoyed with the appearances of night nurses, but not all the routines and procedures in the home were bad. In the next excerpt, Paul tells how timetables arising from daily routines helped him organize his days.

Paul: As I know that I'll have lunch at noon, and after that there's time until four o'clock. So, I'll know that by looking at this clock here, that I'll have that much time and if I have a nap here or I watch some telly or go to do some exercise, all that is easy to manage during the free time I have there. (Excerpt 4, male resident, aged 82)

In the excerpt, Paul talked about his free time in contrast to his routines and paced his day in accordance with his meals. He

used that schedule as a frame inside which he arranged his own deeds independently. It seemed that daily routines could either support or impair resident–facility fit depending on each person's own interests.

Physical environment

The physical environment was yet another factor that influenced resident–facility fit. All the interviewees considered the facility to be cozy and easy to move around inside. There were no stairways inside the group home, but there was a spacious elevator to get outside. The building was located by a lake, and some of the residents had spectacular views from their windows. The neighboring area was park like, and there were wheelchair-accessible routes around the building. As Paul put it, if there were also a liquor store and a pharmacy, the area would have been perfect. There were, however, a couple of shadows still in this paradise. Most of the residents were not able to go out independently due to their physical or cognitive impairments, and the time-constrained staff had no time to take them. Relatives and volunteers were needed to get outside. The next excerpt highlights another way that the physical environment negatively affected the residents' fit with this facility.

When I arrived at the group home, some people were sitting at the table in the dining room. I sat down at one of the tables with three female residents. One of them asked me what ailment was preventing me from opening the door out. She said she can't go out and it feels like being in prison here. I told her that people probably get to go out only with an escort. The lady kept on talking to herself for a while still, about being a prisoner, but I couldn't quite make out what she said. (Excerpt 5, observation notes)

The group home doors were locked and could be opened with a five-number code. The procedure was to prevent cognitively impaired persons from wandering off by themselves. Cognitively fit residents understood this situation, but those whom the procedure actually protected, did not. The woman in the excerpt above felt imprisoned, which is probably the ultimate expression of poor resident–facility fit. It is always an ethically delicate matter to restrain incapable people, and with the ever-growing populations of older people, the prevalence of dementia illnesses will increase. Protecting incapable people demands having ways to control or at least supervise their movements. One possible solution might be to optimize a “free-zone” for people with dementia, as in De Hogeweyk in The Netherlands. De Hogeweyk is a dementia village, surrounded by walls that still allow people to move freely in a larger area (<http://hogeweyk.dementiavillage.com/en/>).

Residents' functional abilities and coping strategies

In line with the previous research (Ball et al., 2004; Morgan et al., 2014) we found that resident–facility fit was connected with functional ability. In the first excerpt, Sarah was asked whether there were recreational activities available.

Sarah: There are. I don't take part because my hands are bad for crocheting all these shawls, and this wrist is bad, too. I

can't risk doing crafts, and I can't crochet any more. But I do cryptic crosswords. I can't do those for more than a little while at a time either before it starts hurting, and I don't let it hurt. It's my own fault for not stopping in time, while it still only hurts a little. (Excerpt 6, Female Resident, aged 86)

According to SOC theory (Selection, Optimization, Compensation), people will use different strategies to deal with changes in their functional abilities in old age (Freund and Baltes, 1998; Rothermund and Brandstädter, 2003). Sarah had to give up crocheting, but she did crosswords instead and explicitly said that she would not surrender to pain. She was still hanging onto the options that were open to her, thus affirming her perceived resident–facility fit. Sarah suffered from a progressive somatic illness, which meant that she needed assistance in all daily functions except for eating. However, when she was asked whether she could move around independently, she answered:

Sarah: Yes I can. I can wheel myself around a bit. They usually take me to the dining room for lunch, for example, but then I sometimes end up waiting at my door for someone to let me in, because I always keep my door locked because of that person. So if I want to get away from the dining room, I'll wait there for someone to open the door. (Excerpt 7, Female resident, aged 86)

In this excerpt, Sarah seemed to affirm her own resident–facility fit by lowering the standards of autonomy—she could roll her wheelchair from the dining room to her door, although she could not open that door without help. The excerpt supports Street et al.'s (2007) notion of a miniaturization of autonomy, which means that older people with hampering abilities hang on to their capacity to make even small choices. In our data, resident–facility fit usually was related to a person's own functional abilities, but sometimes it also related to the abilities of other residents, as in the next excerpt. In it, Laura is asked whether the staff provided enough help for her.

Laura: The help's been enough for me, but I don't know if you'll get the necessary care if you're in worse shape than I am. (Excerpt 8, Female Resident, aged 85)

Laura was proud to say in her interview that she could take a shower and move around independently, and she considered her situation better than that of people with a lower level of functional ability. This kind of distinction was common in our data and not surprising since our interviewees were the residents with the best cognitive capacities. Residents who suffered with dementia illnesses were sometimes described using terms, such as geriatrics or zombies. However, interviewees also expressed sympathy for others and sometimes helped the confused ones.

The influence of dementing illnesses

Mary suffered from both physical and cognitive illnesses, which meant that she could not employ coping strategies (SOC) as Sarah has mentioned earlier. When she moved into the home, she constantly asked her daughters to take her away from there. When she was brought into the dining room for meals, she kept asking to go back to her room. Sometimes she

was allowed to eat in her own room, as in the next excerpt from observational notes. The researcher had earlier taken Mary's dinner to her room and was now checking up on her.

After a while I glanced into the room, and Mary said she was afraid because it was too dark. As I had visited her earlier, she had asked me to turn off the ceiling lamp which was bothering her eyes. There was still the table lamp and the lights in the bathroom. The bathroom light operates, however, with a motion sensor, and hence it turns off automatically after a while unless there is any movement. When the resident had been sitting at her bedside, the light had turned off and the room had gone darker. I turned on the ceiling lamp again. The resident told me that she didn't understand what I was saying about the bathroom lights and that this was not her home. I assured her that she'll get used to the light, little by little. (Excerpt 9, observational notes)

Mary did not understand the environment in the facility. The principle of bathroom lights was confusing to her. Most of the residents suffered from some kind of dementia illness, which sometimes affected their resident–facility fit negatively. For example, Anna often wandered around in the home looking for her own room, reading the names written on the doors. She was always seeming confused about the place she was in and aiming to get into her own room. Her illness directly reduced her resident–facility fit since she did not recognize the space she was in at the time. Poor resident–facility fit for people with dementia seemed to be often expressed as a constant effort to be somewhere else. However, dementia did not necessarily lead to poor fit, as Violet and Martha illustrate in the next excerpt.

Violet and Martha were keenly watching the Olympics, seemingly almost out of habit. The important thing seemed to be the actual act of watching and rooting for the athletes, even though the residents immediately forgot everything, including how well the athletes did. For example, when the nurse asked how the Finnish ski jumper Ahonen did right after he had jumped, the residents could not tell her. (Excerpt 10, Observation Notes)

In this observed situation, Violet and Martha were watching the Winter Olympics in the day room. Their cognitive capacities had declined to the point where they could not keep track of the overall situation in the ongoing ski jump contest. However, it still seemed to be a pleasant moment for them. They cheered when the commentator said it was the Finnish ski jumper's turn and then forgot the statistics of the jumps right away. Watching the games seemed to be an act that was in harmony with their personality, thus supporting their resident–facility fit as *continuity of self*. The close connection between continuity of self and resident–facility fit became apparent when we considered Lidz, Fischer, and Arnold's (1992, pp. 12–16) perception that the autonomy of separate acts should be evaluated in the context of each person's past, present, and future. Individuals' acts relate to one another through the self or subjectivity, and thus the autonomy of an act depends on how that act fits in with a person's life as a continuum. When we think of people with cognitive disorders like Violet and Martha here, the perception of resident–facility fit as continuity of self

seems plausible. The fit of these women were affirmed through their opportunity to continue an old custom (watching the Olympics) even though they could not comprehend the situation in detail as they had done once before. The more there are possibilities to continue life-long habits in AL, the better are the chances for good resident–facility fit (cf. Pirhonen and Pietilä, 2015). We get back to Violet and Martha in the discussion that follows below.

Potential to act

One significant finding was that people living in AL base their resident–facility fit on having the potential to act but not necessarily ever acting. Paul stated there was a great outdoor recreational area nearby if anyone wanted to go there. Violet related that she could always enjoy some fresh air on a beautiful balcony, but she had not done it yet. Hanna said that she had a cell phone to call her son, but she had not yet called him, although she had lived in the home for eight months. These kinds of potentials promoted these older people's resident–facility fits, as long as the potential remained accessible for them. Paul was actually fit enough to visit the recreational area if he wanted to, since he sometimes used his walker to go to a grocery store nearby. The balcony was accessible by wheelchair for Violet, and Hanna's cell phone was working. These kinds of observations gave the impression that having the potential to do something might be even more important than actualizing it, as we shall see soon.

The next excerpt starts with a straightforward reference to people outside the AL, but it also highlights how having a potential to act influence perceived resident–facility fit in AL by affirming control over one's life. In the excerpt, Paul was asked whether he felt connected with people outside the home.

Paul: I do. I can get a ride in a car. My daughters or buddies will pick me up and take me places if I want to go somewhere.*R:* Okay.*Paul:* So I don't have any problems with that. The other thing is that I can go for a walk any time, or catch a bus and go to the city center, but I don't like to do that, go there on my own. (Excerpt 11, Male Resident, age 82)

Paul felt free to leave the home, but that depended on whether or not his daughter or his friends would pick him up. In the latter part of the excerpt, Paul explicitly emphasized the importance of having the potential. He said that he could go for a walk or hop onto a bus whenever he wanted, but he chose not to actualize his potential. Having chances to choose affirmed Paul's control over AL surroundings even if he did not take any actual actions. He also answered the question about whether he felt connected with people outside the home with a straightforward, 'I do,' but then he also provided an account of relational factors that related to that comment in the same breath.

The next excerpt illustrates how having potential makes it possible for residents to feel at home in a care facility. Sarah was asked what the biggest difference was between living at the AL and being at the geriatric hospital where she was previously.

Sarah: It's a good thing this is different, but better in the sense that, of course, I prefer to be alone in my own home and be free to go where I want. I could take a wheelchair-

accessible taxi to go visit my friends, but I haven't gotten around to it yet... (Excerpt 12, Female resident, age 86)

Sarah had lived in the sheltered home for seven months. She spoke about the facility as 'home,' a place where she made decisions. She could go outside if she wanted, and she could take a taxi to visit a friend if she wanted. The potential for taking a taxi was even more accessible to her because her somatic disease gave her the right to use a low-priced wheelchair-accessible taxi. In this case her autonomy was partly conditional since it depended on potentials she had not yet availed herself of, not even once. Yet, this conditional autonomy did affirm Sarah's perceived resident–facility fit. This kind of 'yet talk' was also common in our interviews. People postponed making use of their potentials until later, and this decision seemed to provide them with the expectation of having a future. Saving enjoyable actions for later expressed positive prospects regarding their remaining functional abilities still available in the future. Perkins, Ball, Whittington, and Hollingsworth (2012) found that hope is a key factor in residents' ability to maintain their feeling of autonomy in AL settings. Based on our findings, hope as a seemingly accessible potential is a highly important factor that affirms resident–facility fit.

Discussion

Our ethnographic research frame and our focusing on a single care facility produced certain limitations regarding the generalization of our findings as such. However, the purpose of ethnographic research is not just to provide information, but rather understanding about the everyday reality of the research subjects (Gubrium, 1995). Perhaps our results cannot be generalized as such, but they did help us understand what kind of factors affect older people's perceived resident–facility fit in their AL surroundings. Facilities and individuals will differ in multiple ways, but there always are people who are acting in relational situations with relational resources. Our results illuminate the patterns that may be employed in one form or another in residential settings involving older people and a nursing staff. Therefore, our results can be generalized at a theoretical level, and we thus trust that every manager of an AL facility may utilize our findings to affirm quality of residents' life in that facility.

A universal way to affirm perceived resident–facility fit would be to support residents' relationships with the outside world in every way, since their fit with AL seems to be connected to these relationships. In addition, relatives eased the staff's workload by feeding people, washing their clothes, and taking them outdoors. Thus, relatives and friends can be seen as resources for the staff as well as for the residents and should be allowed to participate as equal members of the community. They can, for example, be involved in decisions about recreational activities and the procurement of items needed at the facility. Regular get-togethers involving the staff, the residents, and the relatives might be a good start. Since not all residents have relationships outside the facility, everything that has been noted here about relatives and friends can apply to voluntary workers as well. Named nurse-procedure may also affirm social resident–facility fit when it functions well, i.e. nurses bond more closely with a few named residents.

The poorer the residents' functional abilities are, the more important the role of the facility regarding fit becomes. Architecture and the furnishings of AL facilities do affect resident–facility fit (see Schwartz and Brent, 1999). Restraining residents' freedom of movement of course is sometimes a necessity for their safety. There are, however, very different techniques to use to do it. We suggest that the broader the “free-zone” is for the residents, the better. We saw people tied in their wheelchairs. Tying someone down is the most radical way to restrain people. Dementia villages, such as De Hogeweyk, enable resident movement within a wide area. In addition to the architecture, the working culture of staff and the routines and procedures in the facility will affect actual resident–facility fit. The attitude of the staff in residential care is crucial. Räsänen (2011) holds that good management is equally important as number of staff members in care facilities regarding residents' quality of life. It depends on the management, whether the staff believe that there are older persons living in their workplace, or alternatively, whether they understand that they are working in an older person's home.

Our findings support the perception of functional abilities as a negotiable phenomenon, and this perception could add something to both future gerontological research and the provision of care in the future. Our interviewees acknowledged that they were impeded in their ability to function, but they hung onto their positive resident–facility fit by using their personal coping strategies (SOC) (Freund and Baltes, 1998; Rothermund and Brandstädter, 2003), thus highlighting remaining abilities and lowering their standards. It seems that it is not just the observable and measurable level of abilities that matters. It is the relational nature of those abilities in a particular AL setting that has significance as well.

Our results suggest that structured tools that capture the objective levels of residents' functional abilities in AL, such as ADL (Activities of Daily Living), label many older people who feel capable as disabled. In previous studies, mortality has been associated with self-rated functional abilities that are independent of actual functional limitations, and disability has been seen largely as a product of attitudes and the organization of our supposedly modern social world (Bernard et al., 1997; Kelley-Moore, Schumacher, Kahana, and Kahana, 2006). Our interviewees based their resident–facility fit on their *perceived* abilities, thus confirming that the ability to function is a highly situational and contextual phenomenon (cf. Jyrkämä, 2008) and further, highlighting the need for more qualitative study on functional abilities of AL residents.

