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The Right to Self-determination for those Living in Dementia Care Homes in Sweden

Current Inconsistencies in Laws, Guidelines and Practice; a Qualitative Online-based Study

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Abstract

Title The Right to Self-determination for those Living in Dementia Care Homes in Sweden: Current Inconsistencies in Laws, Guidelines and Practice; a Qualitative Online-based Study

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Key Words Elder Care, Dementia, Self-determination, Human Rights

This study presents a qualitative online based study on the right to self-determination for those living in dementia care homes. The focus is on how the right to self-determination is implemented in daily practice. The research question was: is the right to self-determination actualized in daily care, and to what extent residents of dementia care homes can influence their daily life? This study also looked to explore how different situations are perceived by care home staff, and how they work to enforce the residents' right to self-determination.

The analytical framework used for this study was based on International Human Rights Instruments, current Swedish legislation related to dementia care and principles and guidelines published by the National Board on Health and Welfare. Based on these documents two different approaches to the right to self-determination were derived: a human rights based approach that enforces the individual's right to self-determination, and a person centered care approach that outsources responsibility of decision making, at least to some extent, to another person. The responses to the survey were analyzed by comparing them to these two identified approaches, to see how these approaches are implemented in practice.

The results supported that a division in approaches regarding issues related to the right to self-determination does currently exist within dementia care services. Based on personal preference staff of care homes may choose to act according to either of the two presented models; respecting the ultimate right to self-determination or choosing a model of assisted decision making. These contradicting practices and viewpoints lead to a precarious situation for both the staff and residents of dementia care homes, as complex moral questions are being solved based on personal preference of the individual workers.

Contents

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Laura Balash
Gothenburg, October 2016

1. Introduction

The right to self-determination for those living in dementia care home facilities is becoming an ever more important issue. The need for elderly care services has dramatically increased during the past years, as the general life expectancy has increased and the population of the baby boom generation is growing older. This increase in the elderly population has resulted in more people living with dementia related illnesses. The amount of elderly people living with some form dementia in Sweden was estimated to be at about 8% of the population over the age of 65, with the amount being almost 50% in the population over the age of 90 in 2014. (Alzheimer Föreningen 2014). In all it is estimated that currently there is approximately 160 000 people living with dementia in Sweden (ibid). By 2025 it estimated 180 000 people in Sweden will be living with dementia, and by 2050 this figure is estimated to rise to 240 000 (ibid.). Globally there is estimated to be 47,5 million people living with dementia (World Health Organization: Dementia Fact Sheet 2016).

Dementia is a syndrome that may be caused by different illnesses, which results in deterioration of cognitive functions, memory, thinking, everyday functions and behavior. (World Health Organization: Dementia Fact Sheet 2016). Dementia related illnesses mainly affect older people, but is not a part of normal aging (ibid). Due to the fact that dementia severally affects cognitive functions and impairs one's ability to express themselves, it is important to determine the amount of self-determination people living with dementia have, as the right to self-determination is currently underlined in most International Human Rights Instruments, Swedish Law and guidelines.

The importance of the human rights for people living with dementia has been recently noted by known actors such as the World Health Organization and the United Nations. The world Health Organization has recently called attention to the human rights of people living with dementia stating:

> "People with dementia are frequently denied the basic rights and freedoms available to others. In many countries, physical and chemical restraints are used extensively in care facilities for elderly people and in acute-care settings, even when regulations are in place to uphold the rights of people to freedom and choice. An appropriate and supportive legislative environment based on internationally accepted human rights standards is required to ensure the highest quality of service provision to people with dementia and their caregivers. (World Health Organization: Dementia, a Public Health Priority and Human Rights Concern 2016) "

The World Health Organization, in co-operation with the United Nations, have in 2015 presented and proposed a Human-Rights Based approach for people living with dementia, calling for states and other stakeholders to protect the rights of people living with dementia. This proposed approach calls for states to reinforce the inherent dignity and human rights of all people, include those living with dementia (World Health Organization: Ensuring a Human Rights-Based Approach for People Living with Dementia: 2015). In addition to this proposed approach, The World Health Organization is, as of March 2015, in the process of forming a Global Dementia Observatory. The purpose of this observatory is to " function as an international surveillance platform for policy-makers and researchers to facilitate and enable future planning and monitoring of strategic objectives across dementia burden, policies and plans, resources, and research (World Health Organization 2016)."

During the recent years there has been an increasing amount of public conversation on the rights of people living with dementia, as the amount of people with dementia is expected to see a drastic increase. Currently, there is no one consistent practice when it comes to dementia care models, and the issue of the amount of self-determination one living with dementia has or should have is a question that has not been adequately addressed. As will be shown, current laws, policies and guidelines related to ensuring self-determination for those living with dementia in Sweden currently lack unison and consistency. Due to this fact staff of dementia care homes face difficult situations in their daily work, ultimately giving the care takers responsibility for making moral decisions on behalf of the residents.

This study was carried out to gather information on current policies and practices, and their possible contradictions in everyday care work. The method of this study was a qualitative online-based survey. The respondents of the survey were workers in different positions in dementia care homes, with most of the respondents being practical nurses. The main objective of this study was to explore how self-determination is encouraged and enforced in dementia care homes, and to determine how are practices and routines used in a manner that promote self-determination. Self-determination refers to an individual's freedom to make their own choices and the process by which an individual controls their own life (Merriam-Webster 2016; Oxford Dictionaries 2016). The main research question was, is the right to self-determination actualized in daily care, and to what extent residents of dementia care homes can influence their daily life? This study also looked to explore how different situations are perceived by care home staff, and how they work to enforce the residents' right to self-determination. The objective was to get a general view on how residents' wishes are taken into consideration, and what are the hindrances in actualizing the right to self-determination.

When possible, primary sources were used during data collection. The secondary data used in this study comprises of International Human Rights Instruments, Swedish Law, Guidelines and principles published by the National Board of Health and Welfare, and inspects them through person-centered care and human rights based approaches. The data on legislation and guidelines has been collected from governmental websites, which assumes high reliability and validity. Secondary data on approaches and statistics has been collected from scientific publications and cross checked with corresponding, other secondary literary sources when applicable, which is visible in the sources.

This study will begin by presenting an overview on dementia and how it effects the individual. This will be followed by statistics about dementia both in Sweden and globally. After this the analytical frame work will be presented. The analytical framework consists of Human Rights Instruments, Swedish Law and Guidelines and Principles related to the right to self-determination for those living in elderly care homes. From these documents two different approaches to the right to self-determination in dementia care will be derived. The analytical framework will continue with presenting a person-centered care model, which is a common model of care in dementia care homes. The second approach to issues of self-determination endorsed in current documents, is be a Human Rights-based approached which will also be presented, after which both approaches will be further discussed in the light of ethical aspects in relation to the right to self-determination. The "Ethical Issues Related to the Right to Self-determination"-section will also discuss current law and contradictions within these approaches and practices. Following this, the results and analysis will be presented, in the light of the analytical framework. Finally, this study will end with the conclusions.

1.1 Overview on Dementia

To understand why the rights of people with dementia is such an essential issue, one must first know about how dementia effects the individual. Dementia is a progressive disorder of the brain that effects ones cognitive functions and memory. The name "dementia" derives from the latin words *de* (out of) and *mens* (mind)- implying that one that has dementia is out of their mind.(Henderson &Jorm 2003: 1). Although extensively researched, there is still an absence in the complete understanding of the causes behind dementia (ibid. 18).

The Oxford concise medical dictionary describes dementia as following:

> "a chronic and progressive deterioration of behaviour and higher intellectual function due to organic brain disease. It is marked by memory disorders, changes in personality, deterioration in personal care, impaired reasoning ability, and disorientation. Dementia is usually a condition of old age, but it can occur in young or middle-aged people" (Martin 2015).

In simpler terms, dementia is a condition that results from brain deterioration. The deterioration of the brain may be caused by a number of syndromes, with Alzheimer's disease being the most common. Other diseases that cause dementia include vascular dementia, Lewy Body dementia and frontal lobe dementia. Some of the less common causes of dementia include conditions such as Parkinson's disease, alcohol abuse, Picks disease, Huntington's disease Creutzfeldt- Jakob disease and AIDS. (Henderson& Jorm 2003:2-9).

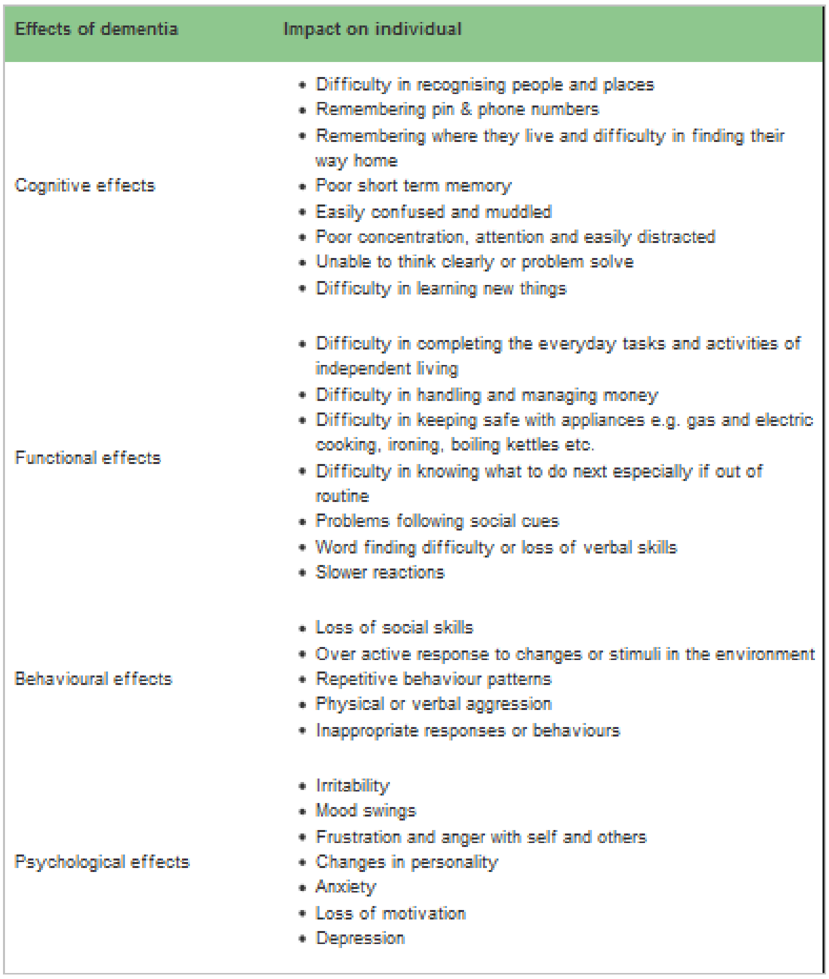
Dementia is a condition that does not lead to death, but does reduce a person's life expectancy (Henderson& Jorm 2003:17). As one could imagine the deterioration of the brain has vast impacts in an individual's life. According to the World Health Organizations ICD-10 (International Classification of Diseases) Diagnostic Guidelines for dementia, each of the following should be present when diagnosing dementia:

1. "A decline in memory to an extent that it interferes with everyday activities, or makes independent living either difficult or impossible.
2. A decline in thinking, planning and organizing day-to-day things, again to the above extent.
3. Initially, preserved awareness of the environment, including orientation in space and time.

4. A decline in emotional control or motivation, or a change in social behaviour, as shown in one or more of the following: emotional ability, irritability, apathy or coarsening of social behaviour, as in eating, dressing and interacting with others." (WHO as cited by Henderson& Jorm 2003: 2).

Due to the fact that there are many causes behind the development of dementia, it is difficult to clearly predict how dementia progresses (Henderson& Jorm 2003: 8- 9). Some may grow worse in their condition rapidly, while for others it might be a slower process (ibid.). Generally it has been stated the dementia takes 7 years from first being recognized, to the advanced stages (ibid.).

How dementia effects an individual depends on the illness and the personality of the individual prior to illness (WHO 2016). The consequences of living with dementia may thus vary (ibid.). Despite this fact, there is a consensus as to the more common symptoms and possible effects of dementia. These effects of living with dementia can be grouped into 4 categories; cognitive effects, functional effects, behavioral effects and psychological effects (Careerforce 2013: as presented in an open online course on dementia in collaboration with Alzheimer New Zealand and Careerforce). Some of the main impacts on an individual can be seen in the chart below:



Effects of dementia	Impact on individual
Cognitive effects	• Difficulty in recognising people and places • Remembering pin & phone numbers • Remembering where they live and difficulty in finding their way home • Poor short term memory • Easily confused and muddled • Poor concentration, attention and easily distracted • Unable to think clearly or problem solve • Difficulty in learning new things
Functional effects	• Difficulty in completing the everyday tasks and activities of independent living • Difficulty in handling and managing money • Difficulty in keeping safe with appliances e.g. gas and electric cooking, ironing, boiling kettles etc. • Difficulty in knowing what to do next especially if out of routine • Problems following social cues • Word finding difficulty or loss of verbal skills • Slower reactions
Behavioural effects	• Loss of social skills • Over active response to changes or stimuli in the environment • Repetitive behaviour patterns • Physical or verbal aggression • Inappropriate responses or behaviours
Psychological effects	• Irritability • Mood swings • Frustration and anger with self and others • Changes in personality • Anxiety • Loss of motivation • Depression

Image 1 Effects of Dementia on an Individual. Source: Dementia, its effect and impact on a person. Careerforce 2013.

As one can see, symptoms and effects vary from mild to severe. While some effects may not influence one’s ability to practice their right to self-determination, more severe symptoms place undeniable restrictions on a person’s capability of decision making. Some of the most severe cases of dementia include symptoms such as: memory loss to the extent that one may not recognize those close to them or their own reflection; losing ability to speak: loss of mobility; problems with chewing and swallowing; loss of continence, changes in behavior; aggression and hallucination (Alzheimers Society 2012: 1-5).

Known risk factors for developing dementia include old age, female sex, family history and genetic factors (van der Flier&Scheltens 2005: 2-7). Some studies have found that overweight, environmental factors, drug use, smoking and low education may be risk factors, but these studies have been contested (Alzheimers Society 2016: 1-12: Chen, Lin & Chen 2009: 754-760). Currently, there are still many unknown factors as to how and why dementia develops. The biggest risk factor that has been determined is old age: as one can see in the below chart, the probability of developing dementia increases dramatically with age (Henderson&Jorm 2003: 13- 15; Van der Flier&Scheltens 2005:4).

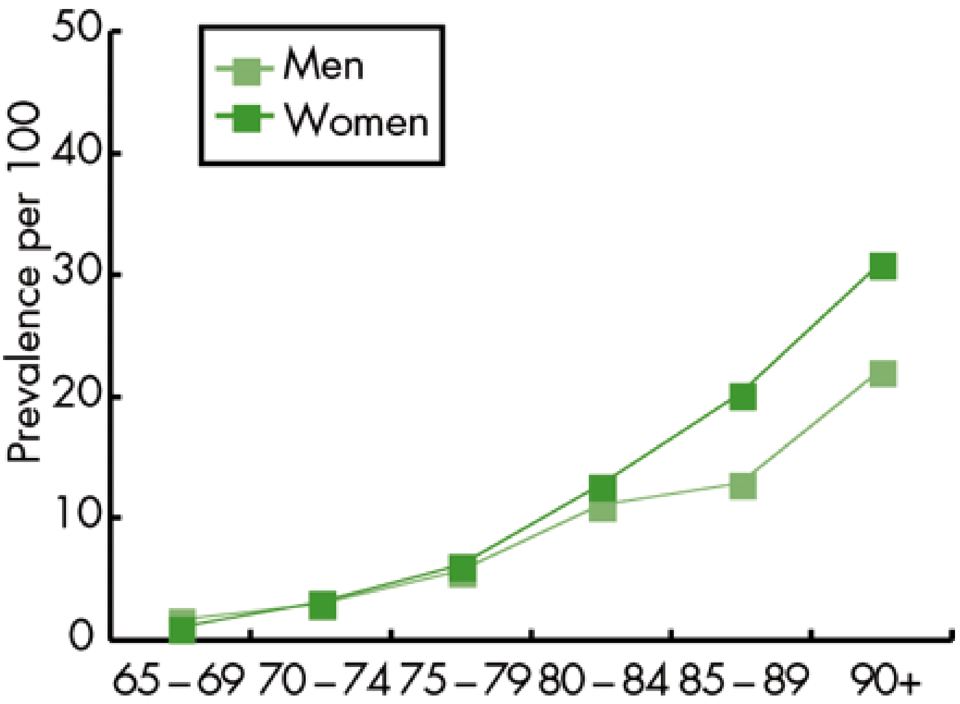


Image 2 Prevalence of dementia by sex and age. Source: Van der Flier & Scheltens 2005:4.

1.2 Statistics on Dementia in Sweden and Globally

The population structure of Sweden has shifted during the past 100 years, with the amount of youth decreasing and the amount of elderly increasing. As we can see from image 1, the population structure pyramid has decreased from the bottom and increased towards the top. There has been a dramatic decrease in younger age groups, while the older age groups (50-90 year olds) have all increased.

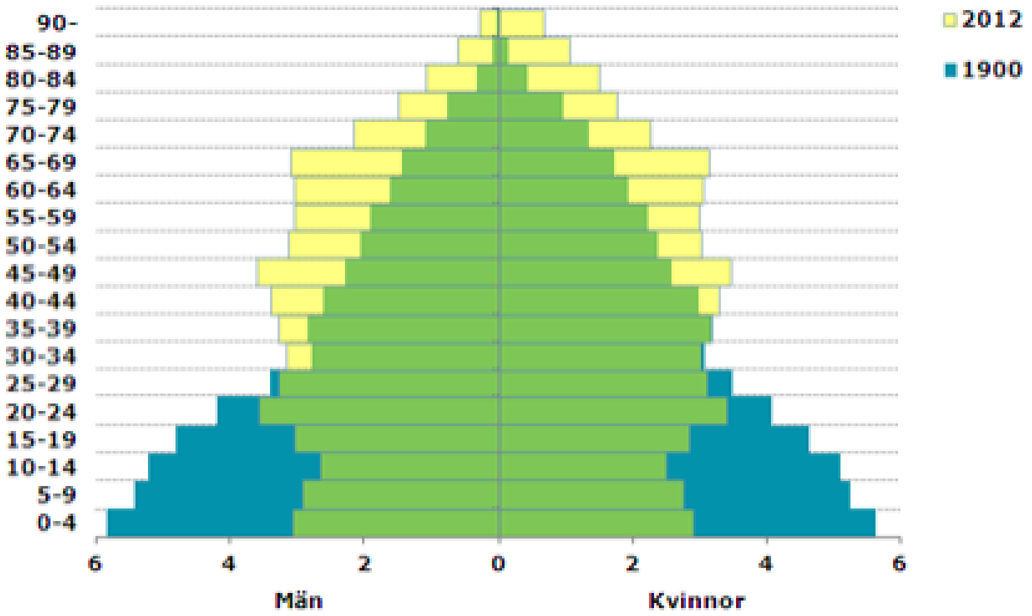


Image 3 Comparison of population structure in Sweden 1900-2012. Män- Men, Kvinnor- Women. Source: Åldrande befolkning. Folkhälsomyndigheten 2014

With the increase of the elderly population, the amount of those living with dementia will be seeing an increase. It is expected that the amount of people living with dementia in Sweden will rise from the current 160 000 to 240 000 by 2050 (Alzheimer Föreningen 2014). This makes the rights and conditions of those living with dementia an ever more topical issue. The World Health Organization has raised dementia as an issue of public health priority in 2012, and according to the World Alzheimer report of 2015, the number of people living with dementia globally will double every 20 years, from the number of people living with dementia globally in 2015 being 46.8 million to the amount being 131.5 million people by 2050 (World Health Organization 2012; Prince, Wimo, Guerchet, Ali, Wu, Prina 2015:13).

This increase in the amount of people projected to be living with dementia in the future has generally been referred to as the “dementia epidemic” or “the silent epidemic”. The hypothesis has been that the amount of dementia prevalence will rise in addition to having an aging population and demographic change (Prince et al 2015: 42-44; Henderson& Yorm 2003:16). This hypothesis has been challenged by recent studies such as studies by Wu, Fratiglioni, Matthews, Lobo, Breteler, Skoog and Brayne and Larson, Yaffe & Langa that have found that the prevalence of dementia may not be increasing per se, but rather the demographic change is the biggest contributor to the increase of dementia cases. (Wu et al: 2016: 116-123; Larson, Yaffe&Lange 2013:2275-2277; Henderson& Jorm 2003:16-17). In other words, the amount of dementia in itself is not increasing; the increasing amount of elderly people is what is causing the increase of people living with dementia.