Pirhonen, Ojala, Lumme-Sandt, and Pietilä (2015) introduced the concept *ability others* when describing how nonagenarians made distinctions in their degrees of autonomy on the basis of functional abilities. Community-dwelling nonagenarians considered those who were living in care facilities as ability others, those who had lost their ability to manage on their own and had thus lost their autonomy. Based on our data, this distinction seemed to be valid inside care facilities as well. When the interviewees compared themselves with less capable individuals, it boosted their own competence and thus affirmed their perceived resident–facility fit. Interviewees proudly stated how they could go to bathroom on their own, or take a shower, or go out whenever they wanted, and they talked proudly about their visitors from outside. In addition to affirming residents' self-esteem, this kind of facts could be cut

out for boosting their status among other residents, in line with previous research (Powers, 1995). Both good self-esteem and high status among others residents are likely to affirm resident–facility fit.

However, coping strategies cannot be employed when residents suffer from dementing illnesses. For people with dementia, good resident–facility fit is manifested as feeling confident in the surroundings, while poor fit appeared as a constant effort to be somewhere else. The key word here is continuity. Viewing *resident–facility fit as continuity*, our findings come close to the core idea of the Capabilities Approach, as philosopher Martha C. Nussbaum (2007, 2011) explained it. AL should support residents' fit with the facility by providing support to their residents' capability of acting in accordance with their authentic selves, a capability defined in a “Nussbaumian” way as the things people want to do and the ways they want to be.

Preserving capabilities supports the continuity of self, which supports resident–facility fit as we discussed it in our Findings section above. As we saw in the case of Violet and Martha watching television, resident–facility fit as continuity may provide fresh support to the quality of life of those people with cognitive disorders, which could be another important idea for care providers to consider. According to Ballard et al. (2001), the quality of life for people with dementia can be studied by observing how they express their own feelings, such as pleasure, interest, and sadness. Observing how residents with cognitive disorders relate to their own activities in an AL setting might be an effective technique to have them assert their resident–facility fit. The more a person seems to identify with an activity as his or her own, the more it will affirm that person's resident–facility fit (cf. Lidz et al., 1992, p. 14). The same goes for watching people with dementia to see how they relate to their life environment.

The role of relatives and friends is highlighted again in the context of dementia, since these individuals have the best knowledge of a resident's lifelong characteristics, habits, and aims in life. Speaking on behalf of someone else is ethically problematic, but just as Nussbaum (2009) justifies in the case of voting, the interests of people with severe cognitive disabilities are generally better ensured if someone who knows their living conditions votes on their behalf. Disadvantaged people need others to make their voice heard. Relatives could support resident–facility fit as a form of continuity by making their loved residents visible to the staff (who have the best perception of all residents' current capabilities) and as persons with real-life histories. Linda Clare (2002, p. 140) holds that the experience of dementia may be well studied when there are observations and interviews of both residents and staff. According to Kitwood (1997, p.15) even people with severe dementia can express themselves meaningfully in words. Studying the resident–facility fit of people with dementia is of high importance when the prevalence of dementia is growing with our aging populations.

Our findings on the importance of *having the potential to act* in AL refer to Norman Daniels (2010), who wrote about exercisable opportunities as a cornerstone of societal justice. His idea was that a just society provides its members with equal opportunities to pursue their aims in life despite their personal characteristics and individual situations. Daniels (Ibid., p. 135) holds that capabilities are those aims that are reasonable for someone to pursue, i.e., the opportunities on which one can

effectively act. If we move this concept to an AL setting, it not only supports social justice, but resident–facility fit as well. Our interviewees talked about their potentials that were accessible, but sometimes conditional in terms of such relational factors as assistance from friends and relatives outside the home. Daniels' exercisable opportunities are more like *accessible potentials* in AL, but they do assert a feeling of autonomy, which is important. Is there, then, difference between having accessible potentials and simply believing that one has potentials? Would it be the same, if Paul was unable to walk and stated that he could go to the recreational area nearby whenever he wanted? Unfortunately, answering these questions goes beyond our data and remains to be done in the future since our interviewees had realistic perceptions about their situation. They did not speak about potentials which were not accessible for them. Of course, highlighting a potential does not negate the value of executing choices; rather, it reminds us that having potentials is a prerequisite for making choices.

Conclusion

This study shows, that AL residents' autonomy is relational to a large extent, since it depends on multiple factors connected to their own personal traits and social, functional, and physical features of the facility. Residents' functional abilities decline over time, which may result in transferring individuals into a higher-level nursing facility. Previously, aging in place encompassed individuals' chances to grow old in private homes without moving into a facility, but today aging in place also encompasses residents' chances to stay in AL without moving into a nursing home or other higher-level nursing facility. Aging in place in AL entails good resident–facility fit, i.e. residents' hampering abilities and level of provided care must be in balance to avoid transfers between facilities. Resident–facility fit has previously been seen as both an outcome and an influence on the management of the process in which both the resident and the facility try to manage resident decline.

In this study, we utilized resident–facility fit as a *perceived* quality to find out, how residents themselves negotiate their fit with a facility. We learned that individuals based their resident–facility fit on both actual and potential ways of maintaining control over their lives in the facility, since it sometimes seemed to be equally important to have potentials to act as to actualize the potentials. Our main conclusion is that perceived resident–facility fit is hardly a clearly measurable individual quality, which a person either has or has not. Rather, resident–facility fit is subject to constant assessment, interpretation, and negotiation on to what extent residents have sense of control over their lives in an AL environment. The truly successful process leads to residents' feeling at home, but if unsuccessful that process may lead to residents' feeling as though they are personally imprisoned.

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Active and non-active agents: residents' agency in assisted living

JARI PIRHONEN* and ILKKA PIETILÄ*

ABSTRACT

Culturally, institutional care has been seen to strip older people of their status as full adult members of society and turn them into 'have-nots' in terms of agency. The substantial emphasis in gerontology of measuring the activity and functional ability of the elderly has unintentionally fostered these stereotypes, as have traditional definitions of agency that emphasise individuals' choices and capacities. The aim of this paper is to discover what kind of opportunities to feel agentic exist for people who have reduced functional abilities and therefore reside in assisted living. In this paper, agency is approached empirically from the viewpoint of Finnish sheltered housing residents. The data were gathered using participant observation and thematic interviews. This study suggests that even people with substantial declines in their functional abilities may feel more or less agentic depending on their functional and material surroundings and the support they receive from the staff, relatives and other residents. The perception that residents' agency in assisted living cannot be reduced to measurable activity has methodological implications for gerontological research on agency. Care providers can utilise our findings in reasserting their residents' quality of life.

KEY WORDS – long-term care, ethnography, agentic space, assisted living facilities, quality of life.

Introduction

At present, gerontological research has privileged activity in particular as the major component of successful ageing (Baltes and Carstensen 1996; Rowe and Kahn 1997) and its different interpretations, such as healthy ageing, productive ageing and active ageing (Nosraty *et al.* 2015). According to Katz (2000), activity has become such a paradigm of wellbeing in old age that questioning it would be considered unprofessional or even heretical. Katz (2000) sees the triumph of activity as deriving from larger societal and ideological

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changes driven by neoliberalism and its anti-welfarist agendas; keeping busy and active has been seen to postpone dependence and the need for help in old age. At the same time, the responsibility for wellbeing in old age is being transferred from the society to choice-making individuals (Jolanki 2009), which is the result of the challenges posed by ageing populations in the Western world (Rozanova 2010).

Katz (2000) maintains that the emphasis on physical activity is partly derived from its applicability in measuring and evaluating age-related phenomena. Meters like activities of daily living (ADLs) were originally created to measure specific physical competencies of maintaining an independent life, but their application has expanded, *e.g.* to determine service requirements and impacts, justify residential location or provide a basis for staffing ratios in care facilities. Katz (2000) suggests that activity is important to the success of care institutions as well. Providing activity programmes is a simple way for professionals to show their resourcefulness and efficiency, and their obedience to official guidelines of care that emphasise activity (*e.g.* Ministry of Social Affairs and Health 2008).

However, questioning the paradigm of activity regarding successful ageing has begun. Critics of successful ageing have even presented it as a technique of regulation that serves to deny older people the legitimate right to bodily dysfunction (Tulle-Winton 1999). The renunciation of bodily dysfunction has been claimed to result in intra-generational ageism (Rozanova 2010) or 'new ageism' (Holstein and Minkler 2003), since older people who do not age successfully become defined as unsuccessful. Critics see activity as too narrow and individual-centred a concept to capture the reality of ageing people (Holstein and Minkler 2003; Katz 2000). Therefore, the concept of agency, which originated in sociology, has lately gained ground in gerontological research (*e.g.* Morgan *et al.* 2006; Wray 2004).

In the sociological tradition, agency relates to the elementary question of the interaction between individuals and structures (Giddens 1984; Ritzer 2000). From the classical, Giddensian point of view, social structures direct individual action, which then feeds back into those structures. Agency deals with activity, but acknowledges the influence of the actor's situation as well. The concept of agency does not easily surrender to strict definitions. Marshall (2005: 59) points out that agency is 'a concept more often invoked than measured', and Emirbayer and Mische (1998: 962) note that 'agency has been associated with selfhood, motivation, will, purposiveness, intentionality, choice, initiative, freedom, and creativity'. Nevertheless, it always seems to involve choice, temporality and structures (Marshall 2005; Sewell 1992). Elder and Johnson's (2003) definition of agency makes this point clearly; agency means that individuals construct

their own lifecourse through the choices they make and the actions they take within the opportunities and constraints of history and social circumstances.

Traditional conceptualisations of agency, which emphasise social structures and situationality, capture the multi-dimensionality of human action better than activity, but there remains a serious flaw regarding the agency of people with severe functional disabilities. Giddensian agency presupposes that individuals possess agentic capabilities. As Wray (2004: 24) expresses it, 'dominant Western conceptualisations of agency are often used uncritically; individualistic notions of choice, autonomy, and in/dependence often pervade accounts of agency'. Old age does not necessarily cohere with agency when we consider Gilleard and Higgs' (2010: 122) argument that the combination of publicly failing in self-management and receiving institutional forms of care in Western cultures makes older people lose their frame of reference regarding their individual agency. Eliassen (2015) holds that this stereotyping frequently colours the interaction of health-care personnel with older people.

Morgan *et al.* (2006) emphasise that older people entering assisted living (AL) have probably already encountered constraints on personal agency, either due to prior circumstances resulting in placement or from the AL setting *per se*. Even today, AL facilities are seen to carry some features of Goffman's (1968) total institutions (*e.g.* Pirhonen and Pietilä 2015), thus creating constraints on agency. As organisations, facilities have certain needs of their own (Sherwin and Winsby 2010), and even the physical and functional spaces may influence residents' possibilities to conduct their lives in AL (Golant 2003). Also, since residents' functional abilities are diminished, third parties, including professionals and relatives, often make decisions on behalf of the residents (Schumacher *et al.* 2005). All this makes residents appear to be 'have-nots' in terms of traditionally defined agency.

However, Kontos (2004, 2005), who has studied people with Alzheimer's disease in AL, sees the human body as a fundamental source of selfhood that does not derive its agency from a cognitive form of knowledge. Kontos (2005: 558) argues that 'the body itself is an active, communicative agent, imbued with its own wisdom, intentionality, and purposefulness'. In their report, Morgan *et al.* (2006) showed how AL residents based their agentic feelings on their temporal context, *i.e.* agency was expressed and enforced in relation to the residents' life continuum. Katz (2000) refers to 'anti-activity activities', such as napping and watching television, when problematising traditional classifications of activity in AL settings. This all suggests that both the activity-emphasising approaches and the mainstream classifications of agency seem to be insufficient to capture the agency of residents in AL.

As Golant (2003) remarks, understanding older people's living arrangements and environments is central to any complete understanding of how a current residential setting influences their emotional responses or behaviours, *i.e.* agency. In this paper, our aim was to shed light on factors enabling AL residents to feel agentic in their living surroundings. Based on ethnographical data, we wanted to study what kinds of possibility exist to execute one's agency with remaining physical and cognitive capacities in a care facility for older people.

Design and methods

This paper is based on research that was conducted within an ethnographic research frame. The data were gathered through participant observation and thematic interviews in a sheltered home in southern Finland in 2013–2014. Sheltered housing is a form of housing service for older people that is ideologically located somewhere between institutional and home care. On our research site, people paid rent for their rooms, and they paid separately for their food, medication and care. In addition to the residents' private rooms, there were common spaces to socialise and watch television. Residents furnished their rooms with their own belongings and wore their own clothes in order to achieve an atmosphere that is as homely as possible. Nevertheless, nursing staff were available round the clock, which makes it AL.

At the time of the study, 114 residents lived in eight group homes. Their functional abilities and medical conditions varied considerably. Some suffered from severe cognitive disorders such as Alzheimer's disease, and some lived there due to somatic illnesses such as multiple sclerosis. Some were bedridden, whereas others moved around independently without mobility aids. The majority of the residents were female (70%), and the residents' ages ranged from 60 to over 100 years. Most of the residents suffered from cognitive disorders to some degree.

Observations were mainly conducted in one group home, which housed 15 residents, to become familiar with the residents and their characters as well as their interactions and daily routines. Staff were consulted in order to find a home of residents with diverse conditions to contrast the influence of the condition on the residents' agency. The observation lasted for two months and totalled 165 hours, which was regarded as adequate since thematic interviews were to follow. The observation consisted of conversations with the residents, staff and visitors, and participation in recreational activities and tasks permitted for voluntary workers, such as feeding the residents. Observations were made on every day of the week and at all times of the day. Once, the observer spent two consecutive nights at the

home to become as familiar with the surroundings as possible, sleeping in an empty residential room, spending time in the day room and having meals with the residents. Such intensive participant observation enabled us to provide 'thick description' of the research site, as Geertz (1973) puts it. Participant observation also helped us to see the setting from the residents' perspective (*cf.* Diamond 1992; Gubrium 1997). Field notes kept from the observations and the transcriptions were included in the data analysis.

In addition to the observation, ten interviews were conducted with residents between May and September 2014. Since the vast majority of residents suffered from cognitive disorders, we had to find the interviewees among the total 114 residents. We asked the staff to propose ten candidates capable of giving their informed consent and participating in an interview. A team of two head nurses and a practical nurse picked these ten residents (six women and four men), and those selected were all willing and gave their consent. This recruitment strategy involved a potential risk that the staff would nominate residents who felt most positive about the home, but since we did not personally know residents outside the group home we observed, it was a both ethically and practically justified procedure. Also, as we will see in the Results section, interviewees were quite critical about their surroundings. Thematic interviews were conducted in the residents' rooms and included themes such as the residents' previous lifecourse, their perceptions of their current living surroundings and their thoughts about the care they received. Themes were loose to enable data use regarding various research themes in the future. Agency as a concept was not introduced in the interviews, but residents were asked questions about the possibilities of them having control over their daily lives. For example, they were asked if they could move around in the home and go outside on their own initiative, how well did they know their finances or if there were desirable activities available in the home. The interviews were 25–65 minutes in duration and they were transcribed verbatim.

The Ethical Committee of the local Hospital District and the manager of the research site approved our research plan. The research was introduced to the staff in a staff meeting and notices providing information on the research were placed on all the notice boards of the facility. The researcher personally explained the research to everyone on the site the first time he encountered them. In spite of these procedures, not all the residents understood that the research was going on due to their cognitive disorders. However, we found the study ethically justifiable since people with such issues have been granted the right to participate in research aimed at improving their lives or the lives of people in similar situations (Bond and Corner 2001; Finlex 1999).

The data were analysed using directed content analysis (Hsieh and Shannon 2005). In the first phase of analysis, we utilised prior definitions of agency

searching for references to motivation, will, purposiveness, intentionality, choice, initiative, freedom and creativity (*e.g.* Elder and Johnson 2003; Emirbayer and Mische 1998; Wray 2004) to separate data extracts that dealt with the residents' agentic position. Both observational and interview data were involved in the analysis; since two different qualitative data-sets and two researchers were joined together, this enabled triangulation (Thurmond 2001). However, due to our research topic the interview data proved to be more powerful in understanding the nature of the residents' agency. As Jolanki (2009: 215) puts it, agency 'brings forth the human ability to ascribe meaning to objects and events and to act on those meanings'. The residents' meaning-giving was obviously more explicit in their accounts of objects and events. The observational data were nevertheless important as well, since they helped us position the residents' accounts within the frameworks of daily life in AL in order to understand the preconditions of their meaning-giving.

In the second phase of analysis, after separating extracts dealing with agency from the data, we noticed two things. Firstly, the vast majority of our extracts dealt with the residents' competence to do things in the AL setting, their motivation (wishes and feelings) and/or their surroundings in AL. This is not surprising since these three areas are, in some form, the cornerstones of any theory of action and agency. Theories inevitably deal with the abilities and motivations of the actor and the surroundings of the action (*e.g.* Joas 2005). Secondly, some of the extracts dealing with the residents' agency refused to fit in with traditional definitions of agency. Thus, we eventually analysed the residents' agency within three frameworks (competence, motivation, AL surroundings), while acknowledging the exceptions that widened these frameworks.

Results

In the data, the residents' agency appeared in relation to three components: their competence, their motivation, and the opportunities and restrictions produced by the AL surroundings. These components were not separate, but intertwined with each other. We present our findings below, with illuminating extracts from the data. All the names mentioned are pseudonyms. In the extracts, 'R' refers to the researcher.

Competence: 'I can take care of my diabetes myself'

In this paper, the concept of competence incorporates the personal qualities the residents needed in accomplishing their aspirations, such as their skills and knowledge, and creativity in applying those skills. Being capable

can be seen as a cornerstone of competence, and it was referred to most often in the data excerpts connected with agency. However, living in AL presumes that functional abilities have diminished (*e.g.* Agich 2003; Sherwin and Winsby 2010). Ida spoke openly about her situation.

- R: Yes. So why did you end up in enhanced assisted living?
- Ida: I can't really remember. My son lives in [mentions a town] and he was the one who got me in this place.
- R: Aha, so your son organised this...
- Ida: My son organised it, yes, I couldn't do it myself.
- R: Okay, well, do you know what reasons there were for it, do you have some physical illness or...
- Ida: No, old age.
- R: Just old age?
- Ida: Old age. I couldn't cope any more, and I couldn't manage on my own, so... (Female, aged 94)

In this short extract, Ida expresses four times the restrictions to her agency, all of which were connected to competence. She was not able to tell (she did not remember) why she originally entered the home. Then, she explains that she was not able to arrange the move herself, that she was not able to cope anymore and that she was not able to manage on her own. Ida considered that hampering abilities due to old age was the reason for her to move into a care facility. She did not seek explanations for living in AL in particular diseases or other reasons like the rest of the interviewees did. For example, interviewees reported that they were in AL because they had lost the ability to walk, experienced dizziness or had been incompetent in managing their finances. At the same time, in giving up her own agency, Ida seemed to delegate at least a part of it to her son, who found the home and arranged the move.

Other interviewees also seemed to delegate their agency to family members, friends, the staff and sometimes each other. Residents' children usually managed their finances and brought them the things they needed. Hilda, who spent most of the time in bed, had her closets kept in order by a friend who visited frequently. Timo was not interested in his own medication since he thought that the doctor was qualified enough to make the right decisions for him. Maria used her male neighbour as a messenger when she needed to give the staff feedback on something. In these cases, residents were still agents who employed decisional agency and then delegated executional agency to others.

Delegating one's agency to others voluntarily differs from having one's agency restricted by others. Anita also said that her children had arranged her a place in AL, but against her will. She had to move because her daughter had found her lying unconscious in her apartment. In the following extract, she was asked what the biggest differences were between living in a private home or in a sheltered home.

- Anita: Well, at home I could of course wake up whenever I wanted to, although I can do that here, too. I had to go grocery shopping and cook. That's a difference right there.
- R: Yeah. Do you miss things like that, going to the store or cooking your own meals?
- Anita: (laughs) Why not...
- R: Uh-huh. And do you think you could still do it?
- Anita: Huh?
- R: Could you still do it?
- Anita: Sure, I could still do it. (Female, aged 78)

Anita missed the opportunity to go to the grocery store and cook her own meals and she thought she still could do these tasks. Earlier in the interview, she explicitly stated that her 'children began to say "you can't manage at home on your own". And I could still manage if I was there'. She seemed to consider herself too competent to live in AL and therefore seemed to feel that her agency was restricted by her children.

Ida felt that she had lost her ability to take care of herself, whereas Anita believed she could still manage on her own. Jan, being a 'young' man (60 years old) who lived in AL for somatic reasons, actually seemed to be considerably competent.

- R: And can you eat whenever you want to?
- Jan: They're organised superbly, the meals. I've had diabetes for 17 years and I can manage it myself. I give myself the shots and check the levels myself. That's my equipment there. (Male, aged 60)

Jan's statement can be read as an ultimate expression of competence in the AL surrounding. He was asked about eating arrangements in the home, and as a diabetic he obviously *knew* the importance of nutrition regarding his condition. 'I can take care of my diabetes myself' expresses Jan's agentic competences; he *wanted to* take care of his diabetes himself and he *knew how* to do it and *was able* to do it with the equipment provided by the care system. 'I can take care of my diabetes' could also be interpreted as expressing self-esteem, implying that he *felt* proud to do it, having already done it for 17 years.

Sometimes the residents supported their competence and thus their agency by aids or other devices, just like the rest of us. Jan was notably modern in this sense:

- Jan: Yup. And then I spend time with that (points to a laptop).
R: You've got an internet connection on it, haven't you?
Jan: I have. I read national newspapers, there are plenty of those. I can even read all the local papers online, even if it's a small town.
R: Yes.
Jan: And then I surf the net for all kinds of things. Recently I've checked the prices for a 40-inch Samsung television. I've got a small TV, a 23-inch one, and I'm going to get rid of that, sell it to someone and then buy that 40-inch Samsung. (Male, aged 60)

Jan's ability to use a laptop and internet seemingly supported his agency. He kept up to date by reading online newspapers and used the internet to obtain information, for example, about buying a new television.

The residents used wheelchairs and walkers to move around, and they had cell phones to keep in touch with people outside the AL setting. Usually, the devices were appreciated simply as aids, but sometimes they enabled deeper agentic feelings, as in the case of Ida.

- Ida: And I can go to the bathroom, that's a big deal.
R: You can go on your own?
Ida: I can go on my own, and then I've got this walker, I can use it to go to the bathroom. (Female, aged 94)

Ida stressed the importance of getting to the bathroom independently, and a walker made her agency possible in this case. The connection between the device and agency was even more significant for Hilda. In the following extract, the researcher interviewed Hilda, who sat in a wheelchair in her room.

But then I came to [mentions the hospital ward she was in before AL] and the first time two nurses, pretty strong, strong-looking ones, tried to get me into a wheelchair, and my legs went all ... one crossed under the other. Then they said we'd all been close to taking a tumble. So that's when they said this isn't going to work, off to the bed with you. And after that it's been bed rest for me. I like to sit there, too (points to the bed). I don't lie down unless I'm sleeping. (Hilda, female, aged 86)

Hilda's account begins with a description of her diminishing functional abilities. She 'lost her legs' due to a progressive illness, after which other people decided she should stay in bed in future, which inevitably affected her chances to feel agentic. However, in this case, the bed itself has given

Hilda a chance to hang on to her agency. Her bed was motorised and she could operate it with a remote control device. She could lift the top part of the bed as a backrest and sit comfortably. The bed enabled her to feel that she was actively sitting instead of passively lying down: ‘I don’t lie down unless I’m sleeping’ expresses that Hilda has her ways of feeling agentic even when she is in bed and cannot get out of it on her own.

Motivation: ‘I refused to take that medicine’

The second widely referred to component of agency in our data was the residents’ own motivation, which manifested itself in their talk about their wishes and feelings. On many occasions, motivation seemed to act as a starting point for agency. Juho gave an apt example:

Juho: Yes. If I want to go outside, I have to let them know.

R: Yes.

Juho: And I’ve got the code to the door. (Male, aged 82)

Juho said that if he wants to go out, he first has to inform the staff about his wish. In the home, the external door was always locked, and it could be opened with a five-number code. This system was designed to prevent cognitively impaired people from wandering off on their own. Juho stated that he had the code, meaning that he knew how to open the door and that he was capable of doing so. In this case, acting would result from motivation in line with traditional teleological theories of action. Sometimes, however, it seemed that the residents’ situation influenced or even generated their motivation, as in the case with Ida.

I don’t really move around. I get dizzy, so I’m a bit timid about going anywhere. But I quite like it here. I’m one of those people, I don’t care much for company. (Ida, female, aged 94)

Ida’s diminished functional abilities (dizziness) resulted in feeling insecure, which motivated her to stay in her room. She compensated for this by stating that she felt comfortable about staying in her room and explained this by adding that she did not long for company that much. Ida also reported during the interview that she would have liked a dog as a companion, but she was no longer able to take care of one. Maria said that she would like to exercise outdoors more often, but that it was not possible because of her diminishing functional abilities. However, the interviewees reassessed their situation in terms of coping with changes in their functional abilities. Hilda, for example, had switched from knitting to completing cryptic cross-words due to aching wrists, and Jan had switched from walking outdoors to

sitting on a bench due to shortness of breath. Coping with age-related changes certainly supported the residents' opportunities to feel agentic.

Sometimes the interviewees expressed their wishes explicitly, such as 'I refused to take that medicine', 'I denied the night nurse permission to enter my room', 'I don't want to wear make-up', and so on. Wishes were expressed explicitly, especially when they referred to things people did not want. Positive wishes were, however, intertwined with talk about restrictions set by circumstances. It seems that not wanting something did not demand explanations, but wanting something seemed to call for an account regarding how the speaker would be able to meet his or her expectations. The following extract is typical in this sense.

R: What expectations do you have for the future now that you've moved in here and lived here for three months?

Juho: Well, I'd of course want to take a short trip abroad at some point. I need an assistant, though, and I can't afford to pay for two people. (Male, aged 82)

Juho stated earlier in the interview that he had travelled abroad a lot with his wife. He still dreamed of taking a trip somewhere, but he admitted the restrictions set by his situation (the need for an attendant and limited finances). This seems to be a kind of accountability for agentic feelings. Residents who had obviously entered the home because of functional problems seemed to reflect constantly on their chances of feeling agentic.

AL surroundings: 'So to say, I prefer men'

The third frequently referred-to component of agency was its entanglement with the surroundings, that is, AL. Like any other surrounding, AL both encourages agency by providing opportunities and discourages agency by setting limitations. Putting the terms 'agency' and 'AL' into the same sentence easily directs our thinking towards restrictions of agency. There were references to restrictions in our data, too. In the following extract, Johanna compared her private home and the sheltered home.

R: That's great. If you think of home as a concept, do you have some kind of idea of what home consists of? What kinds of things make a home?

Johanna: It's the living itself. The things that you do. You don't do them here. There's no cooking or baking here. (Female, aged 85)

Here we have an explicit example of how the AL setting in itself may restrict people's agency. Johanna states that domestic work makes a home. Like Anita earlier, Johanna missed the opportunity to cook for herself.

The official, public business model of the sheltered home we studied explicitly states that residents could take part in the daily chores and household duties, but the kitchen was *de facto* off limits to them for hygiene reasons. Juho said that he sometimes helped other residents, although the staff had tried to prevent him from doing so by appealing to safety regulations. Another female resident once wondered why there were no duties available for her in the home. Providers of sheltered housing in Finland tend to emphasise that sheltered housing units are not institutions but homes. These findings imply that the practice does not yet meet expectations.

Timo, being a relatively young man (73 years old) surrounded with older women, gave a straightforward account regarding how the AL surroundings affected his agency. He was asked if he took part in recreational activities at the home.

Like hell I'm going to go there with those old hags, they're a hundred years old, and I have nothing to talk to them about and nothing in common with them, so I just feel like a damn crank around them. (Timo, male, aged 73)

Timo felt that he had nothing in common with the other residents. Enjoying recreational activities with them would have made him feel awkward, so he decided to stay in his room alone, although he said in the interview that he sometimes missed company. On the one hand, Timo's agency was restricted because of the limitations set by his social surroundings, on the other hand, he executed his agency by isolating himself from the others.

The AL setting was also found to support the residents' agency. For Maria, the setting gave her the opportunity to choose her company.

Maria: So I pick out the ones that somehow suit me.

R: Right, so you can choose your company here.

Maria: Yes. Yes, that's right. And, so to say, I prefer men. (Female, aged 82)

Maria preferred the company of men, and living in a group home of 15 residents made this possible. People were happy to have their own rooms (part of the business model of sheltered housing) and to take part in recreational activities provided by the home. They also appreciated the staff's help which supported their own agency. It is worthwhile noting that for some people, AL was indeed an expansion of their agency compared to a private home, highlighting the core idea of AL. As Ida put it earlier, 'I was not able to cope anymore' (at home).