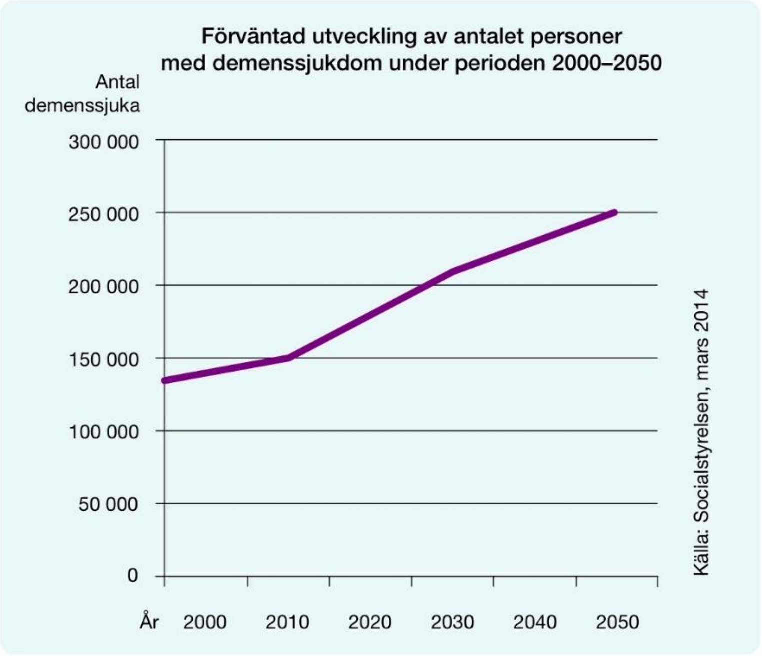
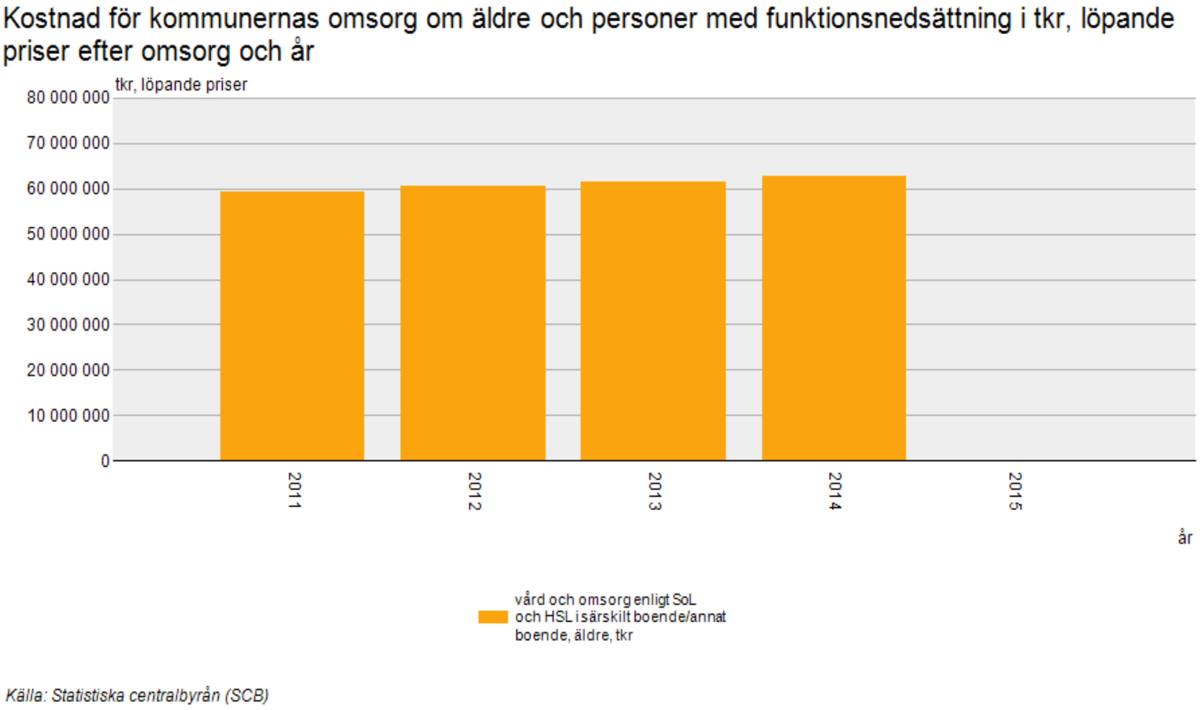


Image 4. Projected Development in Amount of People with Dementia (in Sweden) 2000-2050. Antal demenssjuka- amount living with dementia.. Source: Nationell Utvärdering. Socialstyrelsen 2014

Although it is comforting information that dementia related illnesses may not be on an increase in essence, it is still evident that the amount of people living with dementia will increase in the future. This strong increase in the amount of people living with dementia effects not only those living with the illness, but society and humanity at large. Currently, most people living with dementia live in low and middle income countries, as 65% of the world’s elderly population live in countries listed as low- or middle income countries (Prince at al. 2015: 6). The large amount of elderly people in combination with the profound changes taking place in these low and middle income countries, such as the decrease in fertility rates, increased participation in labor force, urbanization and migration for work, all increase challenges in countries that traditionally have relied on informal family care as the primary source of elderly care (ibid.) In addition to other global challenges, these countries will have to find solutions as to how to care for the increasing elderly population, while the amount of young people is decreasing and migrating to other countries. This is an evident human rights issue that I will not go further into, but want to note as one of the challenges of the rights of people living with dementia.

The upcoming strong increase in the amount of people living with dementia also impacts global economy and produces economic challenges. The World Alzheimer Report 2015 reports an increase of the global costs of dementia rising from 604 billion US dollars in 2010 to 818 billion in 2015 (Prince et al. 2015: 56-58). The costs in Sweden have also increased for elderly care services; as can be seen in image 3, the costs of elderly care homes have been on a slight increase rising from approximately 59 000 000 thousand crowns allocated to care homes in 2011 to approximately 63 000 000 thousand crowns in 2014 (Statistiska Centralbyrån 2016). This amount only shows costs of care homes and does not take into consideration home care services. The increase in the amount of people living with dementia is not merely an issue of public health; it also has a global and societal socioeconomic impact.



Kostnad för kommunernas omsorg om äldre och personer med funktionsnedsättning i tkr, löpande priser efter omsorg och år

Källa: Statistiska centralbyrån (SCB)

Image 5 Cost of Communal Care Services for Elder People and People with Disabilities in thousand crown units, in Sweden (the whole country) 2011-2014. Vård och omsorg enligt SoL och HSL i särskilt boende/annat boende, åldre tkr- Care services according to the Law on Social Services and Health Care Law in care home/ other facilities, ages, in thousand crown units,. Source: Statistiskdatabasen. Statistiska centralbyrån 2016.

The need for care services has a direct correlation with age, as can be seen from image 5. At age 65, the amount of services is just above 0%, with the amount of services increasing to near 100% when closing into 100 years of age. Women use more care services, which can be explained by the life expectancy of women being higher, as well as possible willingness to use services being higher for women. The amount of people living in care homes in Sweden can be seen in image 6, with women over the age of 80 dominating the table chart. The approximate amount of elderly people living in care homes at the end of 2015 in Sweden is just above 200 000 people (Socialstyrelsen 2016, graph below). One prognosis estimates costs of elderly care services in Sweden to increase by possibly 270% by the year 2040 (Seniorguiden 2014). The amount of over 80 year olds living in Sweden is expected to increase from 499 000 in 2014 to 826 000 in 2030 and to 1 210 000 in 2060 (Statistiska centralbyrån 2015).

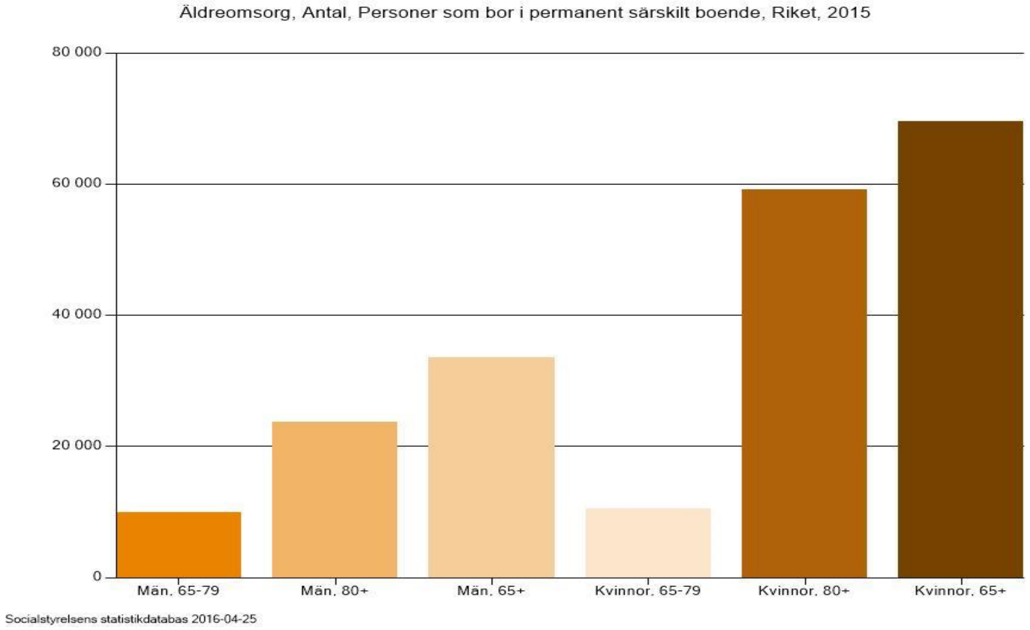


Image 6 Elder Care, Amount, People Living in Care Homes in all of Sweden in 2015. Män- Men, Kvinnor- Women. Source: Statistikdatabas för äldreomsorg. Socialstyrelsen 2016.

The likelihood of living with a dementia related illness increases substantially with age. The proportion of people with dementia doubles for every 5-years age group, with one in five people over the age of 80 having some form of dementia (Alzheimer Society 2014). 80% of people living in care homes have some form of dementia (ibid.). It is currently estimated that one in three people born in 2015 will develop dementia during their lifetime (Alzheimers Society 2015).

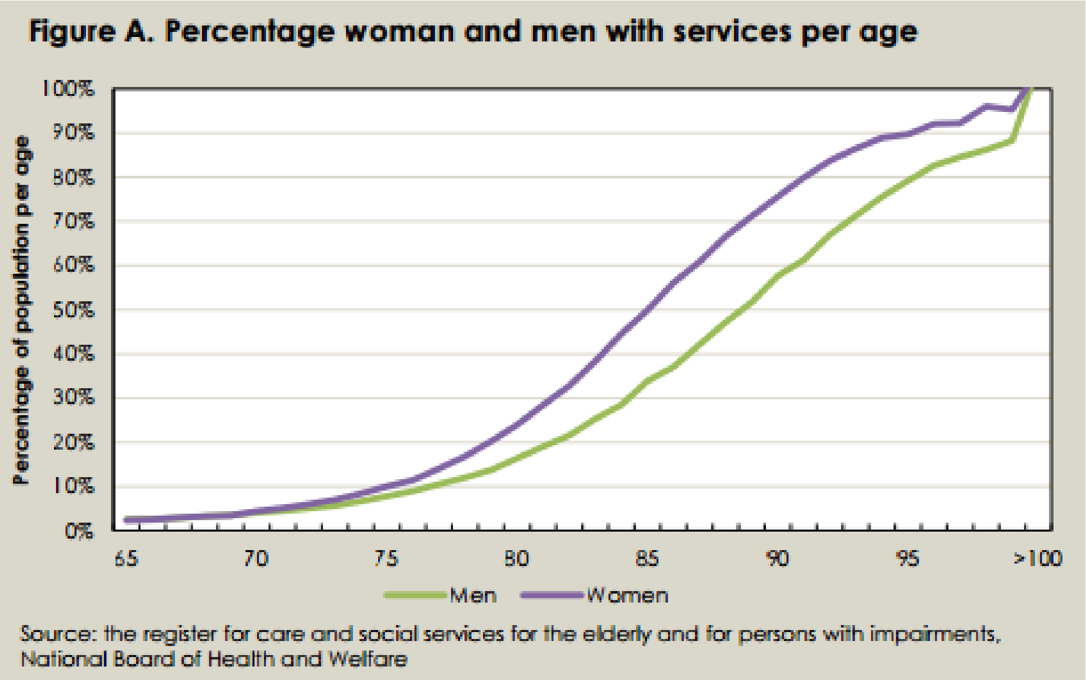


Image 7 Percentage of Women and Men with Services per age. Source: Statistics on Elderly and Persons with Impairments. Socialstyrelsen 2016.

2. Previous Research

Research regarding the issue of dementia care has generally been aimed at alleviating physical symptoms and hindrances (Shaw, Briar-Lawson, Orme & Ruckdeshel 2010: 438). There has been less focus on the psycho-social needs and rights of those with dementia, especially those living in care homes (ibid). Despite a focus on the physical aspects of dementia, the right to self-determination when it comes to people living with dementia has become a more popular subject of research during the past few years. When self-determination of people living with dementia has been researched, it has often been studied from the perspective of care takers or care managers. This can be seen to be due to the fact that elderly people, especially those living with dementia, may have difficulties voicing their opinions.

How self-determination has been implemented has been studied from different perspectives with different theoretical focuses. Already in 1995 Matthiasson & Andersson explored attitudes of nursing home staff in relation to patient autonomy and how they deal with ethical conflict in a project consisting of several different studies. Results of these studies were published as a doctoral dissertation by Mathiasson for the Sahlgrenska Academy. The studies were carried out by interviewing both staff members and residents of care homes, and results are based on data received from 189 respondents from 13 different care homes in the country of Stockholm. (Matthiasson 1995: 15-23)

The first study explored nursing homes staffs' reactions to ethical conflicts with respect to patient autonomy and paternalism. The respondents were asked to respond to 6 case studies relating to the right to autonomy. These case studies presented the following different care home situations with ethical conflicts:

- Decisional Autonomy and the Autonomy of Execution: The case study presents a situation where staff are helping a resident because care work is faster so, instead of letting the patient do things on her own as she wishes.

- Direct and Delegated Autonomy: The case study presents a patient who needs assistance while smoking who wishes to smoke a lot, but is only given the help to smoke a few times a day.

- Competent and Incapacitated Autonomy: The case study presents a resident that is able to express her own will and whom refuses food and liquids, but members of the care staff want to give intravenous infusions

- Authentic and Inauthentic Autonomy: The case study presents a resident that refuses painful treatments, but her son wishes treatment be forcefully continued

- Immediate and Long Range Autonomy: The case study presents an elderly man in rehabilitation after a hip fracture who wants to walk despite constant accidents while doing so. The nursing home decides to restrict him to his wheelchair for safety reasons, but the patient and his son demand his restraints be removed.

- Negative and Positive Autonomy: A resident temporarily needs a wheelchair, but then notices he receives certain prerogatives and additional attention from the staff when in a wheelchair. He refuses to go to physical therapy to work on regaining his skill to walk. His wife pressures the staff to get him back on his feet. The staff do not view the wheelchair as a problem and say they can’t physically coerce or intimidate the patient into walking again.

The respondents were asked to reply to two questions: “What is your personal opinion in this case?” and “What would your unit’s decision be in this case?” The results showed that there is consensual agreement among professional categories, irrespective of if the results supported patients’ preferences or paternalism. The results differed, but the response to the final case on negative and positive autonomy revealed stronger signs of paternalism then other cases. Nurses consistently gave higher priority to patients preference then nurses aids. In general the results showed understanding towards the patients preferences, but time was mentioned as a limitation as to implementing the patients preferences (Mathiasson & Andersson 1995:113-128). Although the word self-determination is not used in this study, patient preference can be seen as a similar concept. The results showed that the patients opportunities to decide what is happening and when, was mainly restricted by a lack of time. The results also showed that nurses found the personal preference of the patients as a more important issue then practical nurses, although underlying reasons as to why this is the case was not explored. This research answers to the questions of personal preference of staff, but does not explore further reasons into why the respondents feel so, and how they view the ethical aspects of this question. It also does not focus on the situation of those living with dementia, which is the focus of this thesis.

Another study by Mathiasson& Andersson (1995) investigated moral reasoning among professional caregivers in nursing homes. The study was carried out by demonstrating the vignette of a patient in a wheelchair, whom tries to walk despite injuries due to falling occurring to him. He is then restrained to his wheelchair, and the respondents are asked what they would do, if he demands to be freed from the restraints. When asked how they view the vignette as an ethical principle and how the unit should respond to such a case, the results showed that 27% placed personal autonomy in the forefront. 57% believed that restricting the patient was “doing good” and thus justifiable, when asked to view the vignette as an ethical principle. When asked for personal opinions, 44% chose” doing good” i.e. keeping the restraints, while 26,6% choose to respect the residents right to autonomy. The response rate for what the units’ decision should be was 51%, when asked about personal views the response rate was 79%.(Mathiasson& Andersson 1995: 277-291). This specific studies results show how there are different approaches one may take to distinct situations; one may choose to respect the right to self-determination, or make a moral judgment based on the “common good”, but limits the exploration of this question to quantitative means and describes a situation taking place in a somatic ward.

A third study by Mathiasson& Andersson of relevance, explored how organizational environment affects patient autonomy. This study used the same 6 case studies as in the study of ethical conflict. For this study, the respondents were also ranked based on how the respondents felt about the organizational climate, based on a questionnaire based on 10 categories and 50 different statements. The responses to this questionnaire resulted in some of the care homes being ranked as having either creative climates or climates with lack of innovation. (Mathiasson& Andersson 1995: 1-17)

Staff in nursing homes with creative climates presented work environments consisting of features such as trust, confidence and an atmosphere where ideas are debated. The nursing homes that fell into the category of lack of innovation presented work environments with features such as work apathy, lacking trust between employees, and showing low support to ideas and debate, which leads to following authoritarian patterns without questioning. It was assumed that the atmosphere that supports debate and "risk taking" leads to higher autonomy of the patients, compared to organizational environments where work apathy and authoritarian patterns are not questioned. The results to the case studies were then compared to the group the nursing home fell in. This comparison showed that nursing homes that had creative climates tended to supported autonomy, while nursing homes that lacked innovation tended to not be supportive of client autonomy, as they did not question the assumed patterns of work . (Mathiasson&Andersson 1995:1-17). This studies results show that the attitudes of the staff of care homes has a significant influence on the amount of autonomy the patients' experience. The working environment can either enforce "questioning" practices, in which case the patients are given more opportunity to actualize their autonomy, or lack innovation during which routines are blindly followed without question. This study shows how moral questions are not only guided by personal preference but also organizational structures. These results show interesting results to how organizational and environmental aspects affect the work climate in care homes for older people, but again makes no differentiation to dementia care.

A similar study to Mathiassons and Anderssons study of organizational environments influence on patient autonomy was conducted by Persson and Wästerfors (2007). They researched how older people often have restricted opportunities to make decisions on everyday matters in care homes, despite the right to autonomy being enforced in policies. For their study, 13 staff members of both dementia and somatic care home wards were interviewed. Their results showed 3 different factors contributing to restrictions: organizational matters, lack of resources and the residents' complaints being perceived as trivial in nature. Organizational matters refers to blaming schedules and working procedures for not being able to fulfill the resident's wishes (for example showers and going to bed must take place within a certain time frame). Lack of resources refers to not being able to fulfill residents' wishes due to understaffing and lack of time. The final category, the residents' wishes being trivial in nature, refers to the interviewees' perception on some of the complaints being trivial. Some were concerned about "spoiling" the residents by complying to all their wishes, as there is so much else to do as well. Some wishes were also deemed as attention seeking behavior (Persson&Wästerfors 2007: 1-11). These three factors provide insight as to why residents right to self-determination in care home settings are restricted and how differently different situations may be perceived; moral issues such as the right to self-determination can be diminished or undermined by viewing them as trivial. The right to self-determination may also be restricted due to external factors, such as lack of time and organizational structures. This shows the complex nature of moral questions and its subjectivity, but does not investigate how workers reflect issues of self-determination in relation to legislation and the distinct situations that take place in dementia care.

Harnett (2009) researched how institutional settings restrict elderly people in a Swedish care home setting. The study is based on results from field observation and unstructured field-based interviews of the staff and residents of an elderly home in Sweden. The focus was to see how residents try to attempt to influence their care and how staff reacts to these attempts. Based on these observations the influence attempts were classified as disruptions, disturbances or harmonizing with institutional routines. Disruptions refer to residents requesting something that broke the routine of the care work, with these requests being commonly ignored. Disturbances refer to sudden situations or events that disturb the staff member from doing what is planned. Unlike disruptions, disturbances were acted upon, but possibly delayed, as they were usually situations that are unpredictable. Finally, harmonizing influence attempts were compatible with institutional routines and thus most often fulfilled. The results showed that depending on how the influence attempts of the residents were perceived, the staff would react in different ways, either limiting or reinforcing autonomy (Harnett 2009:292-301). Again these results show that there are several different courses of action one may take in issues related to self-determination based on the care takers subjective interpretation of the wishes of the clients. This study gives insight into how elderly care workers react to patients attempts to actualize their right to self-determination, but does not take into consideration the distinctly vulnerable situation of those living with dementia in care home facilities.

Erlandsson & Nilsson (2008) studied if assistance officers face difficult situations due to the fact that there are no laws for forceful measures in relation to people living with dementia. For this study, they interviewed 6 assistance officers, interviewing them about their views in relation to forceful measures. The results concluded that the assistance officers had both positive and negative feelings about the lack of such laws. The respondents felt it is important to listen to and respect the right to self-determination, but also noted that people with dementia may be at risk to wind up in situations of danger. The proposition of forceful laws was met with mixed emotions, as the right to self-determination was seen as an important value in the eyes of the respondents, but the difficult nature of some situations was acknowledged (Erlandsson& Nilsson 2008:6-47). The results show that there is no simple answer to the question of self-determination; in some cases forceful measures may be necessary, but taking away ones right to self-determination is seen as an extreme measure not many are willing to actively take. This study provides valuable insight into the situation assistance officers' face, showing a similar inconsistency in law as the one care home workers of dementia wards may face.

Nilsson& Jönsson (2013) completed a qualitative study about self-determination and dignity in aid management with people with dementia. This study was carried out by interviewing 10 care managers in the Gothenburg region to explore how they view matters of self-determination and dignity in care homes. The results of this study showed that care managers often chose to work in a manner that was seen as right, rather than respecting the individual's right to self-determination and dignity. This was due to the fact that the care managers felt that the municipality's responsibility is to determine what is best for the individual, as the law is not designed in regard to dementia care. As the law was seen as lacking, the greater good of the individual was prioritized over the right to self-determination (Nilsson& Jönsson 2013: 6-

57). These results show how some may choose to prioritize common good over the right to self-determination when it comes to people living with dementia. The role as an official that is supposed to work for the common good may be seen as a responsibility that overpowers the individual’s right to self-determination. My thesis seeks to answer similar questions, but from the viewpoint of those doing the actual care work.

A similar study was carried out by Pålsson& Söderberg (2014) which explored the right to self-determination for people with dementia through interviewing professional assistance officers. The study aimed to see how professional assistance officers view the right to self-determination amongst people living with dementia. Based on their research, which consisted of 5 interviews, the respondents saw self-determination for people living with dementia as problematic. The reason behind this was that due to lack of understanding their illness and difficulties communicating, the respondents felt they needed to mediate and consider the persons illness, as their illness may impair them from making informed decisions. The results of these interviews showed, that if the client clearly opposed to help, their wish was generally respected. Despite this, in some cases the respondents voiced feelings of paternalism in their job, as they often felt a need to use persuasion or, in cases that were severe, force to insure the best of the client. This study concluded that assistance offices wished for clarification in the Social Services Act to provide security to both the individual and assistance service officers (Pålsson& Söderberg 2014: 7-57). This study points out the inconsistencies in the current laws regarding the right to self-determination, but does not address how the staff in the care home settings view this issue.

Hjalmarsson& Hjärpe (2014) explored how case managers’ view issues of self-determination in cases that involved people living with dementia. The study was carried out by interviewing 4 case managers in elderly care in Sweden. The results of these interviews revealed that case managers often needed more time to work on cases that involved people living with dementia, as these cases often required persuasion of the client to be involved in care services. In some cases, the right to self-determination was overturned, as some situations were viewed as emergencies and the case managers justified this by stating that respecting the right to self-determination would increase the clients suffering. The conclusion of the authors of this study was that the law on social services was designed to the elderly population in general, not taking into consideration the special circumstances around people living with dementia. This leads to difficult situation for the case managers working with people with dementia, as there are no clear guidelines for challenging situations. (Hjalmarsson& Hjärpe 2014: 1-37). This study shows that the right to self-determination is highly valued, but in severe cases case managers feel it is justified, in the name of the best of the individual, to restrict the individual’s right to self-determination. While the study by Hjalmarsson&Hjärpe explored the views of case managers of dementia care homes, my study seeks to see how issues of self-determination are implemented during daily situations in practice by care staff of dementia care homes.

Previous research acknowledges the challenges to the right of self-determination in elderly care amongst people living with dementia. Previous research shows a will to acknowledge and endorse the right to self-determination for those living in care homes, but presents factors such as organizational structure or trivialization of patients’ wishes as restricting elements. Organizational factors and structures offer an explanation as to why self-determination is restricted, but does not address if patient autonomy or preference would be endorsed more without these limitations. Trivialization of complaints of patients was brought up as one issue that restricts the residents’ self-determination. The trivialization of the right to self-determination is an especially interesting result: is the trivialization of patients preferences a way to distract oneself from the actual underlying moral issue of the dependence of the patients to the care home worker, or a genuine belief that by helping the patient fulfill all needs they will become dependent and needy?

As presented earlier, dementia has profound effects on an individual’s life, which makes discussion about rights and obligations essential in order to be able to offer good quality and morally sound care services. Previous research has focused on how managers and social workers view the right to self-determination, as well as how the organizational environment effects the opportunities to autonomy. Environmental and institutional factors are also reported as hindrances to the right to self-determination, but do not explain how staff *personally* perceive the right to self-determination in everyday care work in respect to current laws and guidelines. There has been less study about how practical nurses, or those who do the practical work, face actual everyday situations regarding self-determination, and I have found no studies researching how care home staff solve issues of self-determination in dementia care homes in Sweden. Thereby the objective of this study is to present what the current contradictions in law and practice are, and illustrate how practical problems are solved by caretakers on a daily basis.

3. Analytical Framework

For the basis of the analysis of this study I will present the different documents that affect how the issue to self-determination in dementia care homes in Sweden are addressed and which approach to issues of self-determination these documents endorse. From these documents two approaches will be identified, and I will then present how these two approaches have developed, their similarities and differences, and describe what their application in practice means. These documents have been selected as the basis for analysis to both show how the right to self-determination in dementia care homes in Sweden is proposed to be actualized according to the instructions of these documents, as well as to present the inherent paradoxes within them. By placing the responses of the survey within these two models, the analysis works to show how the theory behind the practice, presented in the documents essential to the right to self-determination in dementia care homes in Sweden, is actualized. This framework will be used to analyze the responses of the survey, to see if there is preference towards one model, or if both models are used interchangeably.

The analytical framework for this thesis will be developed upon a content and thematic analysis of these documents. To do so, I will identify and present the core points endorsed, as well as the inconsistencies, within the relevant documents guiding issues of self-determination in dementia care homes in Sweden, and group them based on the identified care approach models that are endorsed in these documents. These care approach models will then be used to analyze how issues of self-determination are actualized in practical care work, based on the responses to the questionnaire. The analysis will seek to see if there is a preference towards an approach by viewing the answers in light of the core values and points of the approaches, and identify if the responses show preference towards an approach. I have chosen to use such an analytical framework, as no prior studies have identified and grouped the two inconsistent approaches related to self-determination, that are promoted in the existing documents that present how issues of self-determination should be addressed in dementia care homes in Sweden. As there is a lack of previous research, choosing these two approaches as the basis of the analytical framework seeks to identify how approaches endorsed in the current documents reflect with how care work is being done in practice.

When inspecting the right to self- determination for those living in dementia care homes in Sweden, there are 3 applicable documents or instruments that are of relevance: the International Human Rights Instruments, Swedish Laws, and Guidelines and Principles published by the National Board on Health and Welfare. These specific documents have been chosen as they are generally acknowledged, and in some cases, legally binding documents, describing how dementia care services in Sweden are to be arranged and what requirements they should fulfill. I will start by presenting The Human Rights Instruments and the Human-Rights-based approach that can be derived from them, as this has been proposed by the World Health Organization as the framework of choice for elder care. In addition to being the proposed approach to elder care, the International Human Rights Instruments play a role in the development of laws in nation states, including Sweden, which makes them an important basis for discussion on current elder care policies. As International Human Rights Instruments play a pivotal role in the legislation of nation states, as a type of foundation for the law, they will be presented first, with further description of their origins how they affect legislation.

Following I will present the current legislation related to issues of self-determination in dementia care homes in Sweden, as well as guidelines and principles published by the National Board on Health and Welfare in Sweden. Examination of these documents will show that there is a preference in these documents towards a person centered approach in dementia care, although aspects of a human-rights based approach are also visible. Despite both these approaches being endorsed by various documents, the derived approaches are inherently different. These two different approaches either reaffirm the ultimate right to self-determination, referred to as the Human Rights-based approach, or endorse help from a secondary party while making decisions related to self-determination, which is here referred to as a person-centered care approach.

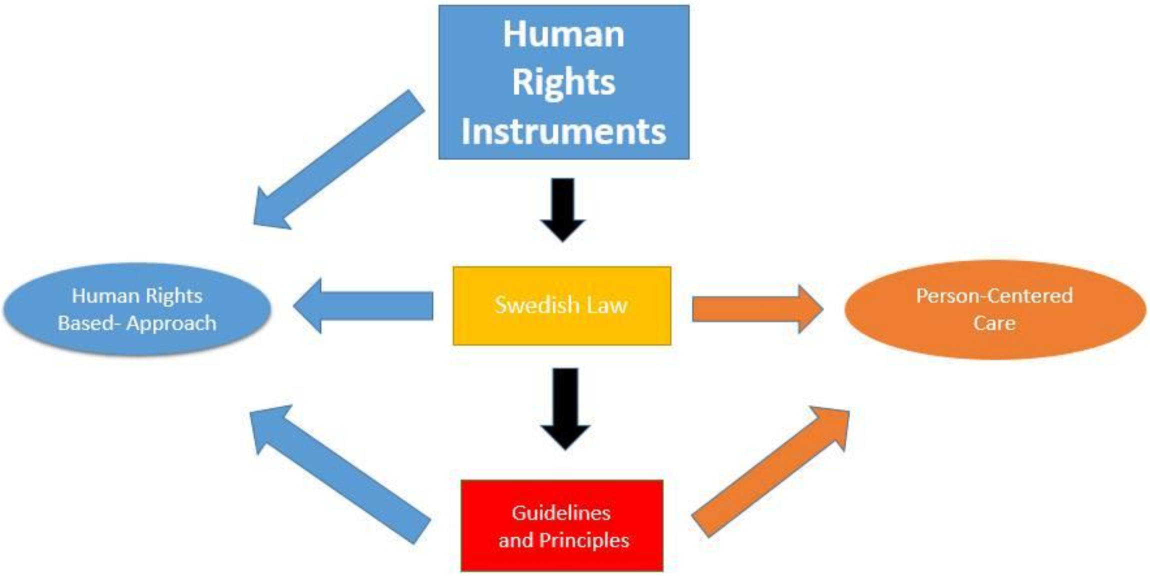


Image 8 How legislation and guidelines are interconnected, and which care approach model they primarily endorse. Human Rights serve as a basis for Swedish Law, which then influences Guidelines and Principles.

These presented documents can be seen as interconnected by the influence they have on the design of care work, as well as by which approaches to dementia care they support. As the graph above demonstrates, Human Rights Instruments, Swedish Legislation and Guidelines and Principles published by the National Board on Health and Welfare are different foundations upon which care work in dementia homes are built upon. In these documents the two different approaches to care work in dementia care homes are visible, either endorsing a human-rights based approach, a person-centered approach or in some cases both approaches. Examination of these documents will present that, in practice, care takers in dementia care homes have a choice of choosing between these two approaches; either respecting and endorsing the right to self-determination, or making decisions on the residents’ behalf.

I have selected to use these two distinct models as the basis of the analysis as they are both promoted in legislation and guidelines, but present different and contradictory practices to be implemented in dementia care services. These two approaches will be used in the analysis to identify how theory is put into practice; if the respondents act according to these promoted approaches, or if other courses of actions are taking place. The benefits of using such an approach as the analytical framework is in that it helps determine if the theory and guidelines aimed for dementia care in Sweden are actualized according to the guidelines issued, and also to show how their actualization looks like in practice. This will be most evident in the vignettes used in this study, which describe distinct care situations and asks for the respondents to describe how they would act when facing the said situation. By comparing the responses of this survey to the approaches endorsed in the relevant documents, this survey aspires to present how workers in dementia care homes react to issues regarding the self-determination of residents, and if it is corresponding with the legislation and documents regarding this issue.

In addition to these two approaches it should be acknowledged that a third approach may be taken; one that does not take into account the residents wishes at all and is based on the care takers personal views on how a situation should be resolved. Such an approach is obviously not acknowledged or endorsed in any existing documents, as such an approach can be reasonably seen as an abuse of power and, furthermore so, illegal. It is generally assumed that staff of care homes work out of a moral standpoint that does not allow such action and, as this is the case, this approach will not be further presented as a part of the framework of this thesis. If such an approach were to occur, it is assumed that the working contract of such a staff member would be terminated. As the focus of this thesis is to explore how issues of self-determination are resolved in dementia care homes as a matter of daily care work as a societal issue, in this thesis it will be assumed that the staff work from a moral stand point that aspires for the good of the residents, and thus such an approach that completely neglects the residents wishes and wellbeing will not be more thoroughly addressed in the analytical framework.

In addition to using the described framework as a basis of analysis, I will also discuss how such a dualistic system leads to ethical and moral dilemmas, as well as compromises the quality of dementia care services due to the lack of a distinct and clear goal when it comes to issues related to self-determination. These two different approaches, the human rights based approach and person-centered care approach, will thus be used to evaluate the data received from the survey, as well as a basis for discussion on current dilemmas and challenges regarding the right to self-determination for those living with dementia in dementia care homes. I would also like to acknowledge that condensing as complex of an issue as the right to self-determination into two different approaches is a rigid solution, and as will be discussed, there are no set definitions for either approaches. As this topic lacks previous research, I will be working with the two existing concepts used in dementia care documents in relation to self-determination. As stated other approaches may exist, but these are the two approaches that are recommended and endorsed. It would be recommended that future research explore the possibility of other approaches, seek clarification of the concepts, and also explore the moral and ethical issues related to these approaches and topic in more detail.

3.1 International Human Rights Instruments

The World Health Organization, in co-operation with the United Nations Office of the High Commissioner for Human Rights, have called for a human-rights based approach for people living with dementia to enforce and ensure their human rights (World Health Organization ensuring a Human Rights-Based Approach for People Living with Dementia 2015). To understand what this Human Rights- Based approach refers to, this part will present an overview of the current International Human Rights Instruments, presenting parts that can be seen as especially applicable for people living with dementia in care home facilities.

International Human Rights Instruments are extensive declarations and covenants, which are designed to protect all individuals, without distinction to race, sex language or religion (Morsink 1999: 3). International Human Rights Instruments refer to treaties, declarations, guidelines and principles that contribute to the understanding, development and implementation of Human Rights laws (United Nations Human Rights Office of the High Commisioner 2016). Here the most common International Human Rights Instruments, such as the United Nations universal Declaration of Human Rights, the International Covenant on Civil and Political Rights, and the International Covenant on Economic, Social and Cultural Rights will be presented, as these are seen as the core international Human Rights Instruments, and are the ones most closely related to human rights issues with a focus on dementia care.

The United Nations Universal Declaration of Human Rights was formed by the United Nations after the World Wars to promote Human Rights and protect fundamental freedoms (Bilder 1999:5). Although the Declaration on Human Rights is not a legally binding document, it has a status of customary international law (Bilder 1999: 7). This supposes the signatory states consent to the obligation of incorporating the international rules in their national laws. (Bilder 1999:5-9). In practice this means that countries that ratify human rights treaties are to implement them by integrating the measures stated in the instruments into national legislation (United Nations Human Rights Office of the High Commisioner 2016). Sweden has signed all of the instruments presented below, and Human Rights are extensively protected under the Swedish constitution (Mänskliga Rättigheter 2016).

Currently, there is no legal document particularly for older people, but one can find articles more applicable for older people amongst existing documents (Rodriguez-Pinson& Martin 2003:918). Articles in the International Declaration of Human Rights that specifically can be seen as applicable to elderly people in care home facilities include:

> “Article 1: All human beings are born *free and equal in dignity and rights.* They are endowed with reason and conscience and should *act towards one another in a spirit of brotherhood.*
>
> Article 5: No one shall be subjected to *torture or to cruel, inhuman or degrading treatment* or punishment.
>
> Article 9: No one shall be subjected to arbitrary arrest, *detention* or exile

> Article 12: No one shall be subjected to *arbitrary interference with his privacy, family, home* or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks.
>
> Article 13: protocol (1) Everyone has the right to *freedom of movement and residence* within the borders of each state. (United Nations Universal Declaration of Human Rights 1948)."

As can be seen above, the International Declaration of Human Rights addresses the fundamental rights of freedom, right to privacy and protection from degrading treatment. How they are applied is country specific, but most commonly these are integrated as a part of the legislation, as stated above. As almost all states in the world are parties of the UN charter, the Declaration of Human Rights can be seen as a part of binding customary International Human Right law (Bilder 1999: 5-8).

The International Covenant on Civil and Political rights (1966) is one of the most basic rights conventions, which requires strong international supervision and immediate protection, as well as general reports (Rodriquez-Pinson 2003: 918). The International Covenant on Civil and Political Rights, starts by stating the importance of self-determination:

> "Article 1 *All peoples have the right of self-determination*. By virtue of that right they *freely determine their political status and freely pursue their economic, social and cultural development.* (United Nations International Covenant on Civil and Political Rights 1966)."

It continues with many other articles which can be seen to be, in some cases, applicable for the elderly living with dementia in care home facilities:

> "Article 7 *No one shall be subjected to torture or to cruel, inhuman or degrading treatment* or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation.
>
> Article 9 1. Everyone has the right to liberty and security of person. *No one shall be subjected to arbitrary arrest or detention*. No one shall be deprived of his liberty except on such grounds and in accordance with such procedure as are established by law.
>
> Article 10 1. *All persons deprived of their liberty shall be treated with humanity and with respect for the inherent dignity of the human person.*
>
> Article 17 1. *No one shall be subjected to arbitrary or unlawful interference with his privacy, family, home or correspondence*, nor to unlawful attacks on his honour and reputation. (United Nations International Covenant on Civil and Political Rights 1966)"

As stated these are some of the most basic rights which are protected by international supervision and reporting. These are again articles that are commonly integrated in the legislation of a country (Bilder 1999:5-9). It is likely that if there were a violation of these rights, it is an issue addressed in the legislation of the country and thus does not require international courts be involved.

The International Covenant on Economic, Social and Cultural Rights (1966) are seen more as goals or recommendation, and are more tied to political and economic resources and process rather than judicial action (Rodriquez-Pinson 2003: 918). Some articles from the International Covenant on Economic, Social and Cultural Rights, that can be seen to be applicable for those living in dementia care homes, are:

> “Article 1 : 1. All peoples have the *right of self-determination.* By virtue of that right they freely determine their political status and freely pursue their economic, social and cultural development.
>
> Article 12 1. The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the *highest attainable standard of physical and mental health*.
>
> 2 (d) The creation of conditions which would assure to *all medical service and medical attention* in the event of sickness.” (United Nations International Covenant on Economic, Social and Cultural Rights 1966)

Violations of these conventions that have included the distinct feature of age as an aspect of the violation have been taken to European courts, but no general guidelines or rules have been published when it comes to the violation of the rights of elderly people (Rodriquez-Pinson & Martin 2003:919-930). Because these instruments were not tailored with older people in mind, one must be able to prove how they are applicable to the case at hand, if one were to pursue a case in the courts.

The International Human Rights Instruments can be seen as moral guidelines, which as stated, are commonly integrated in legislations of countries. In Sweden this means that the government and courts must respect the international human rights documents Sweden has ratified, and human rights are not to be violated on a national or municipal level. (Mänskliga Rättigheter 2016). These above presented human rights instruments are rights intended to protect all individuals and are commonly acknowledged as essential basic rights. Although currently there are no specific conventions addressing older people, fundamentally all the above listed rights apply to those living in dementia care homes.

International Human Rights instruments are of interest when exploring people living with dementias right to self-determination, as the World Health organization and the United Nations have urged governments globally to adopt a Human Rights- based approach to their global action against dementia (OHCHR 2015). United Nations expert, Rosa Konrfeld-Matte, stated at the first ministerial Conference on Global Action against Dementia in Geneva March 2015:

> "Persons with dementia, including older persons with this disease, should be able to enjoy their rights and freedoms in any circumstances." (Office of the United Nations High Commissioner for Human Rights 2015)

As one can see, the International Human Rights Instruments entitle individuals to a high level of security of integrity and self-determination. Under international customary law, Sweden has incorporated human rights into legislation. But do human rights instruments promise too much? Even from the beginning, Human Rights Instruments have been acknowledged as being imperfect (Androff 2016:143). Critique towards human rights questions their position as inherent, comprehensive regulations of what is good and right, as well as criticizing human rights for being western-centered (Ignatieff 2001: 3-22). As human rights-based approaches are built on protecting and enforcing human rights, one must ask can human rights be seen as realistic goals and legitimate moral principles. Further discussion on Human Rights and their legitimacy will follow under "Ethical Issues Related to the Right to Self-determination".

3.2 Swedish Law

The following chapters will address Swedish legislation as well as guidelines and principles published by the National Board on Health and Welfare in Sweden, in relation to the right to self-determination for those living in dementia care homes. As the translations have been made by the author and not an official translator, the original text in Swedish can be found as a footnote.

The right to self-determination can be seen as one of the most essential rights of modern society. The right to self-determination and the possibility to be able to influence one's life is undoubtedly an essential right that a welfare society is built upon. The International Human Rights Instruments mention the right to self-determination many times, and this is also the case in Swedish law. Currently the Swedish law mentions the right to self-determination for people in need of care services on several occasions. The law on Social Services (socialtjänstlagen, abbreviated SoL) chapter 1 section 1 states:

> "Social Services shall with consideration to the human responsibility for their and others social situation strive to and develop individuals and groups own resources. Services shall be built upon respect for people's right to self-determination and integrity. (Sveriges Riksdag 2001: Socialtjänstlagen 1 kap §1)[1]

The same law on Social Services in Sweden continues to state in chapter 5 sections 4 and 5;

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[1] "Socialtjänsten skall under hänsynstagande till människans ansvar för sin och andras sociala situation inriktas på att frigöra och utveckla enskildas och gruppers egna resurser. Verksamheten ska bygga på respekt för människornas självbestämmanderätt och integritet. (Sveriges Riksdag: 2001: Socialtjänstlagen 1 kap §1)"

> “The social welfare board shall work so that the elderly have an opportunity to live and reside independently in a safe environment and have an active and meaningful existence in their community… The elderly person shall, as long as it is possible, be able to choose when and how support and help in their residence or other readily accessible services shall be provided”. [2] (Sveriges Riksdag 2001: Socialtjänstlag 5 Kap 4 §).

Other laws, such as the health care law (hälso- och sjuksvårdslagen) and law on support and service to those with disabilities (lagen om stöd och service till vissa funktionshindrade, abbreviated LSS) also describe the residents or patients right to self-determination. In the health care law it is stated in section 2 a, demands for care homes, to:

> “ Health care services and care homes should be conducted as to meet requirement of *good care*. This means that it especially is required to:
> 1. be of good quality with a good standard of hygiene and fulfill the patients need for security in health care services
> 2. be easily accessible
> 3. *build on respect for the patients right to self-determination and integrity*
> 4. promote good contact between the patient and the health care staff
> 5. Meet the patients need for continuity and security” [3] (Sveriges Riksdag 1982: Hälso- och sjukvårdslag § 2 a)

In the law on support and service for those with disabilities this statement is repeated with an addition. According to section 6 of the law on support and service for those with disabilities, LSS:

> ”Activities shall be based on respect for the individual’s right to self-determination and integrity. The individual shall to the best of their abilities be able to influence and take part in decision making that affects them.”[4] (Sveriges Riksdag 1993: Lag om stöd och service till vissa funktionshindrade § 6)

The law underlines in several parts the individual’s right to self-determination, with the distinction of the addition “ *to the best of their abilities*” in the law on support and service for those with disabilities. It is not elaborated how ones restricted abilities effect ones influence in

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[2] ”Socialtjänstens omsorg om äldre ska inriktas på att äldre personer får leva ett värdigt liv och känna välbefinnande (värdegrund). Socialnämnden ska verka för att äldre människor får möjlighet att leva och bo självständigt under trygga förhållanden och ha en aktiv och meningsfull tillvaro i gemenskap med andra. ” (Sveriges Riksdag 2001: Socialtjänstlag 5 Kap 4§)

[3] ”Hälso- och sjukvården ska bedrivas så att den uppfyller kraven på en god vård. Detta innebär att den ska särskilt 1. vara av god kvalitet med en god hygienisk standard och tillgodose patientens behov av trygghet i vården och behandlingen, 2. vara lätt tillgänglig, 3. bygga på respekt för patientens självbestämmande och integritet, 4. främja goda kontakter mellan patienten och hälso- och sjukvårdspersonalen, 5. tillgodose patientens behov av kontinuitet och säkerhet i vården” (Sveriges Riksdag 1982: Hälso- och sjukvårdslag §2a)

[4] ”Verksamheten skall vara grundad på respekt för den enskildes självbestämmanderätt och integritet. Den enskilde skall i största möjliga utsträckning ges inflytande och medbestämmande över insatser som ges.” (Sveriges Riksdag:1993: Lag om stöd och service till vissa funktionshindrade §6)

daily decision making, but one can assume this addition is intended for people who, due to disability, do not know or cannot vocalize their own will.

Under Swedish law chapter 2 section 6 all individuals are protected against any physical violation and detention.(Sveriges Riksdag 1972: Kungrörelse om beslutad ny regerinsform kap 2 §6) [5] Exceptions to all the above mentioned laws are cases of emergency, *nödrätten*, during which one may take forceful measures to hinder an individual from either harming themselves or others. Cases of Emergency are described in the penal code chapter 24 section 4:

> "A deed that one, in another case then those named earlier in this chapter, and that is done in a time of emergency, constitutes only as a crime if it taken into consideration the nature of the crime, the harm done to others or due to other circumstances is unjustifiable. Emergency takes place when the danger threatens life, health, property or other matter the law finds of protected value."[6] (Sveriges Riksdag 1962: Brottsbalk kap 24 §4)

As provision of health care services are based on consent, forceful measures may not be taken to restrict individuals living in care homes, unless it can be seen as a case of emergency (Socialstyrelsen 2013, meddelandeblad). A case of emergency requires actual threat to the physical wellbeing of the individual or others. (ibid.). This applies to all daily actions; one, according to law and regulation, should not force an individual living in a dementia care home to do things against their will unless it threatens their own or others wellbeing. One should not, according to law, deceit the residents by hiding medication in food or secretly doing actions against their will. Under current law, all action should be based on consent.