As Giddens (1984) points out, social structures affect individuals and *vice versa*. In AL, this means that residents have to cope with the setting, but they shape it as well. Hilda reflected on her interaction with other residents.

But then, little by little ... The other residents wouldn't say anything to anyone. I just went on and asked questions and now I've got four people at the table that I can talk to. And who talk to me, and listen, and answer questions. (Hilda, female, aged 86)

Hilda was a very social person. At first, she was rather annoyed since the other residents would not hold conversations during meals. She decided to change the situation and kept talking to others until they started to respond. Hilda made her social surroundings more social herself.

AL constitutes very specific and compact physical, social, functional and cultural surroundings, which have been suggested to possess features of Goffman's (1968) total institutions (*e.g.* Pirhonen and Pietilä 2015). Nevertheless, based on our findings, the residents are not only passive receivers of care but also active agents utilising opportunities and affecting the AL surroundings.

Discussion

The ethnographic research frame applied in this study sets limitations regarding the generalisation of our results. We studied only one AL facility, and there are numerous forms of care – ranging from geriatric hospitals to sheltered housing – which are provided by various bodies, such as municipalities, private enterprises and foundations. However, the purpose of this ethnographic study was to widen our understanding of the agency of people with declining functional abilities. While our findings cannot be generalised in a practical sense, we believe we have revealed some of the universal features of older people's agency in AL, and thus our findings can be generalised theoretically. We trust that our findings on residents' competence and motivation as well as influences of their surroundings can be utilised to develop both policies and practices for AL regarding the enhancement of the residents' agency.

Residents' competences employed their skills, knowledge and abilities. Competence manifested itself in residents' accounts of managing in their living environment. The residents' functional abilities varied significantly, expressing the heterogeneity of older people in AL, just as described earlier regarding older people in general (Degnen 2007; Featherstone and Hepworth 1989). People highlighted what they still were able to do, in line with previous research (King *et al.* 2012). Our interviewees also reaffirmed Kaufman's (1986) finding that older people tend to avoid feeling old and frail by dealing separately with specific problems and disabilities, which may add to their feeling of still being agentic. As we saw in the results, interviewees (except for Ida) reported that they were residing in AL due to specific reasons.

Despite the differences in functional abilities, residents had their own ways of feeling agentic. The delegation of agency describes how the older people in our data voluntarily gave a part of their agency to other people, for example, when they were not interested in their medication, trusted that a doctor knows better or let a relative take care of their finances (*cf.* Young *et al.* 2003). Allowing someone to do something on one's behalf is agentic since to allow is still to be in charge of things. In our case, residents sometimes delegated execution of an action to other people while the decisional agency remained untouched. George Agich's (2003) differentiation between independence and autonomy is enlightening here. Agich (2003) holds that it is independent to make and execute decisions on one's own, but it is autonomous to make decisions and then get help in executing those. However, according to Sherwin and Winsby (2010), residents' autonomy may be lessened by several reasons like other people's (such as relatives') interests and residents' fear that disobedience may result in abandonment. It seems that allowing someone else to decide may sometimes actually result from constraints set by the situation.

Agentic feelings were also supported by aids. However, supporting agency with aids differs from delegating one's agency to other people in one significant sense. One does not allow an aid to act on one's behalf; rather, the aid extends one's own agency. Using a pill dispenser is an appropriate example. Allowing someone to fill one's pill dispenser delegates agency partly to the filler, but using a filled dispenser supports one's own agency, since it furthers one's own coping with the situation. In our data, residents delegated their agency to other people and supported their own agency with aids and other devices, creating categories of delegated and supported agency. Young *et al.* (2003) discussed shared agency when they described how older people semantically shared their agency with medical personnel or medical devices in their talk (*e.g.* the machine does my breathing). A hi-tech device, such as a ventilator, can be semantically comprehended as an 'other' to whom agency may be delegated. Social and other interactive robots in future welfare services will inevitably have interesting impacts on human agency.

The AL environment provided both opportunities and restrictions on the execution of agency, and it had more in-depth implications for agency, too. In terms of the relation between the residents' motivations and their surroundings, we found Joas' (2005) theory of non-teleological action highly plausible. Joas' basic theory is that the situation (affordances and constraints) is constitutive of action. Traditional teleological approaches to action emphasise the motivation of an actor, but Joas suggests that it is the situation that counts. As traditionally understood, residents in AL would first set their goals (motivation) and then move towards them with the means available (competence) in the situation (surrounding). The

will (motivation) finds a way (competence and surrounding). Joas suggests that the reverse is true. Applying his theory in AL, the residents' reflective response to the situation decides which actions would be appropriate: a way (competence and surrounding) creates the will (motivation).

Our interviewees adjusted their motivations and thus their actions on the basis of their competences and their situation in AL, the situation encompassing both affordances (such as aids) and constraints (such as staff being sometimes too busy). This is in line with SOC (selection, optimisation, compensation) theory, according to which older people use coping strategies to deal with age-related changes in their functional abilities in later life (Freund and Baltes 1998). Both Joas' (2005) theory and SOC theory highlight the situatedness of action, but there is one fundamental difference. SOC focuses on *adjusting* on the basis of one's situation, but Joas' theory is concerned with *creating* on the basis of one's situation. Perhaps we could say that activities may be adjusted to one's situation, but agency is created in one's situation. Regarding the bed case, Hilda did not just adjust her activities on the basis of her diminishing functional abilities (having multiple sclerosis), but created her agency in her situation.

The three components of agency – competence, motivation and surroundings – were not separate but intermingled with each other, providing people with *agentic space*. We suggest that agentic space is something that traditional sociological or 'Giddensian' individual–structure interaction cannot account for (*cf.* Honkasalo, Ketokivi and Leppo 2014). For example, Hilda found her agentic space when sitting on her bed instead of lying down. Her agentic space was constructed from her competence (ability to use her mechanical bed), motivation (preferred sitting during the day) and the surroundings (AL provided her with the bed). Agentic space is the situational affordance of enabling people to feel agentic. It is not visible as such: when Hilda was sitting on her bed, she felt agentic even though her agency was not visible to the eye.

A substantial part of the data used in this study was gathered in interviews with people capable of reflecting upon their situation. It may appear that we have nothing to say about the agency of people with dementia, even though the majority of people living in AL suffer with it. However, our study has methodological implications regarding research on the agency of people with dementia as well. If we accept Joas' (2005) idea that motivation does not lead our action but derives from the situation, people with dementia may be recognised as possessors of agency, and their agency may be studied and affirmed. People with dementia could be seen as a living argument supporting Joas' non-teleological approach to action. However, a specific study on the agency of people with dementia, as well as the methods to capture it, remains work for the future. One plausible approach

to the agency of people with dementia could be joining Joas' (2005) ideas with Kontos' (2004, 2005) work on embodied selfhood. Kontos urges researchers to abandon the Cartesian dualism of mind and body in which the mind leads and the body follows. Embracing the notion that the person is his or her body, its gestures, movements and habits, would provide a new insight and direction for the future investigation of the agency of people with dementia (Kontos 2004, 2005).

Conclusion

How we conceptualise agency has important methodological implications for gerontological research. Research could benefit from widening the concept of agency from 'doing' to also include 'being'. In addition to structured and standardised meters and checklists regarding older people's physical competence and their capacity to manage independently, a more philosophical understanding of agency is required. There is a need for ethnographical research on agentic spaces (including competence, motivation and the surroundings) of older people in different surroundings to widen our understanding of what we should be looking for in our quest for human agency in general and the agency of AL residents in particular.

Our data suggest that sometimes agency is more like a feeling, a state of mind or an affordance of the situation. Based on the analysis of our ethnographic fieldwork in a sheltered home, we claim that even people with substantial declines in their functional abilities may feel more or less agentic depending on their functional and material surroundings, and the support they receive from the staff, relatives and other residents. Adjusting the delivery of long-term care to acknowledge the invisible aspects of human agency would undoubtedly result in better quality of life in AL facilities.

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Patient, resident, or person: Recognition and the continuity of self in long-term care for older people



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ABSTRACT

Becoming a resident in a long-term care facility challenges older people's continuity of self in two major ways. Firstly, as they leave behind their previous home, neighborhood, and often their social surroundings, older people have to change their life-long lifestyles, causing fears of the loss of one's self. Secondly, modern-day care facilities have some features of 'total' institutions that produce patient-like role expectations and thus challenge older people's selves. Our ethnographic study in a geriatric hospital and a sheltered home in Finland aims to find out what features of daily life either support or challenge older people's continuity of self. A philosophical reading of the concept of *recognition* is used to explore how various daily practices and interactions support recognizing people as persons in long-term care. Categories of institution-centered and person-centered features are described to illustrate multiple ways in which people are recognized and misrecognized. The discussion highlights some ways in which long-term care providers could use the results of the study.

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Introduction

Moving into long-term care (LTC) greatly changes the lives of older people (Caouette, 2005; Milligan, 2009). They have to leave behind their home, neighborhood, and often their previous social surroundings (Barredo & Dudley, 2008; Kivelä, Königäs-Saviaro, Laippala, Pahkala, & Kesti, 1996). Gubrium (1997, pp. 84–90) described these changes as *breaking up a home*. He noticed how older people talked about losing their previous homes in terms of losing places, possessions, and relationships, although de facto 'it was their selves that were clearly at stake' (ibid., 85). They were afraid of losing all the place-related memories of people and events, 'all the little things' that had made their lives unique.

If *breaking up a home* was about losing one's self, then we suggest that *building up a home* in LTC might be about retaining

one's self in the new surroundings. Just as Gubrium revealed the fear of losing one's self behind mundane talk about losing things, this article addresses the possibilities of older people to retain their selves in the midst of mundane LTC practices and interactions. These mundane practices and interactions afford older people with new roles and role expectations, which may challenge the continuity of their selves. It makes a difference for older people whether the care institution and its staff see them as persons, residents, inmates, or patients.

The theory of continuity is one of the prevailing theories of aging today (Atchley, 1989; Parker, 1995). It emphasizes the importance of a life-long lifestyle and the continuity of personal characteristics as key elements in successful aging. There is also a rich body of knowledge about the links between the continuity of self and well-being in old age (Andrews, 1999; Atchley, 1989; Bozinovski, 2000). However, aging itself may challenge the continuity of self as it changes the person's appearance and physical abilities (Öberg & Tornstam, 1999; Webster & Tiggemann, 2003) and may lead to cognitive disorders, such as dementia (Cohen-Mansfield, Golander, & Arnheim, 2000; Surr, 2006). Role expectations in LTC

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institutions present another challenge to the continuity of self – especially as many of today's care institutions still seem to share characteristics in common with Goffman's (1968) 'total institution':

A total institution may be defined as a place of residence and work where a large number of like-situated individuals cut off from the wider society for an appreciable period of time together lead an enclosed, formally administered round of life.

[Goffman, 1968, p.11]

LTC indeed is a place of both residence and work where people are traditionally cast in the roles of either patients or nurses. Some of the features of a total institution listed by Goffman (1968, p. 17) are closely reminiscent of everyday life in LTC. All aspects of life in LTC are conducted in the same place, many daily activities are carried out in the immediate company of others, activities are scheduled from above by a system of formal rulings, and the purpose of these activities is at least partly to fulfill the official aims of the institution.

Regardless of these total features, however, the institutions themselves take a very different view on their activities, emphasizing the person-centeredness of care (McCormack, 2004). Both public and private care providers are keen to stress that every aspect of the care they provide is tailored to the individual's needs, that they respect the individual's self-determination, and that they offer care in a home-like environment. Older people are seen as consumers of care to whom care providers need to sell their product (Tilly, Wiener, & Cuellar, 2000). In the United States the care of older people has been a lucrative business for some decades (Diamond, 1992), and it is now a burgeoning industry even in Nordic welfare states (Kröger, 2011). In the Discussion section we consider whether our findings could also provide an inexpensive way to enhance the well-being of LTC residents. In Finland, too, official guidelines emphasize that care provision should be person-centered (Ministry of Social Affairs & Health, 2008). However, as Eyers, Arber, Luff, Young, and Ellmers (2012) and Petriwskyj, Gibson, and Webby (2014) point out, rhetoric may be at odds with the reality of LTC. This poses a significant challenge to person-centered care (Brooker, 2003; Eyers et al., 2012) and gives rise to constant tension between the practice and ideals of care.

This tension may be conceptualized in terms of recognition. Philosophical theories of recognition, as presented by Axel Honneth (2005; 2012) and others, deal with people's relationship to the self, others, and institutions. The core idea of theories of recognition is that people's personhood in a philosophical sense may only be sustained when it is recognized by other people (Honneth, 2012, pp. 204–214; Laitinen, 2002; Ringmar, 2012, pp. 3–7). Our existence as individuals depends on whether other people recognize us as persons and treat us accordingly. Therefore, philosophical recognition is both cognition and action. Older people in LTC, for example, may remain persons only when they are recognized as persons and treated accordingly by staff members. Recognition may also be seen as an institutional action (Honneth, 2012, pp. 56–74; Ringmar, 2012, pp. 3–26). Care institutions necessarily recognize their 'customers' in one way or another, and this recognition is manifested in their daily practices.

In the LTC context, Laitinen's (2002, p. 475) idea that recognition has two distinct powers is particularly interesting. On the one hand, recognition may *generate* objects. When older people move into an LTC facility, the institution's and its staff's practices may begin to create an identity for these people as an inmate or a patient. Recognition may generate roles through role expectations. On the other hand, recognition has the power to *maintain* objects. This means that recognition has the power to sustain older people's life-long identity. When John moves into an LTC facility, he might be recognized, not as an inmate, but as John whose wife still lives at home, who has children and grandchildren, who used to be a bus driver, who likes folk music, and so on. He just happens to live in a sheltered home now. Recognition thus matters: being an inmate is different from being John. It is important for older people to be able to sustain a coherent worldview that takes both past and present into account (Hoogland, 2015). In Honneth's (2005) words, the whole social world might be seen as a struggle for recognition. In LTC, the struggle for recognition might be seen as a struggle for the continuity of self in a world of power relations, reliance, vulnerability, and contrasts between good intentions and limited resources.

By conducting an ethnographic study in an LTC context, our aim is to identify daily practices and interactions that support or challenge older people's continuity of self. The concept of recognition, in terms of recognizing persons, provides us with an instrument with which to approach various daily situations and practices. Recognition highlights that continuity of self is an interactional phenomenon in LTC, since it is both cognition and action by nature. Thus, daily practices and interactions matter. By emphasizing recognition, we wish to give older people living in LTC the possibility for *building up a home* instead of *breaking up a home*.