Chapter 14 section 3 in the Law on Social Services (Socialtjänstlagen) is commonly referred to as Lex Sarah. Lex Sarah was originally introduced in 1999, with the most current alterations to it being from 2011(Socialstyrelsen, Om Lex Sarah 2013). Lex Sarah was drafted and implemented after a practical nurse working in a care home publically came forth with her concerns about neglect of the residents taking place in her place of employment (Sveriges Radio 2013). Under Lex Sarah, all those working in elderly care are mandatory reporters, whom must report if they suspect or witness abuse or neglect taking place (Socialstyrelsen, Om Lex Sarah 2013). Lex Sarah reporting is only applicable to those working in elderly- or disability care and is not accessible to the general public (ibid.).

As can be seen above, ones right to self-determination is extensively protected in Swedish legislation. There are specific laws addressing elder care pointing out ones right to self-determination for as long as it is possible, as well as general laws applicable to all. In addition to legislation, the National Board on Welfare and Health has publications addressing the right to self-determination with further detail, which will be presented below.

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[5] ”Var och en är gentemot det allmänna skyddad mot påtvingat kroppsligt ingrepp ”(Sveriges Riksdag 1972: Kungrörelse om beslutad ny regerinsform kap 2 § 6)

[6] ”En gärning som någon, i annat fall än som nämnts tidigare i detta kapitel, begår i nöd utgör brott endast om den med hänsyn till farans beskaffenhet, den skada som åsamkas annan och omständigheterna i övrigt är oförsvarlig. Nöd föreligger när fara hotar liv, hälsa, egendom eller något annat viktigt av rättsordningen skyddat intresse.” (Sveriges Riksdag 1962: Brottsbalk kap 24 §4)

3.3 Guidelines and Principles

The law strongly protects the individual's right to self-determination, and this is again underlined by the National Board of Health and Welfare General Principles for Elder Care which presents dialogues and principles to work by to secure the elderly's right to a private life, self-determination, integrity and participation (Socialstyrelsen 2013, Nationell Värdegrund). These guidelines are presented in the form of a guidebook for training and development of social secretaries and care home leaders in the field of elderly care, information for the elderly and their relatives, and a report on the outcomes of the training sessions (Socialstyrelsen 2012, Utbildning). These national guidelines have also been adapted into a web-based training program (ibid.). This internet-based training program is aimed for all workers working with care services for the elderly (ibid.)

The National Guidelines as well as other publications published by the National Board of Health and Welfare deliver advice and support to municipalities and counties, which are each individually responsible for providing elderly care services (Socialstyrelsen 2013 Din Rätt till Vård och Omsorg: 3-6). All municipalities and counties must abide to the law while providing services, but may make individual decisions as to how the services are to be provided (ibid.).

In addition to the National Guidelines for Elder care, The National Board of Health and Welfare has also published national guidelines for care homes working specifically with dementia care. In practice, all elderly care services provided in municipalities and cities under the law on social services, are to work according to these guidelines (Socialstyrelsens Nationella Riktlinjer 2010: 6-7). This publication recommends person-centered care as the objective for health care and social services, mentioning that it decreases costs in the long run (Socialstyrelsen, Nationella Riktlinjer 2010:8). The publication describes person-centered care as working according to the following aspects:

- "Encountering the individual with dementia as a person with experiences, self-worth and rights despite decreasing functions
- Striving to understand what is best for the person with dementia from their perspective
- Protecting the individual living with dementias self-determination and opportunities for participation
- Seeing the one living with dementia as an active partner
- Confirming the one living with dementia in their experience of the world
- Striving to involve those living with dementias social network in the care work
- Trying to establish a relationship with the one living with dementia (Socialstyrelsen 2010 Nationella Riktlinjer: 20)[7]"

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[7] "bemöter personen med demenssjukdom som en person med upplevelser, självkänsla och rättigheter trots avtagande funktioner • strävar efter att förstå vad som är bäst för den demenssjuke utifrån dennes perspektiv • värnar den demenssjukes självbestämmande och möjlighet till medbestämmande • ser den demenssjuke som en aktiv samarbetspartner • bekräftar den demenssjuke i dennes upplevelse av världen • strävar efter att involvera den demenssjukes sociala nätverk i vården och omsorgen • försöker upprätta en relation till den demenssjuke." (Socialstyrelsen 2010 Nationella Riktlinjer: 20)

These aspects align with a person-centered care approach, but also give the care taker the rather big responsibility of trying to see the world through the eyes of one with dementia. This description of person-centered care shows a model of shared decision making, as collaboration and communication is underlined, but taking into consideration the individuals' illness is also noted. This raises some questions: if one were to personally contemplate what would be the best for a person with dementia, even out of the perspective of an individual with dementia, one could surely agree that staying inside where it is safe, taking ones medication and taking care of personal hygiene is of importance. On the other hand, one could argue that imposing such a universal view strips ones right to individuality and self-determination. These issues will be elaborated more under "Ethical Issues Related to the Right to Self-determination".

In an information sheet provided for care homes by the National Board on Health and Welfare addresses forceful measures in care homes. In this sheet it is underlined that forceful measures are not to be taken unless it is a case of emergency. This information sheet also addresses the possibility of difficult situations and proposes making a contract beforehand so that the individual may present their wishes for future care. As of yet, such contracts are not in common use, as one always has the right to change their mind and nullify the contract (Socialstyrelsen meddelandeblad 2013:1-6).

The National Board on Health and Welfare has published a learning material, "Turn the interest away from the door- Against force and restrictions" in early 2016, presenting results of a project focusing on environmental restrictions in a dementia care home (Socialstyrelsen 2016 Att vända intresset bort från dörrarna). As one may not restrict ones freedom, there have been creative solutions as to how to confine dementia care home residents without de facto restricting them. One may have the outer door and the doors of the units of a dementia care home locked, as this is customary in most people's homes (Socialstyrelsen frågor och svar om tvångs- och skyddsåtgärder inom vård och omsorg av vuxna). The lock must be one that can be reasonably opened, but it can be one that is slower to open as to give time for care takers to notice a resident leaving, and if an individual needs help in opening the door, one should immediately be able to have assistance (ibid.) In practice, this is often solved by having the door locked with a number pad lock, and having the number code in a visible place.

The project "Turn the interest away from the door" was a pilot project, which aimed to increase the freedom of residents in a dementia care home. Emphasis was put on the physical environment of the care home, coloring each unit a distinct color, and using enticing areas and camouflage to direct attention to more desirable areas and away from, for example, the stair case. Although there were concerns the residents would harm themselves when given more freedom to move around the care home, the results of the project were positive, with few residents trying to leave the care home despite unlocked doors, and new social connections between the residents being made. (Socialstyrelsen 2016 Att vända intresset bort från dörrarna).

The various principles and guidelines as well as other publications by the National Board on Health and Welfare address that there are concerns when it comes to issues of self-determination, as can be seen in the project "Turn the interest away from the door" and in the proposition of contracts concerning future care. The subject matter of these publications show that there are issues related to self-determination in dementia care that are problematic. As a solution a person-centered care approach is recommended throughout the publications, but little information is provided on how to act in actual situations that one may face in a dementia care home regarding the right to self-determination.

3.4 Person-centered Care Approach

“Person-centered care” can be seen as an umbrella term used to describe an approach used in several different (social) care services. Especially in care home facilities for the elderly, a person-centered care model is generally seen as a model that promotes the autonomy or self-determination of the residents (Alzheimers Society 2016, Socialstyrelsen Nationella Riktlinjer). While one can deduct from the name what the term refers to, making the services person centered, the definition of the term is inconsistent. The origin of person-centered care stems from the work of Carl Roger, whom came up with the notion of client-centered counselling as a tool to be used in psychotherapy in the 1960s (Brooker 2007:14). Rogers’ person centered (also known as client centered) therapy is based on 4 hypotheses. These hypotheses are 1. The inherent capacity of an individual to understand aspects causing dissatisfaction, 2. That genuine acceptance and empathy of the counsellor will help the individual release this dissatisfaction 3. In this environment the client will change perception of self and become more understanding of self and others and 4. The counselor-client relationship can be replicated in other interpersonal relationships (Rogers 1963: 4-5).

This thought of reproducing safe relationships has later been further developed by Tom Kitwood, whom in the 1980s and 1990s developed the approach “person centered” in relation to dementia, as a means to decrease disorientation and offer reassurance (Brooker 2007:14). Kitwood discusses in his book ”*Dementia reconsidered*” what those living with dementia need, phrasing his thoughts into a simple sentence: “It might be said that there is only one all-encompassing need- for love” (Kitwood 1997: 81). For clarity, he groups the needs into 5 groups: comfort, attachment, inclusion, occupation and identity (ibid.). Kitwood argues that focusing on and validating the individual, fulfills these needs, increasing the feelings of self-worth and value of the individual. If one living with dementia has even one of these needs fulfilled, they will be less distracted by anxiety and fear (Kitwood 1997: 80-85).

To be able to validate these personal, primal needs, one would need to focus on a person-centered approach or the personhood of the individual. Kitwood presents the notion of personhood, which he describes as

> “a standing or status that is bestowed upon one human being, by others, in the contexts of relationship and social being. It implies recognition, respect, and trust. Both the according of personhood, and the failure to do so, have consequences that are empirically testable” (Kitwood 1997:8)

Kitwood acknowledges the requirements a “person-enhancing” approach bestows upon care takers and has written extensively about the personal development and requirements that are demanded for the care takers to implement such an approach (Kitwood 1997: 118-132).

Kitwood compares individuals living with dementias needs as to those of children (Kitwood 1993:57). While children’s nervous system is in a state of maturation, one living with dementias nervous system is in a crucial decline. Kitwood draws an analogy; if ones gestures receive no response as a child, they will fall into a state of compliance; this may also be the case for those living with dementia (Kitwood 1993: 57-63). Person-centered care could thus be seen as a tool to maintain and preserve ones identity when one is living with dementia, by reinforcement of basic needs. What is important to note is that this approach to person-centered care, from the beginning, emphasizes the role of care takers in validating the emotions and needs of those living with dementia.

As stated, there is no one definition to person centered care, but most descriptions have significant similarities. In her book "Person-centered Dementia Care: Making Services Better" Brooker describes person-centered care as consisting of 4 major elements. These elements (which are abbreviated VIPS) are:

> "V a value base that asserts the absolute value of all human lives regardless of age or cognitive ability
>
> I An individual approach, recognizing uniqueness
>
> P Understanding the world from the perspective of the service user
>
> S Providing a social environment that supports psychological needs (Brooker 2007:12-13)"

Person-centered care often works as the value base in policies presenting dementia care, but has also been criticized for being a vague but politically correct term that is repeated without further description as to what this approach actually includes (Baker 2015:21-24; Brooker 2007:11). One can see person-centered care as a shift from the traditional "task-model" of work, were work is done according to a set schedule, to a working approach that focuses on the needs of the individual. (Baker 2015:21-23). This is also visible in the VIPS-model developed by Brooker above. One could say that a person-centered approach in dementia care places the individuals' needs first, but with recognition to their specific needs due to their illness. This places high requirements for the care staff, almost putting them in the position of a moral compass for those living with dementia in a care home setting.

One simplified interpretation of person-centered care, by the National Health Service in Britain understands the approach as one that offers the individual the opportunity to make choices about their own care (Brooker 2007: 20-22). Unfortunately a person-centered care approach, even when broken down to the simple statement of one being able to decide and make choices concerning their own care, has several challenges and possible limitations when referring to individuals living with dementias right to self-determination, as sometimes the individual may not know or be able to vocalize what is best for them.

The emphasis on a person-centered care approach can be seen throughout the current legislation in Sweden as well as the guidelines published by the National Board of Health and Welfare. In some cases, a person-centered care approach can be seen as serving as a platform to actualize human rights, such as the right to self-determination, depending on which interpretation of person-centered care one takes. Kitwoods model of person-centered care acknowledges the responsibility of care takers, while more modern variants mention, but do not elaborate, as to the responsibility of care takers. Bookers' model, as well as the guidelines of the National Board on Health and Welfare, mention the care taker, but also put more emphasis on the right to self-determination.

This leads to one of the current challenges of person-centered care: in which level and how is it implemented. Kitwood explains in great detail how person-centered care should be used according to his model, but currently there are different interpretations and policies within the person-centered care approach (Brooker 2007:11-23). When referring to person centered care is one referring to a value base or ideal that one should work according to? Is it merely a set of individual-based practices to be implemented in daily work (for example viewing showering once a week as essential for all individuals- everyone must shower no matter what)? Or is person-centered care an approach that can be altered according to different situations (it is okay for a certain individual not to shower this week)? Depending on how one interprets the notion of "person-centered" care, one may end up with many different solutions on how it is to be implemented. Person-centered care could, at its simplest, be referring to just offering opportunities, or be referring to an approach like Kitwoods model, which incorporates several different aspects of the individual's life and sets specific demands on the care staff.

Another current challenge, which will be further discussed under "Ethical Queations Related to the Right to Self-determination" is to what extent can people living with dementia make (informed) decisions and should one be able to restrict this right for the individuals own wellbeing? If one were to deny ones right of self-determination, who should be the one making this decision; a practical nurse, a social worker, a relative or a doctor?

It can be said that person-centered care as an approach lacks consistency in its description. While one may view it as an intricate care model, others may view it as providing opportunities or even just reinforcing the right to self-determination. The National Board on Health and Welfare in Sweden has described a person-centered care approach as an approach where the care taker should: "Strive to understand what is best for the person with dementia from their perspective."(Socialstyrelsen 2010 Nationella Riktlinjer: 20). This perspective that promotes person-centered care as an approach where a secondary party should seek the best from the perspective of the one with dementia, will be used in the following analysis of the survey answers in this thesis.

3.5 Human Rights- Based Approach

A human-rights based approach is built on the notion that the individual is entitled to rights, rather than framing the services used by the individuals as needs (Berthold 2014: 3-6). In other words, the individual is entitled to, for example, good quality elderly care. This puts the individual in a different position: rather than being seen as a person in need that is dependent on others, the person is a rather person that is entitled to certain rights. The human-rights based approach to social work is a rather new approach, which was first mentioned in 1988 in a policy statement by the International Federation of Social workers, in which it was stated:

> “ Social work has, from its conception, been a human rights profession, having as its basic tenet the intrinsic value of every human being and as one of its main aims the promotion of equitable social structures, which can offer people security and development while upholding their dignity. “ (IFSW 1988, introduction, UN, 1994, p.3 as cited in Androff 2016:2)

Since then, the human rights based approach has been a growing approach in social work. A human-rights based approach, as many other approaches, lacks one universal description, but seeks to promote relevant human rights such as human dignity, non-discrimination, transparency, accountability and participation (Androff 2016 26-27). A human-rights based approach can be seen as an approach that puts the individual first, similar to person-centered care, but emphasizing, acknowledging and recognizing the individuals’ human rights, such as the right to self-determination, dignity, autonomy, independence, and freedom to make their own choices (ibid.).

In 2015, the United Nations and World Health Organization published a thematic brief for the first Ministerial Conference on Global Action against dementia. In this brief, the Human-Rights based model, proposed by the World Health Organization and the United Nations, is presented. This Human Rights- Based Approach is built on a framework called “PANEL”. PANEL is an abbreviation of the words Participation, Accountability, Non-Discrimination, Empowerment and Legality. (World Health Organization: Ensuring a Human Rights-Based Approach for People Living with Dementia: 2015: 1).This brief presents this human right-based PANEL framework, clarifying each of the 5 elements. I have italicized parts of this framework to highlight parts that are relevant in the analysis of this document. Participation, according to this framework, is described as:

> “ People living with dementia and their caregivers have the right to *participate in all decisions which affect their lives* and wellbeing. Additionally, *people living with dementia and their caregivers* have the right to *participate in the formulation and implementation of policies* that affect them….. *people living with dementia and their caregivers* should be provided with accessible information and the support they require to empower them to *exercise their right to participate in decisions* that affect them (ibid.).”

As can be seen, this description of participation underlines the individuals’ right to participate in all decisions, but notes that the caregiver also has a role in this process. This addition implies this framework leans more to person-centered model, where assistance from a caretaker is assumed. This can be seen as partly contradictory to the continual emphasis on the individual’s right to decide. When referring to accountability, the PANEL framework states:

> “People living with dementia should be able to exercise their *human rights and fundamental freedoms in all aspects of their daily lives including full respect for their dignity, beliefs, individual circumstances and privacy*. Public and private bodies, nongovernmental organizations and individuals *who are responsible for the care* of people living with dementia *should be held accountable for the respect and protection of their care recipients* and adequate steps should be adopted to ensure this is the case. States, organisations and individuals who care

> for people living with dementia are therefore, responsible for respecting and protecting their human rights. If they fail in this duty then *a person with dementia should have access to justice*, on an equal basis with others, as well as to be able and supported to initiate proceedings for appropriate redress before a suitable court. Therefore, it is important that the creation and implementation of laws and policy, which affect people living with dementia, are transparent to ensure that *people know their rights and how to claim them*." (World Health Organization: Ensuring a Human Rights-Based Approach for People Living with Dementia: 2015: 2)

Here again emphasis is put on the fundamental rights and freedoms of people living with dementia, calling out all whom are responsible for care to be held accountable for the respect and protection of their care recipients. Here again a contradiction occurs; sometimes respecting self-determination may go against ones sense of morality. If for instance a care taker is to protect the inherent right of self-determination and let a resident freely leave a care home, under current Swedish law, this person is likely to be reported under Lex Sarah for neglect. Should one be held accountable for doing something that can be seen as an act of caring and reducing suffering? The brief continues by presenting the notion of empowerment, by stating:

> "People living with dementia should be *empowered to claim their rights* rather than simply wait for policies, legislation or the provision of services. As rights-holders, they should be able to *exercise their rights in all circumstances*. Related to this, people living with dementia should be able to enjoy legal capacity on an equal basis with others. Therefore, clear distinction should be made between mental capacity and legal capacity in order to clarify that the right to exercise legal capacity should not hinge on mental assessments. People living with dementia have, regardless of diagnosis, *the right to recognition everywhere as people before the law* and the right to choose the support that he or she may need or require. Conversely, in many countries, there exist legal provisions that allow forced treatment and substitute decision making in relation to psychiatric and other medical treatments. This affects people with psychosocial and intellectual disabilities and people with dementia. *Those legislative provisions should be abolished and replaced by legislation that ensures free and informed consent to treatment, supported decision-making, and procedures for implementing advance directives* (World Health Organization: Ensuring a Human Rights-Based Approach for People Living with Dementia: 2015 :3)."

Under this statement there is a call to abolish legal provisions that allow forced treatment, but then proposes legislation that ensures supported decision-making. It is not stated whose responsibility it is to support in decision making, but this wording can be seen as implying granting the responsibility, at least in part, to someone else. Under legality the importance of Human Rights is again emphasized and, based on this framework, measures related to dementia are to be linked to Human Rights Instruments.

> "All measures related to dementia adopted by States and other stakeholders *should be linked to human rights standards* contained in, and principles derived from, the Universal Declaration of Human Rights and other international human

> rights instruments. This includes all measures adopted related to dementia, including the development of policies and legislation, the implementation, monitoring and evaluation system and *the entire care chain*, from raising awareness to prevention, diagnosis, *care and services* and research programmes.(World Health Organization: Ensuring a Human Rights-Based Approach for People Living with Dementia: 2015:4)"

This human-rights based PANEL framework ends with stating the following:

> "International strategies and national frameworks for protecting the rights of people living with dementia should include PANEL+ . *It should be highlighted that people living with dementia have the right to participate in society, and ensure that those responsible for protecting the human rights of people living with dementia should be held accountable for any human rights violations*. In addition, there should be increased education about dementia to change attitudes of society and reduce stigma. Lastly, people living with dementia should be empowered to participate in decision making processes and to maintain their legal capacity.(World Health Organization: Ensuring a Human Rights-Based Approach for People Living with Dementia: 2015:4)"

This final statement is one of interest, as it again calls for those responsible for protecting human rights be held accountable for violations. If this human-rights based model were to be implemented, should one report a nurse that "forces" a resident in a dementia care home that, has had an accident, to shower? Or a nurse who restricts a resident from leaving the care home during a cold winter day? Or does the above mentioned supported decision making apply in such situations?

These two approaches, the person-centered care and human-rights based approach to dementia care have both similarities and differences. While a person-centered care approach emphasizes individuality and individual needs, a human-rights approach presents a practice that incorporates all, despite their limitations, as human beings with the same rights. As both approaches certainly aim for seeking what is best for people living with dementia, it is important to discuss what aims and working models are realistic in a care home setting. While a human-rights based approach in dementia care could be seen as a useful platform when discussing the right to self-determination, it is evident it leaves many questions unanswered. On the other hand a person-centered model, which is currently a popular framework in dementia care, takes a more paternalistic approach to dementia care, but currently fails to address how to deal with challenging situations as its description is often vague and sometimes in contradiction to human rights. For either of these models, or even a possible combination of these models, to work as a part of daily care work, discussion, consensus and clarification is required.

To build a working, consistent model, one must inspect the several limitations and problems in both these approaches; is it moral to let one with an illness that degenerates the brain make decisions on their own? What role does medication play in hindering one's ability to autonomy and self-determination? Is there a point at which ones right to self-determination ends, when is this, and what is the common good one is seeking to achieve by restricting those living with dementia? Who should be able to make decisions on the others behalf? Is the right to self-determination an inherent right that should be protected in all situations? Some of these questions will be inspected with further detail in the following chapter.

4. Ethical Issues Related to the Right to Self-Determination

As presented above, the analytical framework of this thesis builds upon two different approaches identified and endorsed in the relevant documents concerning the right to self-determination for those living in dementia care homes. These two approaches do not have one acknowledged set of how they are to be implemented, and as presented they differ in content depending on their interpretation. As these approaches lack consistency, they leave many ethical and moral questions unsolved, depending on their interpretation. This following chapter will present different moral and ethical questions that the right to self-determination encompasses, aspiring to present the most essential ethical questions to be taken into consideration while examining the right to self-determination for those living in dementia care homes. This will be done by presenting the ethical dilemmas of the two presented approaches, as well as the ethical dilemmas regarding the moral of the staff of dementia care homes and the ethical considerations of dementia care on a societal level.

As stated, the right to self-determination amongst those living with dementia in dementia care homes incorporates many ethical and moral issues. Not only is it an issue of self-determination, but it is also an issue closely connected to the implementation basic human rights. As previous research showed, most workers in the field of dementia care prioritize the right to self-determination, but acknowledge that there are severe limitations to actualizing this right. Despite this fact, although one lives with an illness, ones right to make decisions regarding oneself should not be completely stripped from the individual; this is protected by human rights instruments as well as Swedish law.

One of the biggest problems in current legislation and guidelines are that they are ambiguous and contradictory, which leads to unnecessary and unfair amounts of responsibility left on the shoulders of practical nurses and other care home staff. As the amount of costs are expected to rise for elderly care and the amount of people living with dementia increase, the need for workers will surely also increase. To ensure good quality care in the future, it is important to address and answer questions related to the right to self-determination for those living in dementia care homes. To achieve this, moral questions related to the right to self-determination should be discussed on a societal level.

One of the primary issues related to the right of self-determination is that elder care services are voluntary services, and essentially forceful measures may generally not be taken (Socialstyrelsen frågor och svar om tvångs- och skyddsåtgärder inom vård och omsorg av vuxna). In practice the residents are in care homes voluntarily and essentially have the same rights as everyone else in society. The laws related to care services for older people generally promote and protect the individual’s right to self-determination. As care services are voluntary, forceful measures may not, according to law, be taken to restrict the residents. If one were to witness abuse or neglect, which forceful measures can be seen as, under Lex Sarah, care home staff would be obliged to report that action. But are there cases where forceful measures are admissible?

The ethical aspects related to the right to self-determination can be seen from several different perspectives, which I have listed here as:

1. The inherent right of the individual to self-determination, according to international Human Rights Instruments and law – usually implemented in a Human Rights- Based Approach

2. The right for individualized, person-centered care, that takes into consideration the best of the individual from the perspective of others – usually implemented in a person-centered approach

3. The moral responsibilities of the care home staff as caretakers of individuals living with a degenerative illness

4. The moral responsibility of society to either reinforce self-determination or protect the individual

If one is to first inspect the right to self-determination based on Human Rights and current laws, it leaves little ambiguity. According to ones right to self-determination, a resident in a dementia care home should always have a say in matters that affect them. This would be endorsed by a Human Rights based approach, which emphasizes an individual's right to basic human rights, such as self-determination and protection of privacy. This perspective is of course problematic on a societal scale. If society would leave all decisions up to the individuals living with dementia themselves, it would likely lead to a public out roar and accusations of neglect, as people with dementia are often impaired to make informed decisions and may refuse or forget to take care of personal hygiene or eat. The individual with dementia may also want to leave the care home and wander on the streets lost and confused. The ethical questions here are: does ones right to self-determination end when one enters a dementia care home? And if it does, to what extent, when and concerning which issues? How could this approach be viably implemented in dementia care?

In addition to the above mentioned problems, human rights themselves have been critiqued by many. Ignatieff (2001) voices critique and points out limitations to human rights, starting with the limitations of logic and formal consistency. Human rights demand respecting the autonomy of agents and the right to define what type of life one would like to live. This language implies that human rights restrict the life of those who do not confess to these rights. (Ignatieff 2001:17-22). If one would like to lead a life that contradicts with human rights, which are generally viewed as superior moral guidelines, this individual would likely to be prosecuted for breaking human rights. This contradiction is a logical fallacy of human rights which is often brought up in critique.

A second limitation and critique of human rights is the western moral imperialism of human rights, and the desire to spread human rights. With trying to spread human rights globally, the west is intervening with affairs of other societies, making them morally superior (Ignatieff 2001:17-22). This critique points out that other cultures and nations may have different views as to what are inherent rights, and by declaring human rights as universal one is practicing moral superiority over other cultures and nations views on moral issues.

Ignatieff goes on to pointing out human rights principles may in themselves conflict and people may have different interpretations of the contents of the rights. This can be seen in abortion discussions, were both parties agree to protect human life, but disagree as to when human life begins (Ignatieff 2001:17-22). As human rights are subject to interpretation, one must acknowledge that different individuals may have different views and opinions as to how human rights are to be interpreted.

Finally, Ignatieff argues that human rights are essentially politics, which may be useful during moral deliberation, but are not to be seen as rights above politics and discussion. He concludes that one can view rights as either nonnegotiable rights, or as a framework to set reference points and to assist deliberation (Ignatieff 2001:17-22). This final statement points towards a general, ongoing discussion in relation to human rights; can rights that were made by a group of Europeans in the 1940s be all encompassing rules that should reign above all others? When enforcing a human-rights based approach to dementia care, or social work in general, it is important to discuss these limitations and reflect upon the general moral standards of the society in question.

If one inspects the model of a person-centered care approach, there are different kinds of moral issues that arise. The model of person-centered care that is often implemented in dementia care homes emphasizes the experience of the individual, but also often requires moral stances be taken by care home staff (Kitwood 1997:118-132 ; Brooker 2007:12-13). Person-centered care taking place in dementia care homes often mentions the care takers responsibility to try to understand situations from the perspective of the care home resident (ibid.). While in itself one can understand that practicing empathy and trying to understand the situation from the viewpoint of the other will often lead to good intentions and solutions, it does shift the moral responsibility and obligation from the resident to the care taker.

As everyone has their own views and moral stances, situations may differ dramatically when the responsibility of doing the best for the resident is placed in the hands of the care taker. A hypothetical situation could be as following: a resident does not want to shower; maybe the resident is not accustomed to showering often, or just does not feel the need for other reasons. Although the resident has refused, the care taker might think that showering on a weekly basis is a basic need or that the resident is so dirty that they, in the care takers opinion, need a shower. Maybe the resident is so dirty that they need a shower no matter whom you ask. Since the resident has dementia, one can understand that they do not necessarily understand what is best for them, and forcing them to take a shower is the best outcome for the resident themselves.

There are several issues to weigh in such a situation. The care taker must weigh the expectations of the employer and residents’ relatives when working; if the resident is not showered for a long period of time it is likely someone will bring up the situation and demand clarifications as to why this situation has developed. Under current law, one is to respect the residents right to self-determination when they refuse to shower, and is in practice, breaking several laws by “forcing” a person to shower. On the other hand, if the care taker does not help the resident shower, they might be reported according to Lex Sarah for neglect.

The person-centered care model also requires one weighs the individual's right to good quality care, remembering that good care also includes respecting ones right to self-determination. The health care law (hälso- och sjukvårdslagen), which was presented under "Swedish law" states "*good care*" as the requirement for health care services. Here again a moral dilemma occurs: according to whom is good care provided? According to this law, under the description of what good care entails, it is stated it should "*build on respect for the patients' right to self-determination and integrity".* Is the definition of good care providing care that respects the individuals' right to self-determination? Or is good care an approach that looks at the best for the individual from the perspective of what is the common standard of good, when one has an illness that impairs one from seeing it?

This leads to the third moral dilemma; what is the responsibility of the care taker? If there is an outside individual making decisions on behalf of the individual living with dementia, whom should this responsibility be bestowed upon? As everyone lives in a subjective reality, care workers may prioritize needs and wants in a different way. Should a care taker be the one making decisions on the residents behalf? What qualifications should one making decisions have? Or should the loved ones of the individual living with dementia be the ones to make decisions regarding the individual with dementia?

If the care home staff are the ones to make decisions, as is in the current situation, how does their own moral judgment effect the care received? While one may prioritize the need to take medication, another staff member may feel it is more important to respect the right to self-determination. As previous research by Mathiasson&Andersson (1995) and Persson& Wästerfors (2007) showed, organizational structures may also influence how staff value the right to self-determination.

Finally, there is the question of the moral of society. As presented, current policies are contradictory and essentially staff of dementia care homes are tackling these moral questions on a daily basis. One of the problems with the right to self-determination concerning people living with dementia in dementia care homes is that they may have difficulties voicing their intentions or opinions, and it is almost impossible for them to report violations of their right to self-determination. In all reality, it is possible they don't even remember their rights being violated. This leads to a question that should be reflected on both a societal and political level; *if the right to self-determination is being violated for the best of the resident, should there not be clear guidelines and instructions as to what these situations are and how they should be handled?* It is evident not many would be willing to restrict ones right to self-determination, but the current situation places both the residents and the care takers in a precarious situation.

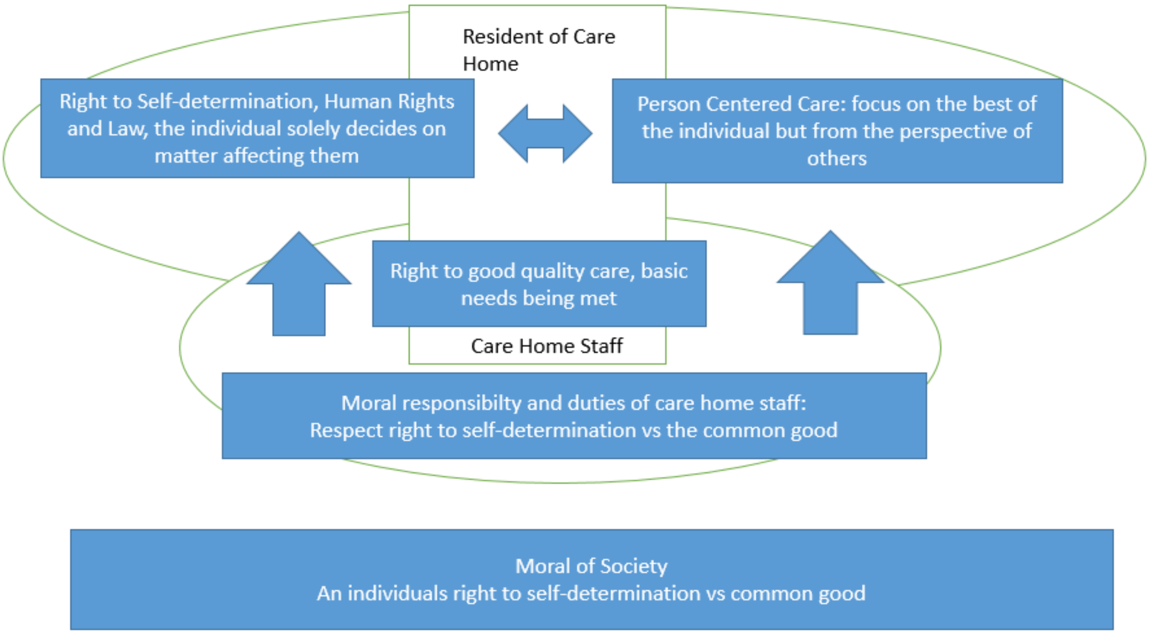


Image 9 The chart above exemplifies the different perspectives of moral questions related to self-determination. The basis for all is the moral of society and the standards of either valuing the individuals' right to self-determination or valuing the "common good", or what is perceived to be good for the individual who is impaired in making informed decisions. Both the resident and the care home staff assume good quality care and basic needs being met as a prerequisite. The care home staff based on their own preference then assumes one of the two perspectives; either respecting the right to self-determination, or striving for person centered care which takes into consideration their illness.

It is easy to understand why a person-centered model is often chosen as an approach used in dementia care homes. It encompasses both the individuals' rights but also requires others help interpret and understand the situation to ensure the best outcome of the individual. Unfortunately, although the approach has the best of intentions, it leaves much up to interpretation, leaving both the individual living with dementia and the care taker in a difficult situation. According to current law, respecting an individual's right to self-determination may in many cases put the care taker in a situation where they risk being reported for abuse or neglect. On the other hand, if one does what is best for the resident in their own interpretation, the residents' right to self-determination may be violated.

The moral responsibility of the care home staff is an issue that should be further researched. As stated, care home staff can almost daily be faced with situations that require moral decision making, with all alternatives leading to a solution that could be classified as a crime. I would propose further research into how this moral responsibility affects the turnover, perceived stress and working moral of care home staff, as well as how this responsibility is perceived by care takers and how would they prefer issues of responsibility be solved. It would also be important to research questions related to the right of self-determination from the perspective of the people living with dementia and their loved ones.

These ethical considerations presented above are often lacking in the discussion and literature related to how issues of self-determination are to be resolved in dementia care homes. The two presented approaches that the analytical framework for this thesis is built upon have opposite solutions to how self-determination should be addressed in dementia care homes. As presented above, addressing self-determination for people living with dementia as an issue of societal significance, rather than an issue of personal preference, is essential if one wishes to solve these questions in a manner that does not compromise the personal morality of the residents and staff, or even the morality of society at large.

5. Methodology

The method used for this study was a qualitative online based survey. The survey was directed to employees working in dementia care homes, with no profession-specific limitation. The survey was addressed to employees, as collecting data from people living with dementia may be both challenging and the reliability of the results questionable. As the subject of this study, the right to self-determination among those with dementia living in dementia care homes, is an emotion provoking and sensitive subject, using an online based survey was chosen as it provides a platform that ensures anonymity and ease.

5.1 Method

My motivation for choosing the topic of issues related to self-determination lies in my personal experience of working in dementia care homes in both Finland and Sweden. Throughout my work history the question of self-determination in dementia care homes surfaced almost on a daily basis- everyone had their own view on how things should be done. As there is lacking consensus and ambiguity as to how the right to self-determination should be implemented, I decided to further research this issue. Based on my personal experience, I acknowledge the challenges in finding respondents- the topic is sensitive and many are unsure as to what is the right way to address these issues. Due to the ambiguous situation, I felt that an online based-study could provide more accurate and honest answers, as the responses are ensured to be completely anonymous.

An online based survey was chosen over a paper survey form for several reasons. Some of the advantages of web page based surveys include speed, audience, economy, added content options, expanded question types, the ability to ask sensitive question and anonymity (Sue& Ritter 2007:11). The combined benefits of speed, possibility to ask sensitive questions, ensured anonymity and reaching a distinct audience were the main benefits of choosing an online survey. Using an online-based survey also provided the respondents the opportunity to reflect and respond individually with reduced external pressure, as they could choose the time and place to fill out the survey. The survey was completely anonymous and no personal information was collected at any point. This was also emphasized to the respondents in the beginning of the survey, to help ensure valid answers.

In addition to these listed benefits, there is the ecological aspect of saving natural resources by reducing unnecessary paper copies. A survey was chosen as the method to research the right to self-determination over other methods, due to its broad perspective. Interviews and observation may provide valuable information, but a survey has the possibility to give a general overview of the situation of those living in dementia care homes. As this is a subject that has not been thoroughly studied, a general overview of the current situation is one of the main objectives of this study.

5.2 Structure

The survey used for this research consisted of 20 questions (See: Appendix 2). First, background information questions were presented: profession, education, how long the respondent has worked in elderly care, length of current employment relationship and the amount of residents in the care home. The objective of these questions was to give an overall view of the experience and educational background of the respondents. The question about the size of the care home was to determine if there is correlation in the answers in regard to the amount of residents in the care home and the amount of self-determination the residents are seen to have.

After the background questions, a quote from Socialtjänstlagen (SoL 5 kap. 4§ socialtjänstlagen 2001:453) was presented which describes principles according to which elderly care should be implemented, including a mention of the right to self-determination. The respondents are asked if they feel the principles in the quote mentioned are implemented in their daily work. This was chosen as one of the first questions to see if the respondents relate to and agree with this principle being implemented, and to be able to compare this answer with the following answers. For example, if one agrees self-determination is enforced, yet the residents may not decide when to shower or are forced medication, there could be an interesting moral conflict or semantic misunderstanding in the answers.

The following question was if the respondent feels that the right to self-determination is respected. After this, multiple choice questions are presented as to if the residents may decide when to eat, when to take part in activities and other questions relating to their daily decision making opportunities. If the respondent answers no or partially, further explanation is then required in an essay-style answer.

The survey also used vignettes, which are brief verbal outlines of a scenario, with hypothetical situations and characters (Oxford Dictionary of Psychology 2015). Vignettes are often used in psychological research, to capture opinions, attitudes, beliefs or judgments (ibid.). Vignettes were chosen to capture how respondents would react in distinct situations. The vignettes chosen for this survey are based on real life events I myself and my colleagues have encountered while working in care homes. Four vignettes were presented, and essay-style answers were requested. The survey concludes with asking the respondent if they have any further thoughts on the right to self-determination and how it could be improved in general.

5.3 Distribution

Internet based surveys have been criticized for being vulnerable to outside respondents; there is a risk of individuals, who are not in the intended target group, sabotaging answers (Mann &Stewart 2010: 161) This online survey was distributed as a direct link to care home managers, to be sent out to the chosen audience, minimizing the chance of invalid answers. This method of distribution was also beneficial in reaching the correct audience; as almost all workers have personal work e-mail accounts, the link can be sent directly to the intended participants.

The demographic of this survey was all employees that take part in care related issues in dementia care homes. The link to the survey was sent out to care home directors, and asked to be forwarded to all employees e-mail addresses. Along with the e-mail a pdf file presenting the questions of the survey was attached, as to allow the respondents to view the questions before deciding to take part in the questionnaire (See appendices 3-6). The survey was sent to 13 dementia care home managers in Göteborg, 8 dementia care home managers in Mölndal, 7 dementia care home managers in Kungsbacka, 3 dementia care home managers in Mölnlycke, 4 dementia care home managers in Borås, the managers of 12 units in Stenungsund, the managers of 6 units in Partille and the director of elderly care in Vårgårda, as well as to the general e-mail address for elderly care services in Lerum. In all the survey was sent to 55 dementia care home managers or care service managers, with the request to forward the survey to the employees of these care homes.

The care homes were then given 1 month and 2 weeks' time to distribute and answer the survey. A total of 14 responses was acquired. Two of these responses were invalid responses by care home managers viewing the survey and mistakenly pressing submit. These care managers sent an e-mail stating they had mistakenly pressed submit at the end and asking if these responses could be deleted, as they were only random numbers and letters. These answers were deleted from the total.

5.4 Challenges

One of the biggest challenges in researching the right to self-determination in dementia care homes was finding participants. Although the survey was sent out to a vast audience, many reminder e-mails had to be sent, and the area to which the survey was sent out had to be extended. Some recipients of the e-mail replied that the subject is interesting, but stated they are not able to take part, without specifying a reason. This was to be expected, as the subject is an emotional one, with many underlying questions as to what is the right way to approach the right to self-determination of those living with dementia.

A notable challenge is the small amount of respondents. Although the survey was available for almost 2 months, only 12 responses were obtained. Although the sample is rather small to give an overview of the situation of the right to self-determination in dementia care homes, it does provide insight into how differently members of the staff perceive questions surrounding this issue. The small sample is still something one must take into account when drawing conclusions from the data.

The fact that data has been obtained from care takers must also be taken into consideration when viewing the answers: the answers reflect the personal view and perception of the employees. An internet based survey was chosen due to the subjectivity of the answers: reaching a larger audience provides better opportunities to obtain a more authentic overview of the current situation. A larger sample was desired to be able to determine if there are differences in practices, and the current data does, despite being a small sample, show conflicting practices.

Reliability and evaluating reliability is an important feature of research (Vetenskåpsrådet 2011: 45). As stated earlier, an online based survey was chosen to increase the reliability, as only the intended audience should have access to the survey. This aspect increases the reliability of the data itself. One challenge of reliability is for the researcher to not overestimate the results (ibid.). The original quotations of the respondents have been left visible to show the exact answers, as well as to minimize the risk of over analysis. The chosen method of analysis, which will be presented below, was also chosen to increase reliability by not grouping answers into too narrow groups.

5.5 Method of analysis

In research, data collected from computer-mediated communication is seen as a method that bypasses the traditional face to face interaction, which is commonly associated with interviews and qualitative data collection (Mann &Stewart 2010:181). Computer-mediated communication presents researchers the opportunity to collect data in an anonymous way, but at the same time also presents challenges in the interpretation of data. Some argue that computer mediated communication can be seen as a mix between oral accounts and written accounts (ibid.). Some view it as its own communication style, as computer-mediated communication has become an ever more popular mean of both formal and informal communication between people (Mann& Stewart 2010: 181-184)

If one is to obtain this view of computer-mediated communication being a mix between two communication styles, written and oral, one must look at the limitations in both methods. Many researchers argue that face to face communication provides a platform for the interviewees to express emotion and atmosphere in greater accuracy, and in a way that cannot be expressed in writing (Mann& Stewart 2010: 182-183) Lack of personal expression in written accounts have also been criticized, although one may see both methods as similar in limitation: as much as an author is writing to a reader an oral account is expression from the speaker to the listener (ibid.).

As in oral communication, spontaneity and the casual language commonly used in computer-mediated communication have been brought up as negative aspects of this mode of communication. Other issues of concern include increased misunderstanding, due to lack of the possibility of asking for clarification which is a similar concern in traditional written communication (Mann& Stewart 2010:184-185). A positive aspects of computer-mediated communication is that it gives the respondent time to reflect on answers, without losing the benefits of casual oral conversation. Often one may express themselves in an informal way when focusing on answers using computer-mediated communication (Mann& Stewart 2010:184-186). This is visible in several answers of this survey, as informal language is used by several of the respondents, giving the responses a feel of sincerity.

Computer-mediated communication can vary according to individual expertise and usage (Mann& Stewart 2010: 182-183:189). This is to be taken into consideration while analyzing results; some respondents may be unfamiliar with computer mediated communication, and for this reason express themselves in a casual or overly formal way. One of the benefits of computer-mediated communication is the opportunity to conduct research in a way that is not overly formal or academic (Mann& Stewart 2010:192). This aspect can be seen as especially beneficial in this study, as practical nurses and other workers of dementia care homes may not be familiar or accustomed to interacting with researchers. An internet survey provided the staff of dementia care homes an opportunity to voice their opinion without any outside distraction and on their own terms.

In oral data text, interpretation by the researcher is sometime required to understand the meaning or mood of the respondent in a way that may result in miscommunication (Mann& Stewart 2010:193). Oral data also often requires some interpretation of non-verbal information by the researcher(ibid.) Computer-based communication has the advantage of capturing some of the non-verbal communication in form of emoticons and expressions, ensuring that the data is what the respondent intended it to be. One of the biggest advantages of computer-mediated communication can thus be seen as the information not being colored by the researchers theoretical and methodological choices, but expressing the reality of the respondent (Mann& Stewart 2010: 193). Due to this aspect the responses are visible in their original format in Swedish as a footnote at the bottom of the page, and translations of the responses are kept as close to original as possible.

The method of analysis used for the data of this study was thematic analysis. Thematic analysis is a method of analysis that searches for themes in the data, by having the researcher identify both implicit and explicit within the data. (Guest, MacQueen& Namey 2012:10-11) Thematic analysis is commonly used to capture the complexities of meaning in a written text, but due to the role of the researcher working as the interpreter, it requires special attention be paid to reliability of the data (ibid.)