Ethnographic research frame

Data collection

The first author (JP) gathered the data through observations in a geriatric hospital and a sheltered home in Southern Finland and through interviews with residents in the latter in 2013–2014. The hospital provided care for community-dwelling people who needed short-term rehabilitation and then returned home. In reality, however, there were many older persons in the hospital who no longer were able to return to their homes and who were waiting for a place in a nursing home or a sheltered home. Some of them had been in hospital for more than a year, so they de facto were LTC residents. One of the wards was entirely devoted to people waiting for permanent placement in a care facility, so this was where JP spent most of his time. The observations in hospital took place over 24 days, totaling 87.5 h.

The sheltered home consisted of eight separate group homes in two buildings. Each group home had 9–15 residents, the total number amounting to 114 people. It was called sheltered housing since the residents had their own rooms for which they paid a rent. They also paid separately for care, medication, and food. In addition to their own rooms, residents in each group home had the use of a day room and a sauna. Assistance from staff was available round-the-clock. JP spent 165 h in the sheltered home, concentrating on making

observations in one group home of 15 residents. On one occasion he stayed in a vacant resident's room for two nights in order to familiarize himself with the research surroundings. In both the hospital and the sheltered home, participant observation consisted of being around, observing everyday life, taking part in recreational activities and talking to patients, relatives, and staff members. In the sheltered home, JP also helped with tasks that voluntary workers are allowed to do, like feeding people and helping staff to move them.

Participant observation is a suitable method for gaining an in-depth understanding of a particular phenomenon (Geertz, 1973; Hammersley & Atkinson, 2007; Snow, Morrill, & Anderson, 2003). It is especially useful for purposes of exploring an institution from within, in order to see it from the viewpoint of daily practitioners (Diamond, 1992, pp. 3–9; Gubrium, 1997, pp. xxi–xxiii). In our case participant observation revealed nuances in daily life in LTC that would not have come to light in interviews alone (cf. Clark & Bowling, 1990). For example, our interview data include no references to how staff members sometimes ignore residents' requests by an automatic 'in a minute' answer, but the observations showed that this was quite common. JP used a method called 'jotting' (Emerson, Fretz, & Shaw, 1995), using key words to make short notes during observation. Immediately after the observations he then used these notes to type up more detailed accounts of different situations in order to get as rich data as possible.

In addition, JP made 10 interviews with residents in a sheltered home. He asked the staff to nominate 10 candidates (out of the whole home of 114 residents) who would be able to give an informed consent for an interview. A team of two head nurses and a practical nurse indicated 10 residents (six women and four men), who all agreed and gave their informed consent. The level of their functional ability varied: three residents could not move independently from their beds and one moved without any assistive devices, sometimes pushing other residents in a wheelchair outdoors. Before every interview, JP informed the participating residents about the research and reminded them that they would be anonymous in the data. He also made it clear that the interviewees could withdraw at any time and that they did not have to answer questions they did not want to. JP conducted semi-structured focused interviews in which the themes revolved around daily life in LTC. JP recorded the interviews, which lasted from 25 to 65 min. The interviews were then transcribed verbatim.

Data analysis

A transcript of the tapes and a fair copy of the observation notes (totaling 360 pages) were analyzed with qualitative content analysis (Morgan, 1993). First, JP read through the entire material three times to immerse himself in the data. He then used directed content analysis (Hsieh & Shannon, 2005) to categorize the data by focusing on extracts which referred to situations related to recognizing and misrecognizing persons. These episodes illustrated different forms of resident-staff interaction, and some of them dealt with LTC routines and practices. A common thread running through these episodes was that staff members or the institution's practices presupposed some perception of residents and their life in LTC. JP picked these extracts into a new document, which was then divided into two parts: one concentrating on daily practices in

LTC and another concentrating on residents' interaction with the staff. Once these extracts had been divided, the second author (IP) joined the analysis, with no prior knowledge of the data. This allowed us to achieve triangulation (Thurmond, 2001) by combining two forms of qualitative data and two researchers. In the joint analysis, we noticed that both LTC practices and interaction with staff had both institution-centered and person-centered features. Thus, the recognition-related extracts were again categorized independently by both researchers into these two groups: institution-centered and person-centered features. Lastly, we together formed five institution-centered and five person-centered features of LTC, which highlight the ways residents are either recognized or misrecognized as persons.

Ethical considerations

Research environments involving people with cognitive disorders require special ethical consideration and close adherence to best scientific practices (Hubbard, Tester, & Towns, 2003; Wilkinson, 2002). We had permission from the managers of both facilities to conduct observations. JP personally introduced our research to the staff members at their meetings, and placed an information letter on the noticeboard at the ward and group home. In addition, he introduced himself to everyone he met at the beginning of the observations.

Yet it was obvious that not all the older people in the hospital and the sheltered home understood that research was going on. However, we found support for our work from previous research. According to Bond and Corner (2001), theory-driven pluralistic approaches to research method, like ours, helps people with dementia to participate in research by emphasizing personhood. Incapable people have the right to participate in improving their living conditions. We also had the ethical approval of the local hospital district's Ethics Committee.

Standard treatments breaking up a home

Based on our analysis, five features of LTC hampered older people from being seen as persons. We identified these features as: invisibility, staff timetables, standard treatment, dominant role of documents, and shifting responsibility. The findings are illustrated below by extracts from observations and interviews. All the names appearing in the extracts are pseudonyms.

She tells me that she is happy with the ward she is now staying on. The earlier ward wasn't as good. I asked her why, and she replied that they didn't greet people there. Nobody said good morning or good night. (Field notes from the hospital)

In this extract, JP was talking in the hospital with an older woman who made a distinction between a good ward and a bad ward on grounds of being greeted by staff. On her previous ward, persons were misrecognized in a fundamental way: if they are not greeted, people may feel that their existence is ignored. In the hospital, JP heard staff members constantly refer to patients by their bed and room numbers: 'The third one in number two needs to be washed.' Staff did use people's names when talking to them directly, but referring to people by numbers is clearly an institution-centered feature (Goffman,

1968). JP also observed incidents where older persons were seeking the attention of a staff member, but all too often these attempts resulted in people not being recognized.

After lunch Anna asked the staff several times whether she could leave and go back to her room. A practical nurse replied that it's better you sit there a bit longer, so that you're not in your room all the time. Next, Anna got dismissive replies. Then one of the practical nurses said she will take her once she's cleared the table. She never did, but went on to do other tasks. (Field notes from the sheltered home)

These incidents usually occurred when immobile people wanted to get to their room or to the bathroom. Staff members often replied with repeated, automatic 'in a minute' answers. Sometimes people's requests were ignored altogether. As in Gubrium's (1997, p. 152) study, residents' requests were not necessarily heard, let alone taken seriously. It was almost as if residents were sometimes invisible. As the following extract illustrates, one obvious reason for *invisibility* was the *staff's timetables*.

A daughter of an 81-year-old resident, Ella, came to visit her mother in the afternoon, only to find that she had already been put to bed for the night.

Ella had been put to bed as early as 4.30 p.m., which was really sad. Her daughter went straightaway to the nurses to ask why her mother was in bed so early. The answer was that staff had arranged their work so that they could be sure everything was done by the end of their shift. So Ella was tucked in, wearing her nightdress, even though she had not yet had dinner. (Field notes from the sheltered home)

Putting older persons to bed early to accommodate staff needs appeared to be quite common in LTC, especially with people who were unable to speak for themselves. When people were put to bed, they stayed in bed all evening. It was more a rule than an exception that day rooms were empty of residents as early as 6 p.m. JP once asked a practical nurse why people were in their rooms even though the time was only 6 p.m. She told JP that according to research, older persons want to retire early in the evening. Individual needs were ignored by appealing to science. Residents' invisibility and the staff's timetables both resulted in *standard treatment* of people. Standard treatment may be seen as a failure to see older people as persons in LTC.

Our data included several notes like the following one.

During lunch one resident was unhappy with having been given too big a portion and rye bread, which she could not eat. I overheard her talking to herself or to someone else at the table about how she loses her appetite when the portion is too big. The staff always tell her to eat what she can and leave the rest. (Field notes from the sheltered home)

For some people it makes a big difference whether they get just the right size of portion or too big a portion with the advice 'eat what you can and leave the rest.' JP heard the woman of the previous extract telling staff members several times that she'd always like to have a small portion of food and half a slice of white bread. Yet for whatever reason, this was ignored time

and time again. Another person told JP that he was angered every time he was served too big a portion since he had experienced the poverty of the post-war years and it was an impossible idea for him to waste food. He could leave nothing on his plate.

An extreme form of standard treatment was a phenomenon we call *the dominant role of documents*. In the following interview extract a male resident describes an incident that happened when he moved to a geriatric hospital to wait for a permanent place in a care facility.

Resident: I was given a single room there and I moved in and then on the first Monday a doctor came in to see me and said: Good morning. So you're the so-called end-of-life-care patient.

JP: Aha!

Resident: I looked the doctor straight in the eye and if I'd been in a different mood I would have punched him in the face. I said to him I'm sorry doctor but it seems you've got the wrong patient, I'm definitely not yet at the stage of being an end-of-life-care patient. And the doctor just nodded and said: "Well, we'll talk about this some other time," and off he went. The next morning he came back to my room and shook my hand and apologized, saying that you were right all along, I'd been reading another patient's papers.

This kind of dominant role of documents in LTC tends to prevent staff from seeing older people as persons. Gubrium (1997, 65–82) reported how care decisions were sometimes made strictly on the basis of documents, without even seeing the person concerned. In the extract above, the man in question was seen but not heard. Even though the doctor was seeing the man for the first time, he chose to believe the (wrong) documents he had read rather than an older person who insisted that there had been a mistake. In acute health care it is understandable that health information and case histories are constantly at hand and that they have a significant role in deciding on treatments. However, LTC for older people, and sheltered housing in particular, is primarily about something other than health care. As Eyers et al. (2012, p. 74) point out, a care home is not a clinical environment. Yet in the sheltered home JP observed many practices directly imported from hospitals.

On one occasion, for example, a resident's daughter asked to see her mother's list of medications. A nurse said that she will check on the computer whether the mother has given authorization for staff to pass on her particulars to relatives. The daughter replied that they could both go to her mother's room right then and there to ask. Later the same evening, JP asked the daughter whether she had got the list she had wanted, but she had not. The mother had told the nurse that it is okay to give the list to her daughter, but in the end the nurse decided not to do so because she couldn't find the confirmation she needed on the computer. The computer overrode the individual person's will. JP observed on several occasions how visiting relatives asked staff members how their loved one was doing, only to hear the reply 'I'll have to check on the computer.'

The dominant role of documents might sometimes conflict with self-determination, as in the case of the medication list. The right to self-determination is enshrined in all the laws and recommendations regarding social and health affairs in Finland (Finlex, 2010, 2012; Ministry of Social Affairs & Health, 2008).

Sometimes, however, the emphasis on self-determination may be taken too far in LTC, where many people suffer from cognitive disorders, and results in *shifting responsibility* for making choices to people who do not have the mental capacity to make them. JP observed incidents where the emphasis on self-determination seemed to lead to abandonment-like situations. Sometimes it seemed to serve the interests of the institution or staff members rather than the resident. For example, some residents needed to be fed by staff, and some of them were really slow eaters. In his capacity as a participant observer, JP helped with feeding residents on several occasions during the research. Sometimes it took him up to 30–45 min to feed a person, even though he is a trained practical nurse himself. He witnessed several instances where a staff member decided after a few minutes of feeding that this slow eater does not want to eat anymore, and took the plate away. These older people were usually unable to speak for themselves. By making the statement out loud that this person did not want to eat anymore, the staff member absolved herself from responsibility for that person's nutrition, and misplaced it in the hands of a vulnerable person.

JP witnessed another self-determination-related incident in a resident's room in the presence of the resident, her daughter, and a doctor. The resident was suffering from a severe somatic disease and dementia and was recovering from pneumonia. She was extremely weak and unconscious. It had been a long time since she had had something to drink or eat, so the daughter asked the doctor to put her mother on a drip. The resident had not made a living will. The doctor seemed reluctant to use a drip so she tapped the resident on her cheeks for a while and asked several times whether she would be uncomfortable with the drip, even though it was obvious that the resident would not be able to answer. In LTC, the dividing line between self-determination and abandonment is sometimes difficult to define: a person-centered feature (self-determination) may actually be converted into an institution-centered feature (making decisions on behalf of someone else). There is a difference between making decisions on someone's behalf and taking responsibility for that person. However, it is essential to support older persons' independent decision-making as long as possible, even when they are diagnosed with illnesses like dementia (Fetherstonhaugh, Tarzia, & Nay, 2013).

Our findings illustrated that daily life in LTC indeed involved several institution-centered features that took precedence over residents' personal needs and wishes. Some daily practices, such as staff's timetables and the dominant role of documents, worked against the recognition of residents as persons. Some features of resident-staff interaction had the same effect. Persons were misrecognized when they were not greeted, they were given standard treatment without acknowledging their own will, or when responsibility was misplaced into their incompetent hands. However, life in LTC is not all gloom and doom. The following section introduces our findings that illustrate person-centered features of daily life in an institution.

Building up a home; joking, arguing, and drinking small beer

We identified five features of LTC through which older people were recognized as persons and which supported the

continuity of their self. These features were: privacy, continuing habits, arguing, humor, and active emphasis on residents' wishes.

In the sheltered home residents had their own rooms, which was greatly appreciated, as is clear from the following interview extract:

Resident: It was just wonderful when I moved in from there (hospital) and I could be all on my own, just as I pleased here in my room, by myself, even though I had a nice room-mate there (in hospital).

This woman suffered from a severe somatic disease which made her completely dependent on other people. She could not get out of bed without help, and yet she was happy to be alone in her room. In this extract she makes an interesting comparison with her earlier situation. When she was in hospital, on the waiting list for a permanent place in a care facility, she shared a room with a 90-year-old woman who became her friend. In fact, this previous room-mate visited her in the sheltered home several times after she moved in. However, the interviewee felt happier alone in her room rather than sharing one, even with a good friend.

This same view was expressed by several interviewees: having one's own room was seen as crucial to self-determination due to the sense of *privacy* it afforded. Cognitively capable residents were allowed to keep their doors locked to prevent cognitively disordered people from entering their rooms. One male resident said he had denied staff the right to enter his room during the night because 'I pay a rent for my room and since I live here alone, I don't want anybody to barge in on their own.' Residents furnished their rooms with their own furniture and mainly wore their own clothes. It became clear that the sense of continuity of self was partly based on privacy.

In addition to privacy, the continuity of self was also supported by *continuing life-long habits*.

Residents had taken sauna yesterday and today. Hanna was very pleased that she had been able to go to sauna after such a long time. She happily enjoyed some small beer afterwards (Field notes from the sheltered home).

For most Finns, going to sauna is not just about bathing and cleaning, but also and importantly a weekly ritual. Sauna is a place for relaxation and socialization (Edelsward, 1991; Hänninen, 1986). The woman in the extract above had been in hospital for a while, waiting for a place in a care facility, and there were no sauna facilities in the hospital. Therefore she was delighted to be able to revert to her life-long custom, indeed she had cried of joy after sauna. When living in a sheltered home, people were able to pick up many of their earlier customs: to visit their children's homes and summer cottages, to enjoy a glass of cognac, to smoke a cigar on a balcony, to do handicrafts, and so on. As Boelsma, Baur, Woelders, and Abma (2014) reported, these kinds of 'small' things mattered a great deal to people in LTC. Furthermore, as Gubrium (1997, pp. 90–106) noted, keeping in touch with friends and relatives was important for the continuity of self.

Having privacy and continuing life-long customs are practice-based ways of recognizing residents as persons. Other ways were related to interaction with staff. In the

interview extract below, JP asked a male resident whether he felt he can do what he wants in the sheltered home.

Resident: Well, so far there have been no real issues with the nurses. A couple of nurses have been a bit like awkward, but otherwise this has been pretty much like living in my own studio.

This man was fairly happy with his situation. There had been some difficulties and arguments with some members of the staff, but he considered this quite normal. *Arguing* might be seen as a type of recognition, since ‘it takes two to tango.’ When a resident argues with staff, this may be read as a sign of the continuity of self and an attempt to protect one’s own values.

Another way of ‘getting onto the same wavelength’ with staff was through *humor*. According to previous research, humor has a positive impact on care relationships (Åstedt-Kurki, Isola, Tammentie, & Kerminen, 2001), and it reduces anxiety and depression in LTC for older people (Houston, McKee, Carroll, & Marsh, 1998). The following observational extract from hospital is illustrative.

A male patient goes to the cafeteria downstairs to buy some buns, taking his wheelchair. A practical nurse opens the door and they joke about him getting lost and the staff having to go to look for him. The man continues the joking when he returns after a while. He is obviously in a good mood (Field notes from the hospital).

Humor plays a significant role here. The man needed help to leave the ward since the door was always locked and opened with a code. Procedure prevented cognitively disabled persons from wandering off on their own. Yet this man was cognitively highly capable and had permission to leave the ward alone. Joking about losing his way serves to emphasize his cognitive abilities. At the same time, this shifts the attention away from the fact that his legs were amputated and that he needed help to get past the door.

Some staff members indeed *actively emphasized residents’ wishes*. Here is an extract from the sheltered home about how a practical nurse actively gave precedence to residents’ needs over everything else. JP was playing a board game with residents in the day room.

When we were playing, one of the practical nurses from the night shift made us milk shakes. He also said that in the future, he could order some popcorn for when we were playing. That’s a good idea. We really enjoyed ourselves, playing in a large group, and having our shakes. At one stage I asked the practical nurse if we still had time for one more round before their evening duties. He replied: “Absolutely, the game on Saturday night is much more important than anything else.” (Field notes from the sheltered house)

The practical nurse in question recognized the residents by appreciating their need for leisure time, and at the same time supported the continuity of their self by emphasizing the casual nature of Saturday nights. He gave the impression that life goes on in the sheltered home in the same way as anywhere else. He also explicitly stated that older persons’ needs should take precedence over the institution’s needs.

In conclusion, having privacy and continuing life-long customs were person-centered features of LTC which had their origin in daily practices. The staff supported residents’ recognition as persons by joking and arguing with them and by actively emphasizing residents’ wishes.

Discussion

There is a rich body of data about daily life and its practices and interactions in LTC. Daily life has been studied particularly from the perspectives of residents’ quality of life (Clark & Bowling, 1990; Houston et al., 1998) and their autonomy in LTC settings (Fetherstonhaugh et al., 2013; Snow, Morrill, & Anderson, 2003). Sometimes the focus has been turned on resident-staff interaction (Hubbard, Tester, & Downs, 2003; Martela, 2012). The continuity of self has previously been studied in connection with dementia (Cohen-Mansfield et al., 2000; Kitwood, 1997; Surr, 2006). In this article, we have approached daily life in LTC from a philosophical viewpoint, combining daily practices, interaction and continuity of residents’ selves.

The key finding of this study is that daily practices and interactions in LTC produce both recognition and misrecognition of older people as persons. The daily practices of an institution can be categorized based on their aims. On the one hand, some of these practices aim to fulfill the purposes of an institution, as Goffman (1968, p. 17) pointed out. In order to be functional, institutions need to have procedures, practices, routines, and rules (Eyers et al., 2012). In a world of limited resources and austerity, everything needs to be practical and efficient. LTC, however, is about taking care of people, so everything cannot be dictated by requirements of efficiency. LTC is driven by humane concerns as well. As the law in Finland states, “long-term care and attention must be provided so that the older person can feel that he or she is living a safe, meaningful and dignified life and can maintain social contacts and participate in meaningful activities promoting and maintaining his or her wellbeing, health and functional capacity” (Finlex, 2012, p. 5). Thus, a care-providing institution has to be both efficient and humane, which creates tension with respect to recognizing older people as persons.

This tension between institutions and individuals can best be reduced by nursing staff. At best, staff can act as an ethical buffer between the institution’s and the older person’s individual needs. Based on their study of resident-staff interaction, Fjær and Vabø (2013) called a similar phenomenon ‘shaping social situations.’ Skilled nursing staff have the ability to steer social situations in a direction that residents will find more comforting. No institution can function properly without practices, but staff can ensure those practices are respectful of residents. Staff also have a more straightforward role than that of a buffer. Theories of recognition (Laitinen, 2002; Ringmar, 2012, pp. 3–7) have it that people can create and maintain positive identities only in relation to their ‘significant others,’ which usually are family members. In LTC, this identity-supporting role is taken over by staff members. ‘Casting’ makes a difference at the stage of LTC: staff should recognize people as persons instead of forcing them into the roles of inmates or patients (Hubbard et al., 2003). Our findings lend support to previous research suggesting that staff attitudes toward older people have a major impact on life satisfaction in

care settings (Gallagher, Bennett, & Halford, 2006; Scott et al., 2002).

One way to conceptualize interrelationships between daily practices and staff in LTC follows from the ideas of philosopher Avishai Margalit (1998) about the decency of societies and the non-humiliation of citizens. In a decent society, Margalit says, institutions do not humiliate people, and in a civilized society people do not humiliate one another. Rephrasing Margalit, we could make a distinction between decent and civilized features of daily life in care facilities. Practices are decent when they are based on the resident's rather than the institution's needs. Since care institutions have to run an efficient operation, some of their practices will inevitably infringe upon residents' individuality. In these cases staff could, however, carry out the institution's practices in a civilized manner. A good example in our findings is provided by the incident where the practical nurse opened the ward's locked doors to let out a man who wanted go down to the cafeteria. The locked doors restricted people's freedom of movement, but this obstacle was handled in a civilized way; the man passed through the doors laughing.

According to previous research (Kitwood, 1997; Nolan, Davies, Brown, Keady, & Nolan, 2004; Packer, 2000), person-centered care emphasizes the (rational) individual's autonomy. In LTC contexts, however, many people have cognitive disorders. Our findings suggest that an overemphasis on self-determination may lead to abandonment-like situations. 'Person-centeredness' calls the individual into play, making person-centered care suitable for people who are capable of self-determination and taking responsibility for themselves. In the case of people with cognitive disorders, one plausible solution might be provided by 'person-sensitive care,' which shifts the responsibility from an incapable person to other people around, while at once acknowledging the person's own needs and opinions as far as possible.

Person-sensitiveness arises from the theory of recognition. According to Laitinen (2009), recognition can be defined in narrow or broad terms depending on the recognized object. In a narrow definition, recognition can only actualize when the recognized understands that he or she has been recognized by someone. This is often not the case in LTC, so the strict definition of recognition fails. A broader definition, which Laitinen (*ibid.*, p. 324) calls 'adequate recognition,' suggests that recognition actualizes when someone recognizes normatively relevant features in another individual and treats that individual accordingly. Normatively relevant features are those that direct our attitudes, such as being a sentient being, being capable of pain and pleasure, being an agent, having merits or achievements, having a personal history, and so on. These features call for responses, that is, treating the subject accordingly. Thus, adequate recognition may require assuming responsibility. In LTC, when staff members see that an older person is unable to assume responsibility for herself, they will recognize this person by taking over responsibility. Person-sensitiveness in LTC means that, on the one hand, daily practices are constructed and carried out in a manner that supports individuality. On the other hand, person-sensitive care shifts the responsibility away from vulnerable persons; staff need to be sensitive about residents' normatively relevant features and treat them accordingly.

Based on our findings, recognizing older people as persons in LTC would support the continuity of their self when self is

understood both as cognition and action. In cases where the self is challenged by cognitive disorders, recognition supports people's continuity of being individual human beings till the end of their days. And, best of all, recognition does not always require any financial investment. Recognition can be supported by administrative actions. JP once asked one of the head nurses why her nursing staff were all the time moving between group homes, even though previous research has shown (Marventano et al., 2015) that it would be better for people with dementia to see familiar faces around them. She said that it would be more difficult for her to make rotas if she tried to keep the same nurses and practical nurses at the same location all the time. Rotas were based on the interests of administration, not on the interests of residents. Administration can make a difference to recognition, too. Many improvements in daily life would also be free of charge. On an organizational level, a sheltered home may support recognition by securing privacy, supporting the continuity of life-long customs, and reducing the dominant role of documentation. On an individual level, greeting people, showing an interest in them as individuals, joking and perhaps even arguing with them would support their recognition and thus the continuity of their self without any additional costs.

Highlighting recognition easily leads to overemphasizing the staff's role, especially of those conducting bed and body work. As Sherwin and Winsby (2010) remind, care facilities operate with budgets that are far less than what ideal care demands and they are short staffed with minimally trained workers. In our study, this was shown especially as residents' standard treatment and compelling timetables of the staff. Adding resources would add to residents' recognition for example by providing the staff more time to spend with them. Structural limitations may prevent staff members from conducting their work according to their best knowledge, which may lead to moral distress (Burston & Tuckett, 2013).

The limitations of this study arise from the method employed. We chose to study two municipally run LTC facilities, yet there is a wide range of care institutions in Finland. LTC is provided by municipalities, private companies, associations, and foundations in hospitals, health centers, nursing homes, sheltered homes, and at private homes. Our findings cannot be generalized to all LTC settings. At the same time, though, the strength of this study also arises from the method employed. We were able to cross-check JP's observations with his interviews and vice versa, which adds to the reliability of the data. Using the concept of recognition as a theoretical framework helped us to focus our analysis on the continuity of self, which increases the validity of findings. Although our findings cannot be generalized as such, this study revealed universal mechanisms regarding the recognition of older people's personhood in LTC. Our findings can be generalized theoretically.

Our findings might be utilized by care providers to improve residents' prerequisites for living a satisfactory life in LTC settings. There already exists several structured tools that are used to capture whether older people's preferences are respected in providing LTC, such as the PELI or MDS3.0 (Van Haitsma et al., 2012). These assessments include wide range of questions for older people to find out their preferences regarding several life domains, which care providers then may use to promote person-centered care. As useful as these assessments are, our findings might add to their validity. As

van Haitsma et al. (ibid.) point out, present preference domains reflect professional gerontologists' rather than older people's perceptions about good life. Older people's own voice might be listened more attentively through qualitative studies like ours. Furthermore, present assessments appear as lists of *activities* older people could choose. Structured tools might be developed to better capture preferable features of *being* in addition to *doing*, since for example joking and arguing are features of expressing oneself. Assessments might improve also by acknowledging the importance of consistency. Separate choices become meaningful only if they are consistent with a person's trajectory. As our article shows, continuing habits, as such, are important for LTC residents' identity. Based on our findings, respecting older people's preferences requires recognizing them as persons.

Conclusion

Critical and philosophical analysis of mundane phenomena allows us to see things from new perspectives. In this article, LTC for older people was analyzed based on a philosophical reading of the concept of recognition. Our analysis showed that both recognition and misrecognition of persons occur in LTC settings today. However, recognition is coincidental: it is not a conscious principle guiding daily practices and interactions. Misrecognition also seems to be unintentional, as in most cases it arises from daily practices that are uncritically transferred from acute health care settings into LTC. Based on this study we suggest that the philosophy of recognition be included in the ethics curriculum for all future LTC professionals, and we urge all managers of LTC facilities today to consider recognizing their residents. We believe that it is possible to support *building up a home* by older persons in LTC.

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Ruptures of affiliation: social isolation in assisted living for older people

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ABSTRACT

Transfer from a private home to an assisted living facility has been pictured as a major change in an older person's life. Older people themselves tend to perceive the change as something eventual that breaks the bonds and familiarities of previous life. The aim of this article is to shed light on residents' chances to reach affiliation (as Nussbaum defines it) in their new living surroundings, and thus adjust to that social environment. Based on ethnographical data gathered in a Finnish sheltered home in 2013–14, we studied residents' affiliations through ruptures, namely residents' perceived social isolation. Social isolation was found to be connected with two separate social worlds: the one inside the facility and the one outside. Social isolation resulted from different factors connected to the quality of social interaction with co-residents and the staff, daily routines of the institution and residents' personal life histories. Also, residents' older friends seemed to avoid visiting care facilities which caused perceived social isolation. This article deepens the insights into the perceived social isolation of assisted living and thus helps care providers to create new strategies to enable due affiliation for their residents.

KEY WORDS—social isolation, affiliation, assisted living, older people, ethnography.

Introduction

Studies show that social isolation has demonstrable negative effects on health, wellbeing and quality of life for older people. Increased risk of mortality (Eng *et al.* 2002; Steptoe *et al.* 2013), heightened propensity for dementia (Fratiglioni, Paillard-Borg and Winblad 2004), an increased number of falls (Faulkner *et al.* 2003) and increased risk for depression (Cornwell and Waite 2009) have been found. These health issues add pressure to statutory health and social care services, and contribute to their costs

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(Devine *et al.* 2014). Much research has focused on social isolation experienced among community-dwellers (*e.g.* Nicholson 2012; Savikko 2008; Victor, Scambler and Bond 2009). However, it is known that social isolation is also present in residential care facilities (*e.g.* Brownie and Horstmannshof 2011; Drageset, Kirkevold and Espehaug 2011). Some studies have found social isolation to be more common among assisted living (AL) residents than among older people living alone (Pinguart and Sorensen 2001; Savikko *et al.* 2005), which has led to growing literature regarding the importance of social relationships in AL.