The objective of the analysis was to collect similar answers, and compare how they relate to the main analytical framework. When applicable, the responses are grouped based on their description of the matter of self-determination and preference towards a person-centered approach that promotes a secondary parties involvement related to issues of self-determination, or a human-rights based approach that emphasizes the individual’s right to self-determination. Responses that can be seen as non-relatable to these categories or philosophical in nature are presented as free standing, individual statements, and when possible, presented as themes that are similar in nature. The focus of the analysis is to show the two contradictory models, and how they are actualized based on the subjective interpretation of the care taker. The focus of the analysis is to show if the respondents are preferential to an approach, and the reasons why they feel so. The analysis also aims to present how issues related to self-determination are either addressed by the two presented approaches, or addressed as organizational or structural issues, where the responsibility of questions related to self-determination are outsourced.

5.6 Ethics

Ethical matters are essential to reflect upon when conducting research. Research is performed to obtain new knowledge, but there are aspects and restrictions one must take into consideration, one of the most important features being assessing risks and benefits (Vetenskåpsrådet 2011: 10). The benefit of this survey was to accumulate more data on practices being used in dementia care homes, to be able to compare how they reflect current laws and guidelines. The risk of this survey was compromising the respondents by insufficient anonymity. This risk has been minimized by choosing a survey platform that ensures anonymity, as described previously.

Evaluating reliability is one aspect of ethical research (Vetenskåpsrådet 2011: 44). Acquiring personal work e-mail accounts of people working in dementia care homes is not possible as they are not public information. Due to this fact, the survey was sent out to care home managers. Here one must assume trust towards the care home managers, in the fact that they only sent links to the survey to employees as requested.

Transparency of research is seen as an essential part of good research practices, (Vetenskåpsrådet 2011: 66) Transparency of this research was insured with detailed information of the research and goals in both the introduction e-mail sent to care home managers, as well as providing the same information at the beginning of the internet survey.

According to laws and moral of research, informed consent should always be obtained (Vetenskåpsrådet 2011: 22) Consent of the participants was insured by informing participants that taking part in the survey is completely optional, and that no personal information will be collected. Due to the survey form being an online based survey, it is impossible to trace which answer belongs to whom, as no information as to where the person works was collected, only occupational title and size of the care home was obligatory information.

Based on the Helsinki Declaration confidentiality is an essential part of good research (Vetenskåpsrådet 2011: 67). Autonomy and confidentiality was also insured by having an anonymous online survey; the collected data was used only for the research process, and the only one with access to the answers is the researcher. Due to the design of the questions and used method it is impossible to trace the answers to a specific individual or even region. The final question of the survey provided the participant an opportunity to give any final thoughts or views on the question of self-determination in general. Contact information to myself and my supervisor was provided in both the introduction e-mail and beginning of the survey, in case the participants had any additional questions or comments on the research.

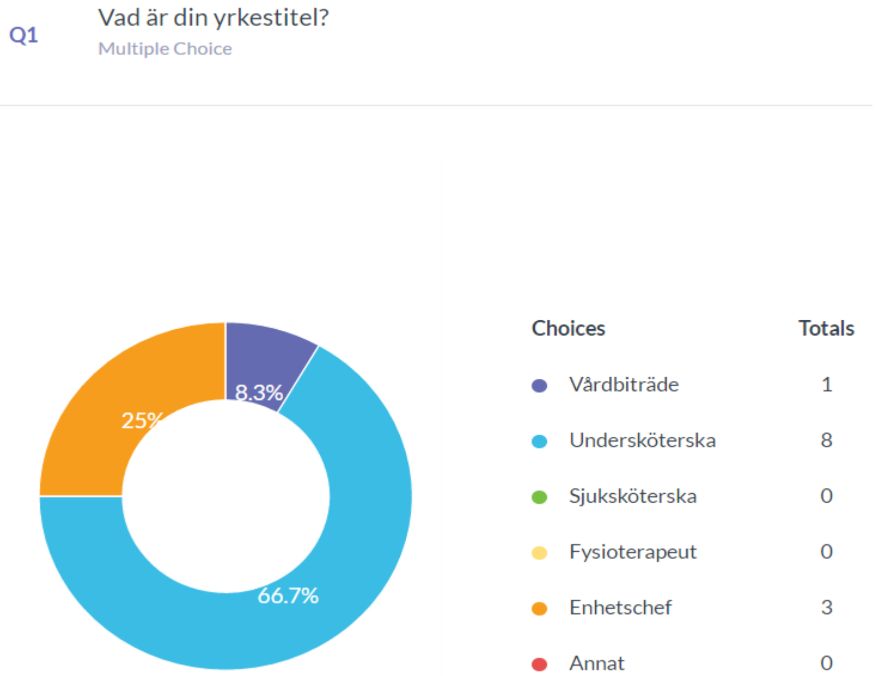
6. Findings and analysis

The survey consisted of background questions, open-ended essay questions on the right to self-determination, as well as vignettes, to which the respondent was asked to respond how they would act in a certain situation. The objective of the survey was to achieve an overview of how the right to self-determination is implemented in care work according to the workers in dementia care homes. The survey consisted of a total of 20 questions. A total of 12 respondents answered the survey. The survey was sent to 55 dementia care home managers and directors of elder care services in the West Coast region of Sweden

The survey was distributed in Swedish, as this was to increase the likelihood of getting respondents to answer. The answers have been freely translated by the author and not by an official translator. The translations have been made as verbatim as possible, with slight alterations as to keep the original message recognizable. The capitalization and punctuation of the answers have been kept identical to the original answers. Due to these aspects, the original quote in Swedish can be found as a footnote at the bottom of the page.

6.1 Background Information

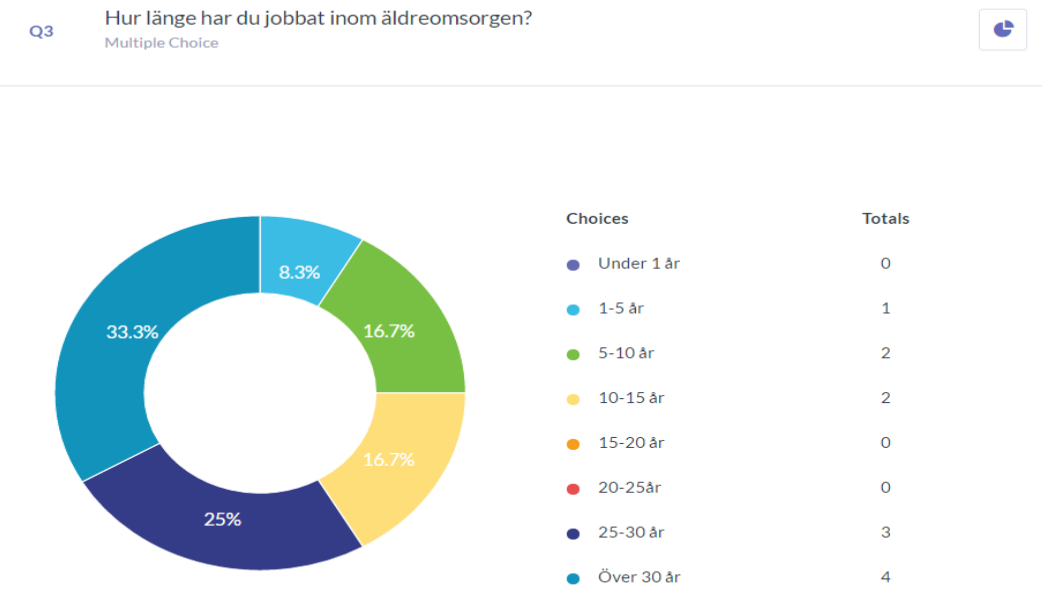
The background questions the respondents were asked to answer were: job title, work experience, highest acquired education, length of employment at current place of work and size of the care home the respondent works at. Out of the 12 respondents 8 worked as practical nurses, one was a nursing assistant and three were managers of a care home. 7 of the respondents had a high school education, while 5 of the respondents had a university degree. None of the respondents had an education lower then high school education.


Q1 Vad är din yrkestitel?
Multiple Choice

Choices	Totals
● Vårdbiträde	1
● Undersköterska	8
● Sjuksköterska	0
● Fysioterapeut	0
● Enhetschef	3
● Annat	0

Image 10 What is your job title? Vårdbiträde- nursing assistant, undersköterska- practical nurse. enhetschef- care home manager.

An interesting detail in the results of the background questions was that several of the respondents had substantial experience in elder care, with 1/3 of the respondents having worked in elder care for over 30 years, and over half the respondents having more than 25 years of experience in elder care. All but one respondent had more than 5 years' work experience in elder care. Two out of the 3 care home managers that responded had over 25 years of work experience. The one nursing assistant that responded had 10-15 years of work experience in elder care.

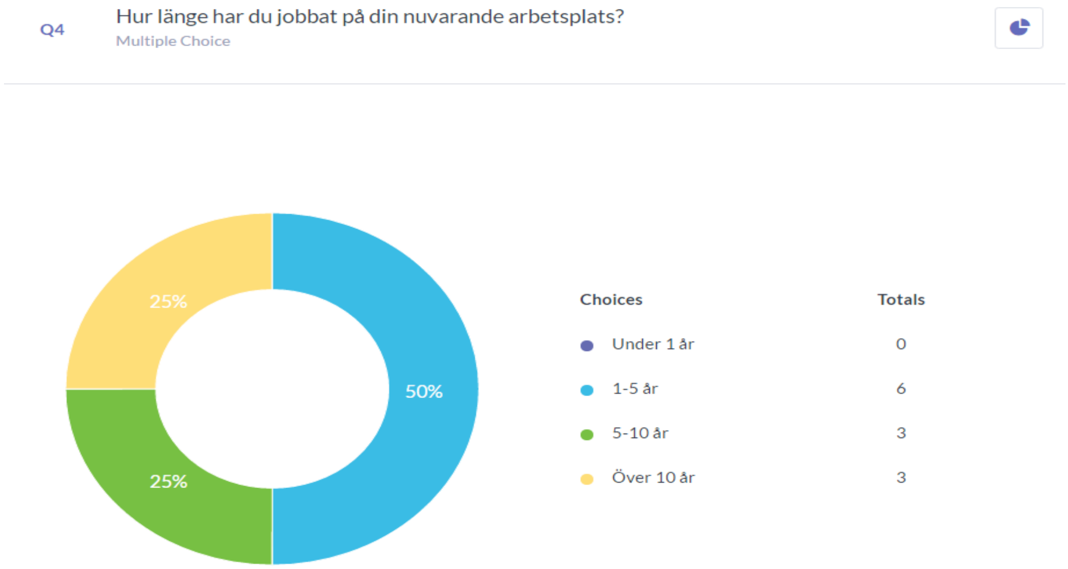


Q3 Hur länge har du jobbat inom äldreomsorgen?
Multiple Choice

Choices	Totals
● Under 1 år	0
● 1-5 år	1
● 5-10 år	2
● 10-15 år	2
● 15-20 år	0
● 20-25år	0
● 25-30 år	3
● Över 30 år	4

Image 11 How long have you worked in elder care?

The respondents were asked how long they had worked in their current place of employment. Although most respondents had substantial work careers in elder care, only 25% of the respondents had worked in their current place of employment for over 10 years. Half of the respondents had worked in their current place of employment between 1-5 years, and the other 25% had worked 5-10 years in their current place of employment. All care home managers that responded had worked in their current place of employment between 1 and 5 years.

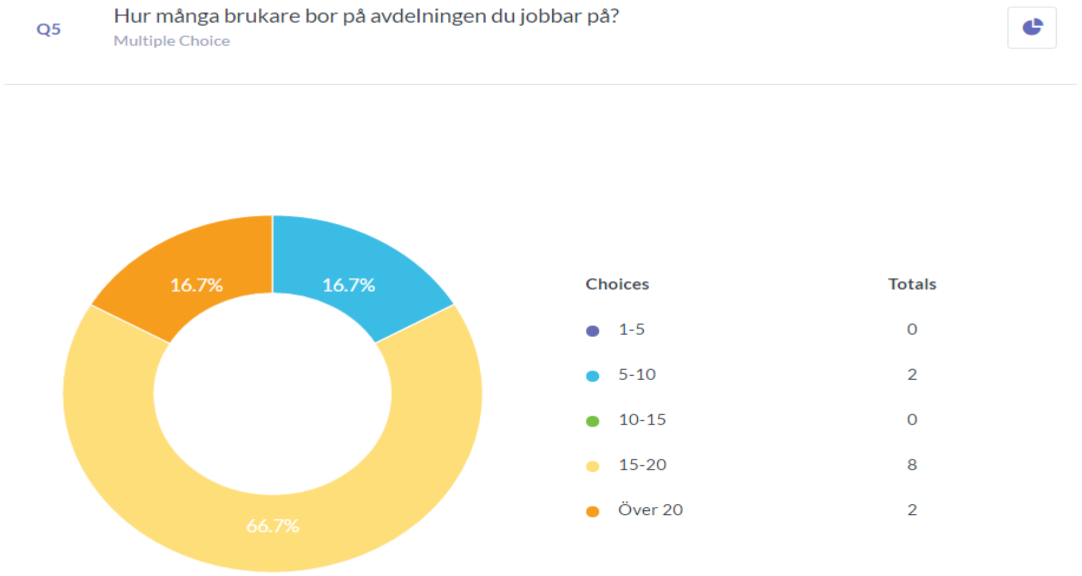


Q4 Hur länge har du jobbat på din nuvarande arbetsplats?
Multiple Choice

Choices	Totals
● Under 1 år	0
● 1-5 år	6
● 5-10 år	3
● Över 10 år	3

Image 12 How long have you worked in your current place of employment?

Over 80% of the respondents worked in care home units with over 15 residents each. Only 2 respondents (16,7%) worked in care homes with 5-10 residents. The general consensus in dementia care, which is supported by research, is that small scale care homes are preferable, with units varying between 6-15 residents.(Cantley& Wilson 2002: p. 7-9) This is to reduce the amount of stress and stimuli as well as increase individualized care and opportunities to take part in daily routines(ibid.) The respondents of this survey worked in considerably large dementia care home units, which is reflected in many answers: a common theme one can see in the answers is concerns about the lack of resources and adequate amount of staff.



Q5 Hur många brukare bor på avdelningen du jobbar på?
Multiple Choice

Choices	Totals
● 1-5	0
● 5-10	2
● 10-15	0
● 15-20	8
● Över 20	2

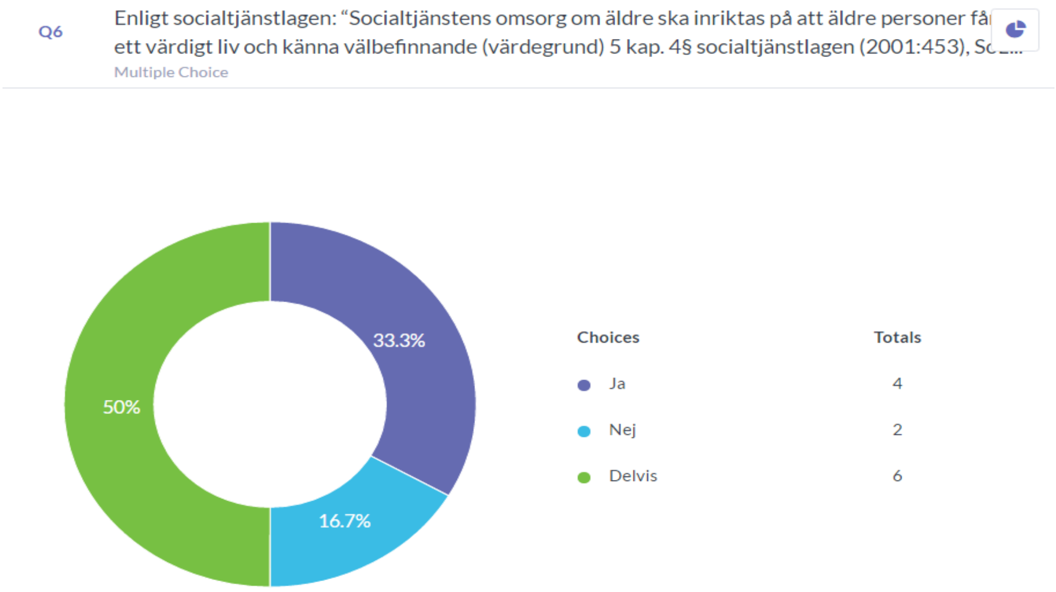
Image 13 How many residents are there in the unit you work in?

6.2 Law on Social Services

Before more detailed questions about self-determination was presented, the following law (5 kap. 4§ socialtjänstlagen (2001:453), SoL.) from the law on social services was presented to the respondent.

> "The social welfare board shall work so that the elderly have an opportunity to live and reside independently in a safe environment and have an active and meaningful existence in their community… The elderly person shall, as long as it is possible, be able to choose when and how support and help in their residence or other readily accessible services shall be provided".

The respondent was then asked if they agree with the statement and if they feel the objectives of this statement are implemented in their daily work. Two of the respondents (16,7%) answered no, 6 (50%) respondents answered to some extent and 4 (33,3%) replied yes. Both participants whom replied no were practical nurses. Out of those whom replied yes the objectives of this law are reached and implemented in daily care, 2 were practical nurses and 2 care home managers. This question was presented to see if the respondents agree, on an ideological level, that self-determination is actualized.



Q6

Enligt socialtjänstlagen: "Socialtjänstens omsorg om äldre ska inriktas på att äldre personer få
ett värdigt liv och känna välbefinnande (värdegrund) 5 kap. 4§ socialtjänstlagen (2001:453), Sc…

Multiple Choice

Choices	Totals
● Ja	4
● Nej	2
● Delvis	6

Image 14 According to the law on social services: " Social services care for the elderly should be aimed so that older people can live in dignity and endorse well-being (values) Chapter 5, Section 4 of the Social Services Act (2001: 453) SOL. In order to achieve this elderly care needs to, among other things, protect and respect the individual's right to privacy and bodily integrity, autonomy, participation and personalized care"." (Socialstyrelsen 2013 http://www.socialstyrelsen.se/aldre/nationellvardegrund) Do you feel that the rights stated above are implemented in daily work? Ja- Yes. Nej-No, Till viss del- to some extent.

If the respondent answered no or to some extent, they were asked to elaborate why they feel so. Many of the respondents state a lack of time and resources as obstacles to the right of self-determination for the residents. One respondent mentions the high amount of workers without competence as a hindrance for self-determination of those living in a dementia care-home. It is mentioned that there is not enough time to do “little extra things” such as go for walks with the residents. The right to self-determination and the importance of the right to say no is brought up in several answers; one respondent stated one should work as one self would like to be treated and another states that although one ages, one still has the same rights.

One concern brought up in several answers is the reduced time for actual care work, with documentation and administrative work taking up more of practical nurses time:

> “Practical nurses do the best they can with the resources they have available. More administrative work is required, so that the care work has decreased compared to 25-30 years ago”.[8]
>
> ”Because on paper it looks so good, but it does not work in reality due to too few workers. And because we as practical nurses have become clerks instead of care takers. We don’t have enough time with everything that should be done.”[9]

One respondent states that guidelines sometimes collide with the actual wishes of the residents:

> ”Because we as workers must occasionally see to that the residents hygiene and medicinal status is as good as possible and sometimes that goes against the residents wishes.”[10]

The responses to if the right to self-determination according to the description of the National Board on Health and Welfare is implemented showed mixed results. Although in further answers no one answers a definitive no to any of the presented question, two responded to this question with a no. In general the responses show that lack of time is seen as a hindrance for the right to self-determination. Some respondents provided more reflection on moral issues, such as one respondent stating that the workers must work for the good of the patient, which collides with the residents’ right to self-determination. Others bring up the importance of the right to say no, and one brings up the golden rule; treat others as you would like to be treated.

These answers show both previously presented approaches to dementia care work being implemented; a human rights based approach where the rights of the individual is emphasized, as well as a person-centered care approach, were the good of the individual from the point of view of a subjective other is seen as the best approach. In general, the right to self-determination is appreciated, but the results show that there are several explanations to

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[8]” Usk gör så gott hen kan med de resurser som finns att tillgå. Mer admininistriva sysslor läggs på ,så att omsorgsarbetet har minskat jämnfört med för 25-30 år sedan”

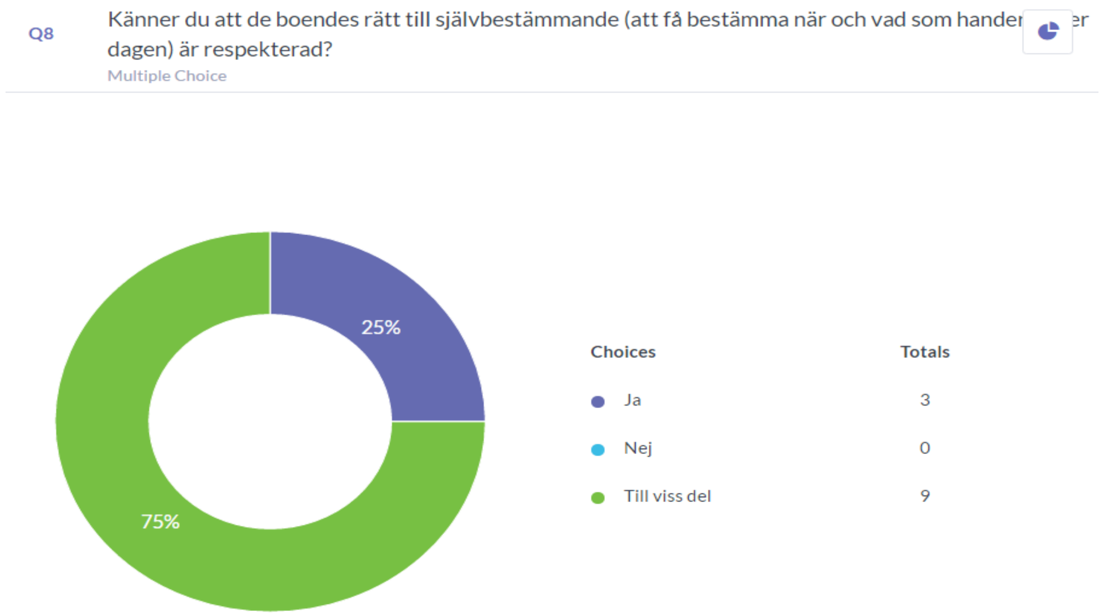
[9] ”För att på pappret är det så fint, men detta fungerar inte i verkliga livet pga för lite personal. Och att vi som uskar har blivit kanslister istället för vårdande personal. vi hinner inte med allt som skall göras.”

[10]” För att vi som personal måste emellanåt se till att de boendes hygien och medicinska status är så bra som möjligt och det kan ibland strida mot den boendes önskemål.”

the hindrances to the right to self-determination being offered. These results reflect that the right to self-determination is, according to the respondents, being compromised not because of an approach that is being implemented, but rather a lack of resources.

6.3 Right to Self-determination

The respondents were asked if they feel the residents right to self-determination, in other words what is happening and when, is respected. Three respondents (25%) replied yes the right to self-determination is respected, the remaining 9 (75%) replied to some extent. Two out of the three whom replied yes were care home managers, one was a practical nurse. If the respondent replied "no" or "to some extent", they were asked to elaborate how they felt the right to self-determination was not respected.



Q8 Känner du att de boendes rätt till självbestämmande (att få bestämma när och vad som hander er dagen) är respekterad?

Multiple Choice

Choices	Totals
● Ja	3
● Nej	0
● Till viss del	9

Image 15 Do you feel that the residents right to self-determination (decide what is done and when) is respected?

The most frequent answer as to what the respondents feel compromises the right to self-determination was the lack of workers, resources and time. Being brought to activities although the resident has previously refused is brought up as an issue that compromises the residents' right to self-determination. It is brought up in several answers that residents are sometimes brought to events by workers who either do not know or have not asked if the residents wants to take part in a certain activity. This shows an approach that is steered towards a person-centered approach that endorses thinking of what is best for the resident; the resident is possibly being brought to activities as this is seen as something important for the wellbeing of the resident.

Sometimes what compromises the right to self-determination is that the resident may not themselves know what is best for them. Refusal of showering is brought up in several answers as something those with dementia may not realize they want to do until afterwards:

> “Sometimes the resident may not want to shower even though it is necessary, it can be that one may have feces on their hands and do not want to wash them and such. It is mostly these types of incidents that go against. Sometimes a tenant may want to make things difficult for another tenant. Someone may want to go into another person’s room and be stopped”[11]

> ”Sometimes it is hard for those with dementia to understand their need for example showering/hygiene. The workers must then eg. flirt, divert attention, postpone showering/ hygiene to another moment, do positive things first like eating chocolate etc. The staff also tries to find a way to get the individual with dementia to accept taking a shower/bathing. Those with dementia are pleased when the shower is over, but if those with the dementia would have decided completely on their own without the above mentioned measures maybe they would never want to shower…”[12]

These answers show a problematization of self-determination, showing self-determination as a challenge to overcome with various different solutions. These responses show strong inclination towards a more person-centered care focus, as the desirability to live up to the right to self-determination is questioned. It can be seen as the care taker, or another outside force, determining what actions are expected and desirable. One respondent even states that the worker is to take the role of a leader when working.

> “The illness changes their way to communicate and perceive things around them- sometime you must take the role of a leader when questions arise.”[13]

Taking charge may be a way to actualize person-centered care by thinking of what is beneficial for the resident from the perspective of the care take. Many responses voiced concern over the fact that people living with dementia do not know what is best for them, and it may be that the staff, by taking charge, are acting in a way they feel is the most moral and compassionate. This is also, to some extent, endorsed in the description of a person-centered approach as they are thinking of the situation from the perspective of how they would like to be treated.

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[11] ”Ibland vill den boende kanske inte duscha trots att det är nödvändigt, det kan vara så att någon har avföring på händerna och inte vill tvätta dem eller så. Främst den typen av olika intressen som går isär. Ibland kan en av hyresgästens vilja göra det svårt för en annan hyresgäst. Som att någon vill gå in i en annan persons lägenhet och blir stoppad.”

[12] ”Ibland är det svårt när dementa inte förstår sina behov av t.ex. dusch/hygien. Personalen får då t.ex. lirka, avleda, skjuta upp dusch/hygien till ett annat tillfälle, göra positiva saker först som att äta choklad m.m. Personalen försöker alltså hitta en väg för att få den dementa personen att acceptera dusch/bad. Den demente är nöjd när duschen är klar, men om den demente hade fått bestämma helt själv utan beskrivna åtgärder så kanske den inte hade velat duscha någonsin.....”

[13] ”sjukdomen förändrar deras sätt att förmedla och uppfatta allt rund om - ibland måste man ta rolen som ledare då kommer frågor”

Lack of time and resources is listed as a reason in 5 answers, and it is a consistent theme that is stated all through the survey as an answer for several questions. These answers show a critique towards the organizational structure, while also addressing the issue of self-determination as an unattainable goal in itself:

> ” Time wise it is not possible. If everyone wants to wake up at 8, there are no resources for that.”[14]
>
> “Everything that takes up the staffs’ time has been taken away”[15]
>
> “lack of staff and lack of time”[16]
>
> “The practical nurses do the best they can with the resources available. More administrative tasks, have been added, so there is less care work compared to 25-30 years ago. More staff is needed.”[17]
>
> ” Depending on how many staff there are we can perform the residents wishes, not always when, how and where the resident wants”[18]

Lack of time and resources as a hindrance for self-determination can be interpreted as both a critique towards the organization and as a transference of responsibility to an outside force. Because of restricted time and resources, the possibility to fulfill the right to self-determination is either restricted, delayed or ignored. Some state that even colleagues restrict the residents’ right to self-determination by forcefully taking them to activities, presenting either a lack of communication or different views as to how the residents are to be treated to achieve the staff members’ perception of good care. One states that often it may be taken for granted that someone does not want to take part in activities because they often decline, which can be interpreted as the staff not offering the same amount, or restricting, the possibilities of these individuals. Taking part in activities is brought up as an example where the right to self-determination is broken, despite the respondents’ objection, which presents a more human-rights based approach from the respondents regarding the issue of self-determination.

> ”Sometime they are forced down to activities that they have declined to in the morning, still staff shows up that drags them down (to the activity)”[19]
>
> ” Even if I as a member of the care staff ask everyday if they want to go to different events, they say NO. We have staff that come to the unit and start pulling and tugging the people (saying) yes they like it. As a member of the care

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[14] ”Tidsmässigt går det inte. Om all vill komma upp kl. 8 finns det inga resurser för detta.”

[15] ”Allt som tar av personalens tid har tagits bort.”

[16]” personalbrist och tidsbrist”

[17] ”Usk gör så gott hen kan men de resurser som finns att tillgå. Mer admininistriva sysslor läggs på ,så att omsorgsarbetet har minskat jämnfört med för 25-30 år sedan.Mer personal behövs”

[18] ”På grund av hur stor personalbemanningen är kan vi utföra de boendes önskemål, inte alltid efter när, hur och var de boende vill.”

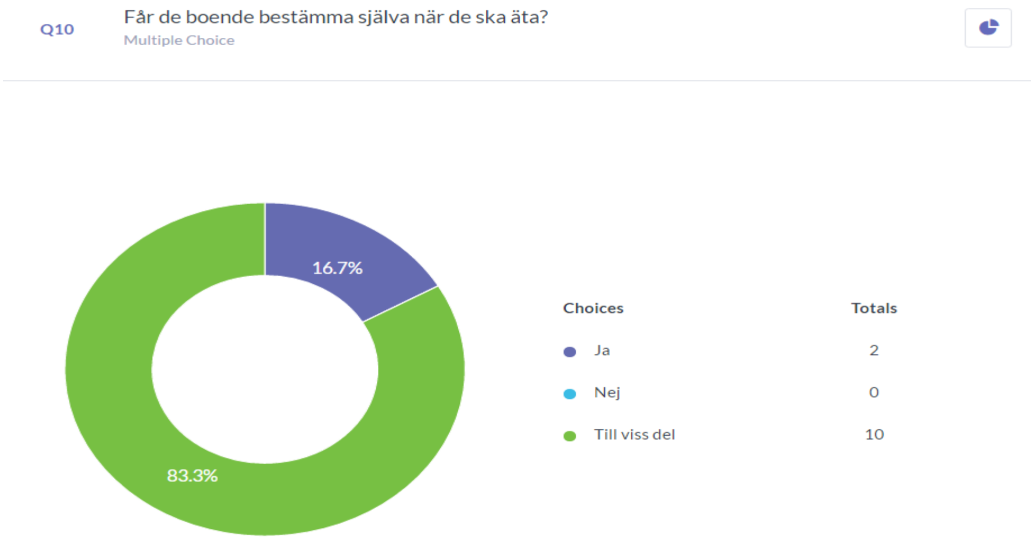
[19] ”Ibland tvingas dom ner på aktivitetеter som dom på morgonen har tackat nej till, ändå kommer det upp personal som släpar med dom ner.”

> staff I can only speak of what I have seen spoken of the resident, but it is not respected.”[20]
> because
> ”sometimes it is taken for granted that one does not want certain things, just because one often may decline”[21]

These responses show that the right to self-determination is valued by the respondents, but that the right to self-determination is compromised, either due to lack of resources or differing views of the staff. Many responses address the issue of self-determination of the residents of dementia care homes as an organizational issue: it is perceived as either restricted or unattainable due to lack resources. Depending on what the issue of self-determination is concerning, self-determination is valued in different ways; showering is given as an example of a necessity, while forcing residents to take part in activities against their will is disapproved. These responses show that opposite views on issues regarding the right to self-determination take place; while one may feel taking part in activities is a good thing *because* of their illness and possible lack understanding, others believe in the individuals inherent right to decline, *despite* their illness. Below more detailed questions about specific issues such as eating, hygiene and activities and how the right to self-determination is actualized in concrete daily decision making is enforced will be presented.

6.4 Right to Self-determination Concerning Eating

The respondents were asked if the residents are able to decide themselves when they want to eat. 2 (16,7%) respondents replied yes, the remaining 10 (83,3%) replied to some extent. Out of those who replied yes both were practical nurses. If the respondent replied no or to some extent, they were asked how they feel the residents eating is restricted.



Q10 Får de boende bestämma själva när de ska äta?
Multiple Choice

Choices	Totals
● Ja	2
● Nej	0
● Till viss del	10

Image 16 Are the residents able to decide themselves when to eat?

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[20] ”Även om jag som omsorgspersonal frågar varje dag om dom vill gå på olika evenemang, och dom tackar NEJ. Så har vi personal som kommer upp på avd och börja dra och slita i mäniskorna jo då detta tycker dom om. Som vårdpersonal så kan jag bara tala om vad jag sett hört av boende. men detta respekteras inte.”

[21]” Ibland tas det för givet att man inte vill vissa saker, bara för att man ofta tackar nej ”

The most common restriction when it came to eating was set times for eating certain meals, although most respondents stated eating later was also acceptable. Other restrictions mentioned were illness related restrictions (for example diabetes) as well as conflicting thoughts of nutritionists and relatives as to what the residents should eat.

> ” We serve breakfast in the order the residents wake up. If someone does not want to eat the staff tries to attract them to eat with something good or try again later. Sometimes the staff offer food often for those with dementia often eat too little during meal times. Sometimes there are conflicts between nutritionists and what the relatives think and what the individual with dementia wants. The environmental administration has clear directives as to how long food can be saved, reheated etc. It’s not that easy…”[22]

The mention of nutritionists and relatives restricting the residents eating presents an approach that breaks against the residents right to self-determination. The decision as to what to eat is being compromised by either a professional (nutritionist) whom is assumed to have knowledge on the matter of how and what one should eat, or relatives who take the role of the decision maker based on their previous knowledge. These restrictions present an interesting conflict to the residents’ right to self-determination; assuming that others know better what the resident should eat presents a person-centered approach to the issue of diet, where the wellbeing from an outside perspective is more important than the residents’ right to self-determination.

One respondent mentions that the food provided is not the best possible and is not appetizing if reheated, which can be seen as a critique towards the institution rather than a restriction to self-determination per se:

> “The food is not the best here, we heat the food so it is not appetizing later”[23]

Illnesses such as diabetes are brought up as a restriction to eating. This can be seen as a restriction from an external force that compromises the right to self-determination. This restriction may be perceived as a fundamental restriction as it is closely health related, but is just as much an infringement of self-determination. If one were to wish for foods deemed not suitable for a person with a distinct illness, restricting or denying this is taking away the individual’s right to self-determination. This again presents a view were an external force restricts an individual with the objective of a greater good i.e. a person-centered approach that seeks the best of the individual from the perspective of a secondary party.

> ” Can depend on illnesses eg. diabetes”[24]

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[22] ”Vi serverer frukost i den takt de boende vaknar. Om ngn inte vill äta så lockar personalen med ngt gott eller försöker ge mat senare. Ibland erbjuder personalen mat ofta om den demente äter för lite vid måltiderna. Det kommer ibland en konflikt mellan vad dietister och anhöriga tycker och den dementes önskemål. Miljöförvaltningen har tydliga direktiv också om hur länge maten kan sparas, återuppvärmas o.s.v. Det är inte alldeles enkelt....”

[23] ”Maten är inte det bästa här, värmer vi maten så är den inte aptitlig senare,”

[24]” Kan bero på sjukdomsbild tex diabetes.”

Many responses show strong respect to authoritarian patterns and institutional restrictions regarding eating, stating that there are distinct times for eating. Despite this fact, many do state that exceptions can be made.

> ”The warm food is served during common mealtimes in the middle of the day and evening food. The food should not be kept heated so long and it is often most practical to eat together. If someone strongly states they will not eat with the others and during another time they are provided this (opportunity)”[25]
>
> ”We have determined times for mealtimes but if one wants to eat later it is completely ok.”[26]
>
> ”The food is served during specific times but it is ok to eat later.”[27]
>
> ”Mealtimes are controlled mealtimes such as 8:00-10:00& 13:00-14:00 evening food=17:00-18:00”[28]
>
> ”Restricted is not the right word but there are fixed meal times, it does not work with the staff if everyone wants to eat differently, on the other hand if one or a few want to eat earlier or later there is of course that possibility”[29]
>
> ”It’s us staff that serves the food”[30]

The main issues regarding self-determination in respect to eating, based on these results, are organizational issues and outside influences, such as relatives and nutritionists. Paternalism of the patient is visible in the restrictions related to eating; decisions regarding eating are outsourced to a nutritionist or restricted due to illnesses such as diabetes. This coincides with the person-centered approach and the thought of assisted decision making. Some respondents do say that it is possible to be flexible and arrange to have meals outside of set meal times, but in general it can be seen that there are organizational and authoritative restrictions to eating, which align with a person-centered care approach.

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[25] ” Den varma maten serveras i gemensamma måltider mitt på dagen och kvällsmaten. Mat ska inte varmhållas så länge och det är ofta praktiskt att alla äter tillsammans. Om någon starkt uttrycker att hen inte vill äta med de andra och på annan tid så får hen givetvis det. ”

[26] ”Vi har bestämda tider för måltider men vill man äta senare så är det helt ok.”

[27] ”Maten serveras vid visst klockslag men det är ok att äta senare”

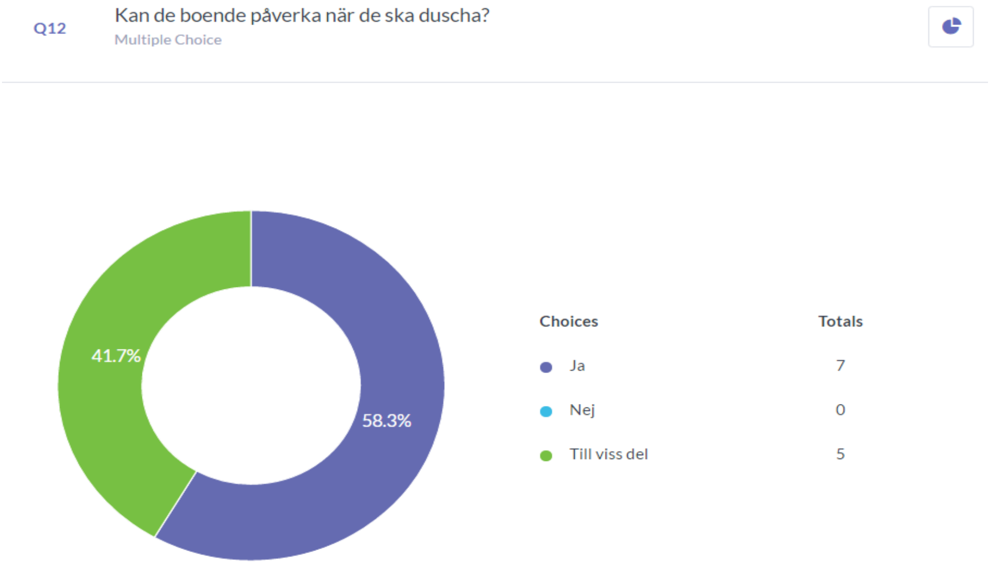
[28] ” Måltider är på kontrollerade matider såsom 8:00-10:00 & 13:00-14:00 kvälsmat= 17:00-18:00”

[29] ”hindras är inte rätt ord men det finns fasta mattider, det hade inte gått ihop med personal om alla ville äta olika, om däremot någon el några vill äta tidigare eller senare finns såklart möjlighet”

[30] ” det är vi personal som serverar mat”

6.5 Right to Self-determination Concerning Hygiene and Activities

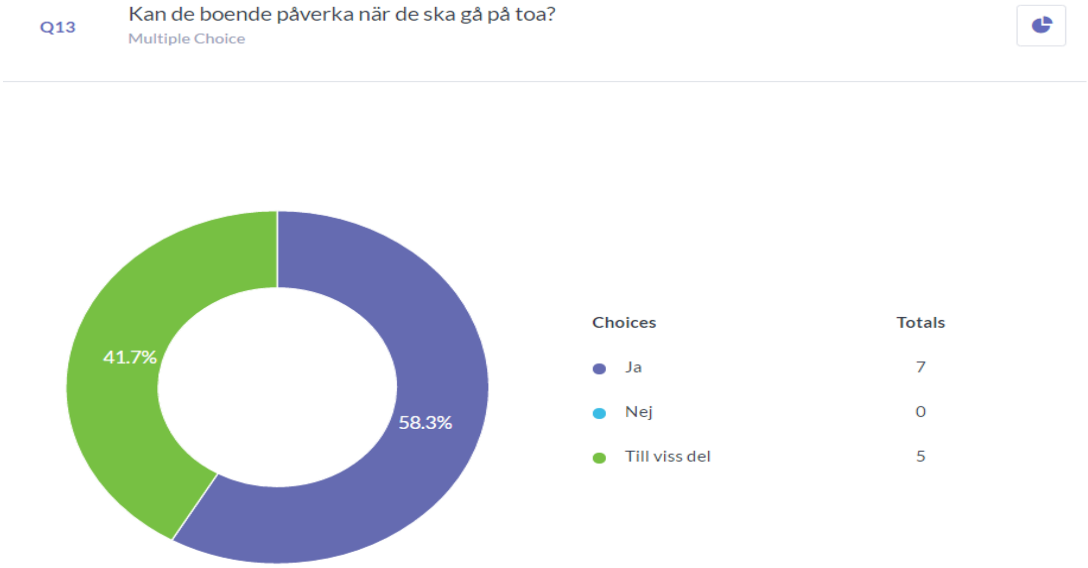
The respondents were asked if the residents are able to influence when they shower. None answered no, 7 (58,3%) answered yes and 5 (41,7%) answered to some extent. All care home managers replied yes. The issue of difficulties in taking care of hygiene has been addressed in answers further below.


Q12 Kan de boende påverka när de ska duscha?
Multiple Choice

Choices	Totals
● Ja	7
● Nej	0
● Till viss del	5

Image 17 Are the residents able to influence when they shower?

When asked if the residents can influence when they use the bathroom, the results were identical to how they can affect when they shower. 7 respondents (58,3%) replied yes, while 5 (41,7%) responded to some extent. Only 1 care home manager replied yes, the other care home managers replied to some extent, to the question of if the residents can affect when they use the bathroom.


Q13 Kan de boende påverka när de ska gå på toa?
Multiple Choice

Choices	Totals
● Ja	7
● Nej	0
● Till viss del	5

Image 18 Are the resident able to influence when they can use the bathroom?

When asked if residents are able to influence when they take part in activities, 9 respondents (75%) replied yes, while 3 (25%) replied to some extent. None answered that residents cannot affect when they take part in activities. All care home managers replied yes. Previous answers from the question on self-determination stated that sometimes the residents were brought to activities even when they had declined, which may explain the high amount of “to some extent” answers. In general when it comes to daily actions, such as hygiene and activities, the respondents felt residents do have at least some influence in these matters. Based on these responses it is difficult to identify an approach to the right of self-determination, but these results do show that the residents have the opportunity to make decisions regarding their care and daily activities.

Q14 Kan de boende påverka när de ska vara delta i aktiviteter?
Multiple Choice

Choices	Totals
● Ja	9
● Nej	0
● Till viss del	3

Image 19 Are the residents able to influence when they can take part in activities?

6.6 Daily Decision Making

The respondents were then asked how residents could be involved more in daily decision making and what they think would be required for this be implemented. Here again the lack of staff and time was stated as requisite for better opportunities for residents to influence their daily decision making. Having more staff, according to respondents, would provide more time to help the residents in a peaceful manner.

> ”If one could have enough time to figure out what is valuable for them. Often the residents have difficulties expressing themselves.”[31]
>
> ”Lack of time, sufficient with ”good” will less residents- less stress, good co-operation with relatives…”[32]

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[31] ”Om man kunde ta sig tid att ta reda på vad som är värdefullt för hen. Ofta har våra boenden svårt att förmedla sig.”

[32] ”brist på tid , tillräcklig med "god" viljan mindre boende - mindre stress , bra samarbete med anhöriga.....”

> ”More staff to able to allocate more time. To help calmly.”[33]
>
> ”More people in the care (home)”[34]
>
> ” If one informs many times about the activities and routines and asks if it is ok for the person”[35]

One respondent wishes for more co-operation with relatives to determine what the residents want. This shows a person-centered approach in regard to the issue of self-determination; e response shows a preference towards assisted decision making regarding issues related to the resident. It is often brought up that residents may not be able voice their will, and then it is up to others to try to interpret what they want. The need for an outside force to help in decision making is emphasized. This is an essential question in dementia care work: when one can no longer voice their opinion, who should be the one determining what is best for the residents; a relative, a care taker or maybe set guidelines as to what to do in a certain situation?

> “If one had both the residents and relatives’ advice to address current issues and desires possibilities could increase. If this were the case one would also have to have appropriate staffing for what it would require to work in reality.”[36]
>
> “Healthier patients! As said, most don’t know their own names or were they are, without us steering them a little they would probably never eat of use the bathroom or take part in daily activities. The few that can- naturally choose on their own.”[37]
>
> ”It’s easier for those with dementia who can say what they want. Some people with dementia lack speech and one must interpret body language. Sometime a lot of people need help at the same time and then they must wait until the staff has time. Otherwise they can get up and go to bed as they wish.”[38]
>
> “Because elderly people with a dementia diagnose may often have difficulties in abstract reasoning one must be able to present concrete choices. Many of the tenants may also find that they feel bad having to make decisions many times a day. If the contact person has a lot of time with “their” tenant they could have more opportunities to do individual trips and conversation. In short- increased staff- larger staff budget”[39]

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[33] ” Mer personal för att kunna avsätta tid. att i lugn och ro få hjälpa”

[34] ” Fler personer i vården.”