Transfer into an AL facility has generally been seen as a risk factor for ruptures in social engagement *per se* (Johnson 1996; Prieto-Flores *et al.* 2011; Street *et al.* 2007). Gubrium (1997) describes the transfer from the private home to a care facility as the process of ‘breaking up a home’, wherein people draw constant comparisons between their past and current lives. They are still attached to people, places, belongings and memorable events from the past, although they do understand that life cannot continue the same way it had earlier. Residents’ contacts with friends, relatives and neighbours significantly decrease after transfer into a care facility (Port *et al.* 2001), and relationships become less intimate at the same time (Lindgren and Murphy 2002). Sinclair, Swan and Pearson (2007) have drawn attention to the ‘separateness’ of care homes, which can produce feelings of being ‘cut off or remote’ from society (Victor, Scambler and Bond 2009: 206–7).

In addition to lack of contacts outside, relationships with the staff may be task-oriented, with little support given to residents’ psychological needs (Marquis 2002). Further, limited time resources and constant turnover of staff have been seen as preventing any real resident–staff bonding (Grenade and Boldy 2008). While some studies have portrayed connections with peers in a facility (Fessman and Lester 2000) or the role of people outside the facility (Burge and Street 2010) as very important to prevent social isolation, others have emphasised the role of the staff, especially when residents have significantly lost their functional abilities (Drageset 2004). Roos and Malan (2012) also found that older people with the capacity to establish meaningful relationships experienced the care facility as unsafe and lacking in care, which limited effective interpersonal relationships.

Perceived social isolation and affiliation

Social isolation is often regarded as an objective and quantifiable reflection of the paucity of one’s social contacts and reduced size of the social network (*e.g.* Nicholson 2012; Steptoe *et al.* 2013); however, it can also be

understood and addressed as a subjective experience. Robert Weiss (1973) has referred to social isolation as a lack of a sense of belonging or dissatisfaction towards one's social network. Victor, Scambler and Bond (2009) define social isolation as a lack of communion between individuals, and detachment from the socio-spatial context of daily life, highlighting the spatial elements of social isolation (*see also* Sinclair, Swan and Pearson 2007). On the other hand, Brownie and Horstmanshof (2011) picture loneliness in the context of residential care as an imbalance in one's actual and desired social worlds. When social isolation is seen as a sense of not belonging (Weiss 1973), a lack of communion (Victor, Scambler and Bond 2009), and loneliness in AL as an imbalance in one's actual and desired social worlds (Brownie and Horstmanshof 2011), we suggest that what we should be looking for in AL is *perceived social isolation*. The concept of perceived social isolation acknowledges its objective and subjective natures – it is an experience linked to one's situation and surroundings.

In this article, we explore perceived social isolation as ruptures of affiliation utilising Victor, Scambler and Bond's (2009) conceptualisation of social isolation and Nussbaum's (2007, 2011) concept of affiliation, which can be described as a two-dimensional capability. Firstly, affiliation entails 'being able to live with and toward others, to recognize and show concern for other human beings, to engage in various forms of social interaction, and to be able to imagine the situation of another' (Nussbaum 2011: 34). Since older people reside in AL full time, they should feel like members of a community, living 'with and towards' others. Secondly, affiliation is about 'having the social bases of self-respect and non-humiliation and being able to be treated as a dignified being whose worth is equal to that of others' (Nussbaum 2011: 34). This second precondition of affiliation presupposes that residents may keep the social basis of their self-respect while residing in a facility; namely their prior social connections remain despite the transfer to AL. We argue that affiliation is not something that people simply have or have not, but the sense of affiliation can vary, depending on the level and quality of social embeddedness both inside and outside the AL facility. Perceived social isolation thus reduces affiliation.

Based on ethnographical data, we explore older people's perceived social isolation, which is pictured as ruptures regarding affiliation. We aim to grasp the possibilities for and barriers against affiliation in a context where one is physically close to others, yet at risk of feeling separated from the everyday social environment as well as from the relationships formed before the transfer to AL. We ask how the experiences of social isolation are embedded in the social context and structure of the AL environment, and examine the opportunities of conceptualising and addressing perceived social isolation as ruptures in affiliation. The results offer important knowledge on the

diverse and socially constructed experiences of social isolation, which are needed before effective intervention policies and preventative strategies in AL can be developed.

Materials and methods

The data were collected within an ethnographic research frame by observing daily life and interviewing residents in a sheltered home in southern Finland in 2013–14. Sheltered housing is a form of AL in Finland, ideologically located somewhere between institutional and home care. Residents lived in private rooms for which they paid rent; food, care, medicine and safety service were charged separately. The rooms were furnished with residents' own belongings, and residents wore their own clothing. The goal was to provide as home-like a surrounding as possible. In addition to resident rooms, there were shared living rooms, balconies and a sauna available for the residents.

The research site consisted of two five-storey buildings, including ten group homes. Two of the group homes were run by a private enterprise. We studied the publicly run section where 114 residents lived in eight group homes. The doors of the group homes were always locked and opened with a five-number code to prevent cognitively disordered residents from wandering off on their own. Thus, the residents' social contacts were largely limited to people inside their own group home. The only common space for all the residents was a small room for group activities and physical exercise, yet they could go there only when escorted by the staff.

The majority (about 70 per cent) of the residents were women, yet in each group home there were men and women living together. The residents' ages ranged from 60 to one 100-plus, and their functional abilities varied considerably. Most had cognitive illnesses, such as different forms of dementia or Alzheimer's disease; some lived there for somatic reasons like multiple sclerosis or other chronic conditions. Therefore, their physical abilities varied from independently mobile to being bed-ridden, and their cognitive and therefore communicative capabilities also varied. Only a few of the 114 residents could go outside the home on their own.

The eight group homes were divided into three administrative units (two or three group homes per unit) run by a head nurse, and the staff circulated throughout the group homes of one unit. The staff were available at all times. Usually there were two practical nurses (per 15 residents) working both morning and evening shifts. In Finland, practical nurses locate professionally between registered nurses and nursing assistants. They complete a

three-year nursing programme and may, for example, hand out medicine and take care of wounds. In addition, there were several registered nurses, two physiotherapists and two leisure activity instructors working in the building. The latter organised group activities, such as pottering, and trips outside, such as visiting a marketplace nearby. Some nursing assistants helped with the kitchen work during meal times.

There were also some volunteer workers recruited by the local parish to keep residents company, take them outside and escort them outside the facility (*e.g.* when they went to a doctor located elsewhere). These volunteers usually came once a week or when they were called to escort someone. Residents' relatives and friends visited sporadically, and many residents had their own phones to keep in touch with them.

Participant observation was chosen as a research method to gain a deeper understanding of the research site (Geertz 1973; *see also* Diamond 1992; Gubrium 1997). It lasted two months and produced a total of 165 hours of observation by a single researcher (the first author). The observations were concentrated in one of the group homes, in which four men and 11 women lived. The researcher participated in daily living by talking to the residents and taking part in the recreational activities; he also participated in tasks available to volunteer workers, such as feeding people or moving them along with the staff. Short notes were written into a notebook during observations, and the lengthier descriptions were transcribed on a computer right after the observation sessions, employing a method called jotting (Emerson, Fretz and Shaw 1995).

Along with observation, ten thematic interviews were undertaken with the residents. The interviews lasted from 25 to 65 minutes and were transcribed verbatim. Thematic interviews (Fylan 2005) were conducted in order to give the interviewees a chance to describe their own experiences openly. The themes of the interviews were broad-based to allow for a study of the multiple phenomena related to life in AL. The themes were formed around residents' pasts, their perceptions of the sheltered home as a living environment, the care they received and the course of their everyday lives. Residents were allowed to include other topics as they wished, yet were guided by the chosen themes. Referring to Hughes (1992: 444), 'I [we] did not simply ask the questions; the questions were asked when they were appropriate and when there was something to ask about'. Although certain themes were discussed, all the interviews were unique since questions were asked based on the situation. Perceived social isolation was thus not a particularly accentuated topic in the interviews, but we found the issue to be present in all the interviews when analysing the data.

Since most of the residents in the more closely observed group home suffered from cognitive illnesses, the staff were asked to nominate ten possible

interviewees out of a total of 114 residents. The risk of this procedure was that the staff could have nominated people who have the most positive views of the facility in which they live. However, the personnel were perceived as the most qualified to decide who were cognitively capable of giving informed consent and participating in an interview. Alongside this process, the study was prepared and conducted using thorough ethical consideration, as good scientific practice demands (Hammersley and Atkinson 2007; Wilkinson 2002). Both the ethical committee of the local hospital district and the manager of our research site approved the research plan.

The staff were informed of the research in several staff meetings, and the researcher told every person about it when meeting them for the first time on-site. In addition, information notices written in plain language were placed on notice boards. Despite these arrangements, not all the residents understood that there was a research study going on due to their severe cognitive illnesses. However, there is precise understanding that cognitively incapable people have the right to participate in research intended to improve their situation when that research does not cause them any harm (Finlex 1999).

The data were analysed using directed content analysis (Hsieh and Shannon 2005), seeking excerpts that referred to experiences of social isolation as described in previous research (*e.g.* Victor, Scambler and Bond 2009). In the first phase of the analysis, the first author who conducted the field study searched the data for references to social isolation, which was perceived in AL in multiple forms. People rarely talked about it as such, but residents missed people, places and activities from their past. They also described the difficulties they had regarding bonding with other people in the facility. Observational notes lent positive support to residents' accounts and also revealed new nuances of social isolation caused, for example, by staff timetables or physical features of the facility. In the first phase of the analysis, excerpts referring to social isolation were gathered from the main data.

In the second phase of the analysis, the data excerpts were categorised on the basis of reasons for feeling socially isolated. The first and second authors coded the data and the third author participated in interpreting the findings. Triangulation (Thurmond 2001) was achieved by combining two forms of qualitative data by three researchers. Eventually, two distinct categories were apparent: social isolation appeared as difficulties in connecting with people inside the facility and as separateness from the social world outside AL. We realised that reading the data in the light of prior conceptualisations (*e.g.* Victor, Scambler and Bond 2009) had brought us to Nussbaum's (2007, 2011) definition of affiliation. In our Results section, we thus examine our findings in relation to two distinct social worlds: the

one inside the facility and the one outside. All the names in excerpts highlighting the results are pseudonyms. ‘R’ stands for the researcher in interview excerpts.

Results

Detachment inside the AL facility

According to Nussbaum’s (2007, 2011) definition of affiliation, residents should be able to connect with other people on-site. In Finland, older people primarily enter the AL environment through the municipal authorities, who refer people to care facilities based on their needs and the spaces available. One can express a wish regarding the facility of choice, but in practice, people have to take the first vacancy to which they are appointed. This means that the person transferring to AL does not have an opportunity to choose his or her social surroundings, which eventually becomes his or her primary social world. The fact that residents cannot influence the composition of their primary social world sometimes results in feeling socially isolated.

One of the residents, Andy, felt out of place in his group home, where the majority of residents were female and much older than him. Just over a year before the interview, Andy had played up to five gigs per week in a dance band as a drummer. Then a somatic disease broke his health down quickly and considerably, and after a rather long stay in the hospital, he moved into the AL facility. Now Andy needed help in all his daily functions except for eating. During the interview, Andy referred to himself as a drummer, emphasising its importance in his social identity. Although Andy was 73, he described the other residents as *oldsters*, drawing a clear distinction between other residents and himself as a professional musician.

R: Well, so do you spend time anywhere else than in your room? Do you go to the common room to watch television?

Andy: Well I really can’t; you know I’m a musician, so normal people’s stuff just don’t work, you know...

R: Okay.

Andy: It just doesn’t work. They can’t deal with my stuff.

R: Okay. So do you miss the company of other people in here?

Andy: Well I do miss someone to talk to, but there’s no one on my wavelength here except for me – there’s no one like that.

R: Okay. I get it.

Andy: So it’s like talking to a wall. It’s really different for musicians than for normal people. (Male, 73, moving only with assistance)

There were recreational activities available, but Andy was not interested in being in the company of co-residents, since the company did not meet his

requirements. Elsewhere in the interview, he stated that ‘doing activities with damn bitches like that, bitches who are a hundred years old – there’s nothing to talk about you know, and we have nothing in common, so I feel like a hairy troll, fuck it’. Thus, he had chosen to spend time alone in his room. Perhaps the other residents did not even know about his background and his passion for music.

Another resident, Henry, implied being very different from the other residents. Most of the people living in Henry’s group home were cognitively disordered. Henry had asked the staff to keep his door locked to prevent co-residents from entering his room, in order to gain privacy. Furthermore, Henry indicated that he did not blame the other residents, since it was their illnesses that made them act inappropriately. Henry said that he sometimes helped the others, guiding them to their rooms and helping them get up from armchairs. However, he had only a few persons with whom he could really interact and engage.

R: Have you made friends with anyone? Nurses or other residents or...

Henry: Yeah, there are a couple of guys who still have their marbles left.

R: Yeah.

Henry: Some of them just stare out in space. Can’t really connect with them.

R: You mean some guys have some kind of memory disorders?

Henry: Memory disorders.

R: Yeah, then it’s kind of difficult to make contact.

Henry: No, it won’t work. Even when we were in the sauna with a couple of these guys, you can’t really have a decent conversation with them. (Male, 82, moving independently with a walker)

Other studies have provided evidence that Henry is not alone in his dilemma; the mix of high- and low-dependency residents within the same facility creates problems for both residents and staff (Roos and Malan 2012). However, when Henry was asked if people with dementia should not reside with cognitively capable people, he stated, ‘Well, they have to live somewhere, and it is probably cheaper that they live with us’. By referring to costs, Henry meant that in homes aimed solely for people with dementia, the staffing ratio would have to be higher. Like we saw, he often helped the confused ones himself. Sarah also said that she encouraged other residents to socialise, and Tim mentioned that he often pushed wheelchairs for other residents when they were exercising outdoors as a group. Paula stated that she could plan leisure activities for others if the staff encouraged her. It seems that mixing high- and low-dependency residents produces unused potential to both ease the workload of the staff and to provide low-dependency residents with meaningful activities.

Andy, Henry and Ida pictured social interaction with other co-residents as problematic, but the heterogeneity of the fellow residents was also

appreciated. The fact that there were both men and women living in this same group home suited Sally since she preferred the company of men. Sarah told us how she had decided to have conversations and would keep talking to other residents during meals until they began to answer. Eva and Judith became friends after they moved into the home. In one group home, there was even a short romance between residents. Making significant, emotional bonds with their peers seemed difficult but not impossible for these AL residents.

In addition to co-residents, the staff also played an important role in the social world of the older people residing in AL, especially when relations outside were rare, and cognitively capable co-residents were few and far between. However, a close relationship with the staff was not self-evident, as Paula implied:

Paula: Certain people – nurses and others – are close, but then there are those who barely remember my name.

R: I get it. So all nurses don't know your name nor what your individual needs are?

Paula: No, and they don't want to know. Some of them are like that. (Female, 85, moving independently with a walker)

Sometimes the residents' personal characteristics kept the staff distant. Andy, who indicated that he preferred to avoid the company of 'damn bitches', spoke about his relationship with the staff. He said that the nurses did not really know who he was and rarely came to talk with him, and if they did, it was something 'work-related'. Andy was quite a straightforward person, which may be the reason why the staff avoided, or at least appeared to avoid, contact with him. Andy described that he sometimes had to wait until 4 or 5 pm for the staff to help him go for a smoke on the balcony. During the interview, it was just past lunch time, and he was still waiting for a nurse to help him with his morning routines. Toby highlighted the importance of interacting with the staff. He related positive events in the home to attention given by the nurses: 'It's nice to sit with the nurses and talk and laugh about things with them when they are not busy working'.

The staffing ratio at the research site met the national recommendations on paper, but in reality, both residents and staff found it too low. Almost all of the interviewees implied that there were too few hands and help available. One commented that there was enough aid for her, but not for those with severe disabilities. Only one interviewee said that she was able to get all the help that she needed. However, residents felt sympathy for the staff. Sarah stated that 'they [staff] rush all the time and get exhausted. They don't show it, but I learned to see it on their faces that they become tired'. Paula said

that she did not ask for an escort to get outside since she felt sorry for the overworked staff, who mentioned themselves that their resources covered only basic care.

Many of the residents were not able to get out of bed independently, so the minimal staffing ratio resulted in being helped out of bed only once a day, usually for lunch. This meant that these residents stayed alone in their room for most of the day. Furthermore, as the staff members had stated, their time was directed towards basic care. Many said that they were sorry about this policy because they would have preferred to spend more personal time with residents. The maxim of keeping the staffing ratio to a minimum came from the economics of staffing, but it had negative influences on the wellbeing of both the residents and the staff. At our research site, residents had fewer social contacts and the staff felt moral distress when they felt they could not perform their work as well as they wanted (*cf.* Corley 2002). Some other procedures, such as serving supper in residential rooms instead of eating together in the dining room, lessened social contacts as well.

According to previous research (Roos and Malan 2002), AL residents are not exposed enough to activities that could facilitate the establishment of interpersonal relationships. In our research site, there were common activities for residents available only when there were outsiders (like an activity instructor or physiotherapist) in the home. In addition, Paula told us she missed the daily chores in her private home, stating that ‘one does not cook or fry in here’. Laura also once wondered why there was not work available for her in the home. It seemed that providing residents with opportunities to take part in daily chores would have been an efficient way to involve residents in social interaction. In addition to participation in daily chores, prior research has emphasised the importance of giving the residents a voice regarding how residential settings should be organised and managed (Abbott, Fisk and Forward 2000).

Separateness from the social world outside AL

Nussbaum’s (2011: 34) second precondition for affiliation was about ‘having the social bases of self-respect and non-humiliation and being able to be treated as a dignified being whose worth is equal to that of others’. As we pointed out in the introduction, transfer to a care facility is often perceived as a rupture in social engagement *per se* (Gubrium 1997; Johnson 1996; Prieto-Flores *et al.* 2011; Street *et al.* 2007). According to previous research (Gubrium 1997) and observations made in this study, relatives and friends visiting the facility have a significant impact on the social embeddedness of older people living in AL. Visitors improved the residents’

status in the eyes of other people living there, which became evident during interviews like Ira's. After the researcher had shut off the recorder, Ira said, 'You did not ask the most important question – do your relatives visit you often?' The researcher turned the recorder on again and asked her that question; Ira proudly stated that her daughter had visited just last week and was coming again in the current week; her son visited with his family and even her son's parents-in-law visited sometimes. It was important for her to feel that she was still part of the family while residing in AL.

Our results lend support to the prior understanding (Zimmerman *et al.* 2005) that older people avoid becoming a burden to other people, especially their close family members. Ida had a cell phone to call her son. She had lived in the home for eight months, but had never called, although she obviously missed her son, stating that 'I only have one son and he's got his own family and they've got their own lives, so I'm really lonely'. She understood her son's situation with his own family and did not seek his attention for herself. It appears that Ida chose the experience of social isolation over the risk of becoming a burden to her son.

Toby indicated that he was happy with the relationships inside the group home, but missed the company of his own sons:

Toby: I would like my sons to visit me more often. Both of them could come here more often.

R: I get it. You miss your sons.

Toby: Yes (moved).

R: Have you told them this?

Toby: I have told them. In an e-mail. But they are both so bitter about their childhood years, when I was drinking a lot. I never raised a hand against my children nor my wife, but I had a foul mouth. That's why they are hurt, still, even if it was such a long time ago, they are still hurt, so... (Male, 60, moving independently with walker)

Toby and his wife were divorced, and the relationship with his two sons became problematic. The older son visited him rarely, and the younger had broken ties with him altogether because of Toby's prior drinking problem. Toby was a 'young man' (60) who was already living in a sheltered home, as his rough life had taken its toll, hampering his abilities to function inasmuch that he needed round-the-clock attention. However, Toby did not feel isolated all the time. He was connected to the world outside via his laptop and internet connection, and he talked on the phone with some of his friends. He also explained how he talked and joked with the staff when they had time, and he also said that there was one resident he spent time with. Toby perceived social isolation in relation to his children.

One plausible means of reducing residents' feelings of social isolation today is communication technologies (Choi, Kung and Jung 2012). Most

of our interviewees had cellular phones. However, having a phone is not a solution *per se*, but one needs the ability to use the phone, people to call and a working telephone network. Residents had problems regarding phone calls that were related to the building itself. Like many buildings in Finland today, the house was insulated so well that wireless networks did not necessarily function well. The building itself also had another flaw, which made it sometimes difficult to enter from outside, as the next excerpt shows.

When I arrived, the front door was locked and there was an angry woman, some resident's relative, standing at the door. It was raining and she could not get inside. She had already pressed all the buzzers outside, but nobody had answered her. She said that it had always been the same kind of hell with this building. (A note from observation diary)

This note was written on Christmas Eve, when there are more visitors in AL facilities than usual, since many people have their holidays, and visiting people in institutions at Christmas time is a tradition. The front door had an electrical lock, which meant that it automatically opened in the mornings and locked in the evenings. For some reason, it was locked all day during midweek holidays, and visitors had to press a buzzer connected to a group home to get the door opened. The buzzer sounded in the staff's office, which was usually empty since the staff were working around the group home. Many times people had to press all the buzzers to get contact with people inside. It often took time, and people got frustrated. The situation is still the same today, although many visitors have made complaints about the door to the management.

Most of the residents were visited by family, such as children, but for many, contact with friends had decreased or even ended when moving to the facility. 'I used to have friends when I was home, but none of them have been over to visit me, even though my daughter asked them to come', Ira described. Sarah also indicated that her husband had encouraged their common friends to visit her, yet nobody had come. One staff member had a clear idea about why residents' friends and relatives do not necessarily come to the facility, stating that older people who are still living in private homes find care facilities frightening and avoid visiting them.

Discussion

In this article, we studied AL residents' chances for affiliation through experiences of perceived social isolation. According to our findings, social isolation (Victor, Scambler and Bond 2009; Weiss 1973) was mainly perceived in connection to two different social worlds. Our results suggest

that, on the one hand, perceived social isolation in AL seemed to arise from difficulties in reaching other people on-site. Prior research has emphasised the importance of co-residents regarding the older people's overall well-being in AL (Street and Burge 2012; Street *et al.* 2007). Yet, our interviewees had only a few close relationships with other residents due to feelings of otherness in relation to co-residents. Our findings lend support to indications (Roos and Malan 2012) that the mix of high- and low-dependency residents within the same facility is an issue for the latter. The less-dependent residents had a dilemma regarding their actual and desired social surroundings. Andy and Ida solved this by staying alone in their room, while Henry took a helping role in the facility.

Prior research has emphasised the importance of sufficient mental stimulation in old age to postpone mental impairment (*e.g.* James *et al.* 2011). Our cognitively fit interviewees seemed to avoid common leisure activities. Andy, Henry, Toby, Sarah and Ida explicitly stated they did not wish to participate. Toby said that common activities were aimed for 'the older people', and Paula said she would be happy to organise something herself. Paradoxically, the available activities seemed to isolate the cognitively fit residents. Based on our results, cognitively fit residents should be provided with activities of their own, and their willingness to help others could be better utilised to affirm their affiliation in AL.

There has been a vivid public discussion in Finland about the neglect of older people residing in care facilities ever since a survey was published which indicated that 93 per cent of nursing staff admitted to having witnessed resident neglect in their workplaces (Valvira 2016). Some parties, such as trade unions for nursing staff, claim that the phenomenon strictly rests on resources. Some others, such as many of the residents' relatives, consider that there are problems regarding the nursing staff's attitudes towards their work and towards older people. Based on our results, both parties have a point. Both residents and staff considered the staffing ratio too low in terms of residents' needs. However, our interviewees stated that there were also problems with the attitudes of some members of staff. The dispute between resources and attitudes is not a matter of black and white. Based on prior research, we know that good management and opportunities for staff to design their own work may compensate for low resources in care facilities regarding residents' quality of life (Räsänen 2011; Shepherd *et al.* 1996). On the other hand, all the resources in the world make no difference if a resident feels that people surrounding him or her pay no interest.

In addition to relationships inside the facility, social isolation was felt in relation to the social world outside. Interviewees missed the company of old friends, as well as contact with family members. Pirhonen *et al.* (2016)

found that Finnish community-dwelling nonagenarians feared their own transfer into a nursing institution, sometimes even more than dying. Thus, negative representations may isolate residents from their previous friends and same-age peers who are still community-dwellers. Gilleard and Higgs (2010) even argue that public failure in self-management and transfer to a care facility alienate older people from the rest of society. Also, AL residents do not live up to expectations set by the paradigm of successful ageing (Baltes and Carstensen 1996; Rowe and Kahn 1997), which may isolate them socially and culturally. However, social ties outside the home are of high importance. As we reported in another study (Pirhonen and Pietilä 2016a), residents even based their feelings of autonomy partly on outside people, who took them out of the home and brought them items and goods they needed. They also supported their own agency by transferring it voluntarily to their friends and relatives (Pirhonen and Pietilä 2016b), and people outside the home also affirmed residents' continuity of self (Pirhonen and Pietilä 2015). All this emphasises the importance of making AL facilities as accessible as possible regarding outside society.

In our research site, residents had problems keeping in touch with people outside the home due to problems with audibility of cellular phones. The electrical front door also posed challenges for friends and family trying to visit the residents, since it was closed during the holidays and the doorbell did not always reach the staff. Communication and other technologies have been pictured as one possible solution to reduce social isolation and loneliness of the elderly in the future (e.g. Sharkey and Sharkey 2012). Video calls and other telepresence systems are being developed in Finland (Kelo and Haho 2016). In addition to ethical dilemmas regarding technology in care (e.g. Zwijsen, Niemeijer and Hertogh 2011), there seem to be problems with the basic technology, which should be overcome first.

There are conflicting results in the previous research regarding the importance of residents' social relationships. Sometimes, relationships that are formed before one transfers into a facility have been pictured as being more important to the residents' wellbeing (Burge and Street 2010), and other times, relations inside the facility have been more emphasised (Fessman and Lester 2000). Our study obviously highlights the importance of both kinds of relationships for positive affiliation with AL surroundings. For example, Toby seemed quite happy with his relationships inside the facility, but missing his sons made him feel isolated. Henry's friends and his daughter visited him a lot, but being less dependent than other residents in the facility increased his social isolation. Andy was one of the worst in terms of isolation; he felt socially isolated from the other residents and he had no connections to his prior musical circles outside AL, which he seemed to miss a lot. Affiliation in AL seems to be a twofold

capability as Nussbaum (2007, 2011) stipulated; one has to feel connected to both people inside and to life outside the facility to reach due affiliation.

Since we studied life in a single AL facility, we cannot suggest that our results are generalised as such. AL includes a wide range of facilities that are operating according to different policies and principles. However, an ethnographic study is not basically designed to provide facts, but to deepen understanding about the daily life of its research subjects (Gubrium 1995), thus revealing a variety of people's interpretations and perceptions regarding the phenomenon being studied. The reasons behind social isolation, which we found in our research site, may be tracked as well in other facilities that are providing round-the-clock care for older people. Thus, our results can be generalised theoretically. Care providers may utilise our results to detect and then to ease social isolation in their own facilities.

The biggest drawback regarding this study is the absence of people with dementia, although dementia is a significant cause of institutionalisation in Finland as well as in other countries (Aaltonen *et al.* 2012; Agüero-Torres *et al.* 2002). We involved ten residents capable of giving informed consent and an interview, which ruled out experiences of people with dementia. Our observational data contained some information on affiliation of these particular people. Sometimes a lack of cognitive competence seemed to cause conflicts between residents, sometimes it seemed to cause unsociability and sometimes people with dementia made friends inside the home. According to Linda Clare (2002), people with dementia in AL may be studied when there are observations and interviews of both residents and staff. Tom Kitwood (1997) holds that even people with severe dementia can express themselves meaningfully in words. However, the study on their affiliation remains to be done in the future.

Our focus on constraints of affiliation in terms of residents experiencing social isolation may make life in AL seem all doom and gloom. This is not our intention. Drawing from ethno-methodological tradition (Heritage 1984), it is plausible to study social order by observing disturbances regarding it. Residents' chances for affiliation may thus be studied by concentrating on issues rupturing it. Another justification for the approach comes from philosopher Avishai Margalit (1998: 4), who considers that there is a weighty asymmetry between eradicating evil and promoting good. It is much more urgent to remove painful evils than to create enjoyable benefits. This justifies concentrating on perceived social isolation to find ways to diminish the 'evil'. Margalit's idea could perhaps function as a maxim regarding the development of AL: it is more urgent to remove suffering than to promote enjoyment, especially since removing flaws (like structures furthering social isolation) promotes good (like affiliation) as such.

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