[35] ” Att man informerar många gånger om verksamhet och rutiner och frågar om det är ok för den personen”

[36] ”Om man hade ett boende- och anhörigråd som tar upp aktuella saker och önskningar kanske möjligheterna öka. Men då måste också man se över personaltätheten, vad som krävs för att det skulle fungera i verkligheten.”

[37] ” friskare patienter! som sagt, de flesta vet inte vad de heter eller var de är någonstans, utan oss som styrde lite skulle de antagligen aldrig ätit eller gått på toaletten eller kommit iväg på daglig aktivitet. de få som kan- väljer naturligt själva”

[38] ” Det är lättare för dementa som kan tala om hur de vill ha det. Vissa dementa saknar språk och personalen får tolka kroppsspråket. Ibland behöver många personer hjälp samtidigt och då kan man behöva vänta tills det finns personal som har tid. Annars så stiger man upp när man vill och lägger sig när man vill.”

[39] ”Eftersom äldre personer med demensdiagnos ofta har svårt att förstå abstrakta resonemang måste man kunna presentera konkreta val. Några av hyresgästerna kan också tycka att de mår dåligt av att fatta beslut flera gånger

The inability of residents to express their own will is brought up as a restriction to the right of self-determination and it is stated that sometimes it is someone else that must be the one to make decisions on behalf of the residents. This shows a strong inclination towards a person-centered care approach. The responses show a desire to have assistance in decision making from the residents or their relatives, but mention the lack of resources as a restriction to the actualization of this proposal. Lack of time with the residents is also mentioned as a restriction to the right to self-determination. In general, it is organizational issues that are brought up as the biggest restriction to the right to self-determination, but the lack in knowledge of the residents will is also underlined, showing preference towards a person-centered approach in the responses.

6.7 Vignettes

Fictional situations, vignettes, were used in the survey to see how the respondents would personally react in different situations. Vignettes were chosen to see how the respondents solve everyday situations that are related to the residents' right to self-determination. These situations were based on real events that practical nurses and nursing assistants have encountered. The objective of the vignettes was to see how the right to self-determination is implemented in daily practices.

6.7.1 Showering

The first vignette posed the following fictional situation:

> "A resident has refused to shower for a week, despite you and your co-workers efforts to try to convince the resident to shower. The resident becomes aggressive when confronted about the need to shower. The need to shower the resident has become apparent, but the resident simply refuses."

The respondents were asked how they would react in the above mentioned situation. The most common approach was to try flirting and persuasion to get the resident to shower. Asking a colleague to try to get the resident to shower was also proposed. Some would solve the situation by washing the resident with wash clothes instead of showering. Many respondents noted that this is a common situation in dementia care homes, and almost all use some form of persuasion or coercion to get the resident to shower. Only one states that they don't need to shower as long as it doesn't disturb others:

> ”Don't have to shower as long as it doesn't disturb anyone else. Socialstyrelsen (the welfare board) has regulations for that.”[40]

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om dagen. Om kontaktpersonen har mycket tid med "sin" hyresgäst kunde hen få mer möjlighet att göra individuella utflykter och ha individuella samtal. Kort sagt - ökad bemanning - större personalbudget.”

[40] ”Behöver inte duscha så länge det inte stör någon annan. Socialstyrelsen har regler för detta.”

This answer reveals a more human-rights based approach to the care work, but also externalizes the responsibility by referring to regulations set by the welfare board. This was the only response in favor of a human-rights based approach to this issue. One respondent states forced measures may sometimes be needed, but shows concern about how such action breaks ones right to self-determination:

> “Have unfortunately been in such situations. Sometimes one can wait for a better time but sometimes one is forced to do it anyways. Against the residents own will and right to self-determination!?”[41]

The most common solution to this vignette was to use various different forms of coercion:

> ”I create a new encounter and ask if I should help with washing their back with a wash cloth for example.”[42]
>
> ”Then we find a way but respect the resident. This is why one should have worked and be acquainted with dementia so you know how most of them work”[43]
>
> “One tries to work with (the resident) leaves for a moment, comes back and proposes a shower, tries with another person if it is easier for them to connect with the resident. Speak with the nurse if it gets too difficult. In the worst case the resident might need some sedatives to be able to shower. Have we made a BPSD? *(Authors note: BPSD- Beteendemässiga och psykiska symptom vid demens- behavioral and psychological symptoms in dementia)* Do we have a plan on how one wants to be met? This is a very common situation in a dementia care home.”[44]
>
> ”There can be many solutions, the easiest is to de-dramatize the situation and just do it without big words and explanation the reflexes are left give soap into their hand help but just help…”[45]
>
> ”Try in connection with morning chores in the bathroom. Take time to talk to the resident.”[46]

---

[41] ”Har tyvärr varit i sådana situationer. Ibland kan man vänta ytterligare någon tid men ibland har man varit att tvungen att göra det ändå. Tvärtemot den boendes egna vilja och självbestämmande rätten!?”

[42] ”Jag skapar ett nytt möte och frågar om jag skall hjälpa till med att tvätta ryggen med en tvättlapp tex.”

[43]” då hittar man ett sätt, men vi respeketerar den boende. det är därför man bör ha arbetat och vara van med dementa så man vet hur de flesta fungerar”

[44] ”Man lirkar, går ifrån en stund, kommer tillbaka och föreslår dusch, kollar med en annan personal om hen har lättare att få kontakt med den boende. Talar med sjuksköterskan om det börjar bli alltför svårt. I värsta fall kanske den boende behöver något lugnande för att kunna gå med på att duscha. Har vi gjort en BPSD? Har vi en bemötandeplan? Det här är ju en rätt vanlig situation på ett boende för äldre med demensdiagnos.”

[45] ”kan finnas många svår , det enklaste är att avdramatisera händelse bara göra utan stora ord och fökloringar refleksen finns kvar ge tvålen i handen hjälpa men bara hjälpa......”

[46] ”försöker att det i samband med morgonbestyren inne på badrummet.Ta mig tid att prata med den boende”

> ”Try to lure and convince., not ask them if they will shower but carefully do it when they are in the bathroom”[47]
>
> ”Try convincing, find a moment when the person feels ready. Find out if there is someone they feel safer with. If it doesn’t work I wait until it does. Usually it solves itself :-)”[48]
>
> ”There can be many solutions, the easiest is to de-dramatize the situation and just do it without big words and explanation the reflexes are left give soap into their hand help but just help…”[49]

As one can see, the issue of showering a resident when the situation requires so reveals a strong preference towards a person-centered approach; the workers try their best to help the resident, by helping them shower. This reflects a person-centered approach that views the residents’ wellbeing from the perspective of oneself or others. One response in particular showed much reflection to the issue of showering, stating that such situations are common and demonstrating several different possible approaches. The response also acknowledges that such situations can be extremely challenging, suggesting that one that could solve such problems deserves a Nobel Prize. This answer exemplifies how there are many approaches to such issues, but no one right answer:

> ”It is important to build a good relationship. If it has already gone wrong and the resident is aggressive it is best to let some other member of the staff go in to the resident, try to divert with something they like for example coffee, candy, look at photos talk about memories etc. One can ask if they would like to shower now of in 1 hour or tomorrow if that is possible (if it is a resident covered in feces it is obviously more difficult…) One can talk about doing something nice afterwards. One can put on music they like, start with touching the water with their hand, then start the showering from below the feet if possible, spread a towel around the shoulders and feet so that the resident feels clothed. There are thousands of knacks, but sometime the shower must be delayed until the resident feels safe. One can often manage without a shower for a few weeks. The one that can solve the problem when the resident is covered in feces and is aggressive and will not shower I would love to get advice from. The one that has the solution for that in the middle of an acute situation deserves a Nobel prize!”[50]

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[47] ”försöka med lock o pock., inte fråga om hen vill duscha utan försiktigt göra det när hen är i badrummet”

[48] ”Försöker lirka, hitta en stund när den personen känner sig redo.Tar reda på om det är någon som hen kanske känner sig tryggare med. Om det inte går får jag avvakta tills det går. oftast så löser det sig :-)”

[49] ”kan finnas många svår , det enklaste är att avdramatisera händelse bara göra utan stora ord och fökloringar refleksen finns kvar ge tvålen i handen hjälpa men bara hjälpa......”

[50] ” Det är viktigt att skapa en god relation. Om man redan kommit fel och den boende är aggressiv så är det bäst att ngn annan personal går in till den boende , försöker avleda med ngt den tycker om, t.e.x. kaffe, godis, titta på foton, prata minnen m.m. Man kan fråga om när hen vill duscha nu eller om 1 timme eller imorgon om detta är möjligt. (är den boende full med avföring är det givetvis svårare.....) Man kan tala om att man skall göra ngt trevligt efteråt. Man kan sätta på musik den tycker om, börja med att känna på vattnet med handen, sedan börja duschning nerifrån fötterna om det går, lägga badlakan runt axlar och på benen så att den boende inte känner sig avklädd. Det finns tusen knep och knåp , men det ibland får duschen dröja tills den boende blir trygg. Man kan oftast klara sig utan dusch i ngr veckor. Den som kan lösa problemet om ngn är full med avföring och är

The responses show that showering is seen as an action that is vital for the wellbeing of the resident and thus trumps over the right to self-determination. The responses show much reflection of the subject and different means of actions are proposed. It can be seen that a person-centered approach is chosen when it comes to showering and the hygiene of residents in a dementia care home; all but one would try to get the resident to shower despite their reluctance.

6.7.2 Dentures

The next vignette asked how the respondent would react if the resident demanded to keep their dentures during night despite doctors' orders. The situation was described as following:

> A resident wants to sleep with their dentures in their mouth, despite doctors' orders. Having dentures in during the night will cause gum disease according to the doctor. You successfully remove the dentures, and place them in the bathroom but the resident goes to get the teeth and puts them back in their mouth, and does this every time you take out the dentures. You have the same struggle every night.

The responses to this vignette can be divided into two different approaches; few take a more person-centered approach where what is perceived as the best for the resident is the motive for the chosen action:

> "Lock the dentures in a lockable cabinet. Try to get the resident to focus on something else."[51]
>
> ”Lock the dentures in the bathroom cabinet”[52]

Most respondents in this case would respect the residents' right to self-determination and let the resident keep their teeth:

> ”If one wants their teeth they can have them”[53]
>
> ”I would say let them have their teeth, try to make sure they are clean and that there is no danger of suffocation” [54]

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aggressiv och inte vill duscha vill jag gärna få del av tips från. Den som har lösningen på det mitt i en akut situation är det värd ett nobelpris!”

[51]” låser in tänderna i låst skåp. fösöker få den boende att focusera på annat”

[52] ”lås in tänderna i badrummsskåpet”

[53] ”Vill man ha sina tänder får man det.”

[54] ”Jag skulle säga att hon fick ha sina tänder, försöker se till att de är rena och att det inte föreligger någon kvävningsrisk.”

> ”Ok then the resident can have their dentures in their mouth I will check the mouth extra well the next day”[55]
>
> ”Brush their teeth and let the person have their teeth!!”[56]
>
> ”Then the person can keep their teeth, I am not anybody’s mother, they are still grown people, and when one has tried to help several times one gets to the point where one helps them more by letting them have their way”[57]

Some propose weighing the good and the bad and determining the risks of letting the resident keep their teeth before deciding what to do:

> ”Take it up with the dentist how big of a risk of inflammation is there and then weigh it against the resident’s night rest”[58]
>
> ”There are 2 alternatives: 1.The resident gets to keep their teeth, and the staff checks the dental hygiene more attentively every day 2. lock the teeth (in a cabinet) , which I think shouldn’t be done”[59]
>
> ”One can listen to the dentists recommendations but respect the residents will (can try to put the dentures in the bathroom cabinet but………) sometimes it is hard to decide what is best.”[60]
>
> ”One can always talk to the dentist if it is necessary to not have the dentures in the mouth. Maybe a dental hygienist could come and check the oral mucosa and gums more regularly. Could the person with dementia rinse their mouth with cordosyl so there would be less bacterial growth?”[61]

These results show two distinct responses: either doing what is deemed is best for the residents, or respecting their right to self-determination. The responses to this vignette illustrates the preference of the care taker, choosing between the two different care approaches; the human-rights based approach, and the person-centered care approach. These responses also show that how issues of self-determination are approached may differ depending on the situation; while in the previous vignette on showering all but one would choose a person-centered approach, here the division between a human-rights based approach and a person-centered approach is more divided.

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[55] ”OK då får boenden ha sin protes i munnen jag kollar extra i munnen nästa dag.”

[56] ”Borsta tänderna och låt personen ha sina tänder!!”

[57] ”då får personen behålla sina tänder, jag är ingens mamma, de är fortfarande vuxna mönniskor,och när man försökt upprepade gånger att hjälpa så kommer man till en punkt där man hjälper dem mer genom att de får som de vill”

[58] ”Tar upp det med tandläkaren hur stor risken för inflammation är och sen väger detta mot den boendes nattro.”

[59] ”Det finns 2 alternativ: 1 att boende får ha sina tänder, och att vi som personal kollar munhålan x-tra varje dag. 2 låser in tänderna, vilket jag inte tycker man skall göra.”

[60] ”Man kan lyssna på tandläkarens rekommendationer men respekterar hens vilja. (Kan försöka lägga löständerna i badrumsskåp men ....)ibland är det svårt att avgöra vad som är bäst.”

[61]” Man kan givetvis prata med tandläkaren om det verkligen är nödvändigt att proteserna inte sitter i munnen. Kanske kan tandhygienist komma och undersöka munslemhinna och tandkött oftare. Kan den dementa penslas med corsodyl i munnen så att det blir mindre bakterietillväxt?”

6.7.3 Dirty Clothes

The respondents were then asked how they would respond in a situation where the resident forbids the washing of their clothes. The situation was described as following:

> “A resident does not want their clothes washed and wants to wear the same, dirty, clothes continuously. When you try to go collect laundry, the resident forbids you. The resident feels that the clothes are clean and they want to continue wearing them.”

The responses to this vignette were highly consistent; none of the respondents would let the resident keep their dirty clothes. All respondents showed attempts to accommodate the resident by distracting the resident or taking the clothes while they were sleeping. If the clothes were especially dirty, the clothes were taken, disregarding the residents’ wishes:

> ”Depending on how dirty they are and with what, the resident can have them for a while longer. If they are covered with for example feces I must take them.”[62]

Distraction of the resident was a commonly proposed method, with one respondent proposing to the relatives they buy similar clothes:

> “One can ask the relatives to buy similar clothes so the person with dementia does not realize they are not the same clothes. If it doesn’t work the staff can wash the clothes during the evening and let them dry over the night while the resident is sleeping. Sometimes it is difficult to get the residents to take off their clothes and then one must inform the relatives about the situation and try persuading until it is possible to wash the clothes. Sometimes it takes time. Again, it is difficult if there is feces on the clothes….”[63]

> ”Take the clothes and wash them all at once so they get the clothes back quickly”[64]

Some respondents took the residents right to self-determination to consideration in their responses, expanding the responsibility of their duty to another time or possibly night nurse:

> ”I dont know. Would probably try to carefully sneak out the clothes and wash them while the tenant is sleeping...”[65]

> ”Can try washing the clothes during the night” [66]

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[62] ”Beroende på hur smutsiga och med vad, så får boende ha dem ett tag till. Är det fullt med tex. avföring så måste jag ta dem ändå.”

[63]” Man kan be anhöriga köpa likadana kläder så att den demente inte märker att det inte är samma kläder. Om det inte går kan personalen tvätta kläderna på kvällen och låta dem torka över natten när den boende sover. Ibland är det svårt att få den boende att ta av sig kläderna alls och då får man informera anhöriga om läget och lirka tills det går att få tvättat kläderna. Ibland får det ta tid. Återigen är det svårt om det är avföring på kläderna....”

[64] ”ta kläderna och tvätta dom på en gång så hen får tillbaka dom snabbt”

[65] ”Jag vet inte. Skulle nog försöka smuggla ut kläderna och tvätta dem när hyresgästen sover...”

[66] ”Kan försöka tvätta kläderna på natten.”

> ”Try to wash the clothes during the night and put them back in clean before the person wakes up”[67]

> ” co-operate with night staff they can change the clothes to new ones- they are still the persons clothes, the illness changes the way they see everything….”[68]

> ”Then one sneaks in in the evening and washes them, they have probably forgot which clothes they were the next day”[69]

One of the respondents would go as far as to create a distraction to help accommodate the residents' sense of self-determination:

> ”Ill have help from my colleague who has a sing-along during that time I will go get the clothes”[70]

These responses show a strong will to accommodate to the residents right to self-determination, despite breaking against it. The responses show that the respondents would act according to what is seen as a common good, but in a fashion that causes the least disturbance and distraught to the resident. These responses show a strong preference towards a person-centered care approach, valuing the health and wellbeing of the resident over the right to self-determination.

6.7.4 Refusal to Take Medication

The next vignette presented a situation where the resident refuses to take their medication. The following situation was presented:

> “A resident refuses to take their medication and spits out the pills given to them. This happens continuously at every attempt to provide medication.”

The most common solution for this predicament was to either contact the registered nurse, doctor, or try to give the resident the medication with something good, for example jam or candy. Half of the respondents' solution to this dilemma was to outsource the problem to the nurse or doctor:

> ”Then Ill talk to the registered nurse and if necessary doctor. Is it absolutely necessary medicine? They can decide what we do”[71]

> ”Inform the registered nurse about it”[72]

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[67] ”Försöker tvätta kläderna under natten och lägga in dem rena igen innan hen går upp”

[68] ”samarbeta med nattpersonal de kan bytta kläder till nya - det är förtfarande personens kläder , sjukdomen förändrar våra sätt att se på allt....”

[69] ”då smiter man in på natten och tar dem till tvätt, ataglgen har de glömt vilka kläder det var nästa dag”

[70] ”Jag tar hjälp av en kollega som har allsång under tiden hämtar jag kläderna.”

[71] ”Då talar jag med sjuksköterskan och ev läkaren. Är det absolut nödvändig medicin? De får ta ställning till vad vi gör”

[72] ”Jag meddelar ssk om detta,”

> “Contact the registered nurse”[73]

> “Find out if it is hard to swallow or tastes bad. If it taste bad, give the medicine with something the resident likes (jam, candy etc.) Important to notify the registered nurse! Maybe crush the medicine of give it in a liquid form instead? The registered nurse and doctor should give their opinion.”[74]

> ”Change the form to liquid, patch .,,,,,,, “[75]

Many also contemplated changing the form of the medication to a liquid form, in case the resident has difficulties swallowing. Interestingly, none of the residents replied they would ask the resident why they are refusing medication, and coercion and sweet talking, such as in previous answers, is only proposed by one:

> ”see if it can be changed to a liquid form and put it in a drink. convince (sweet talk)”[76]

While sweet talk and coercion is proposed in previous vignettes, the issue of medication is likely seen as a more essential, or easier, situation to handle through other means. Some respondents would crush or hide the medication and try giving it to them in secret. This response shows an approach more inclined towards a person-centered care approach, seeking for the best of the resident.

> ” Try in another way, crushed in jam, put under the toppings of a sandwich etc.”[77]

> ”If they are important one can try to give them with a little fix (for example under a slice of cheese). A necessity for their wellbeing. But if they are not necessary we can discuss a change.”[78]

> ”Try with quark, jam, candy or whatever else is good, crush the medication, sweet talk Take it up with the doctor if it is necessary”[79]

One respondent replies one cannot force anyone to take their medication, presenting a human-rights based approach to this vignette:

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[73]” Kontaktar SSk.”

[74]” Ta reda på om det är svårt att svälja eller om det smakar illa e.d. Om det smakar illa, ge medicinen med ngt som den boende tycker om (sylt, godis m.m.) Viktigt att informera ssk! Ev. krossa medicinen eller ge flytande medicin i stället? Ssk och läkare tar ställning”

[75]” rätt medicin form flyttande , plåster .,,,,,,”

[76] ”se om kan byta till flytande form o ha det i dricka. lirkar”

[77]” Försöker då på andra sätt, krossade i sylt, lägga under pålägg på smörgåsen mm.”

[78]” Är dom viktiga så kan man få i dom med lite fix(tex under en ostskiva). Ett måste för deras väl. Men om dom inte är nödvändiga så får vi diskutera ändring.”

[79]” prova med fil, sylt , godis eller vad som är gott, krossa medicinen , lirka Ta upp med läkare om den är nödvändig”

> ”Ok inform the registered nurse, one cannot force anyone to take their medication”[80]

Again the results show mixed practices when it comes to the right to self-determination; some would hide or crush medication for the wellbeing of the resident, while some would not force the resident to take their medication but instead contact the registered nurse or doctor. The responses again show the duality of the right to self-determination in dementia care homes; while some choose a course of action that is perceived as the best for the resident (a person-centered care approach) others choose to respect the right to self-determination (human rights-based approach).

6.8 Final Thoughts

Finally, the respondents were asked if they had any thoughts as to how self-determination (the right to decide when and what is done) of the residents could be improved in general. Some respondents replied they have nothing to add, while others were more extensive in their answers. Concerns about resources were brought up again in several of the answers.

When asked for any other thoughts on the topic of self-determination many voiced concerns about the state of elderly care, stating they themselves do not want to have to live in a care home. One goes so far as to say care homes have become storages, and that there is not enough time to do all that should be done:

> “ Yes I do not want to grow old and wind up in a home, this has become merely a storage. One does not have time to sit down with the elderly. I, being a practical nurse for the past 30 years, have seen the welfare being taken down. We that work in care services are not worth anything. We cost society and out employers’ money in long term sick leaves, as well as repetitive strain injuries, aching backs and STRESS! What needs to be done is have the right amount of staff to the number of residents. MORE TIME FOR INTERACTION!! Less administrative work. Half of my day goes into documentation. (How) The to do-list is longer than our working time is scary for example 3 different data systems, documentation on paper as well as HSL= Hälso och sjukvårdslagen (Authors note: Health care law), incidents/injuries, discrepancies, contact with the registered nurse, other staff and that everyone gets the right information. And above all that the BOSSES would listen to the staff,”[81]

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[80] ”Ok meddelar ansvarig Sjuksköterska, man får inte tvinga någon att ta medicin.”

[81] ”Ja jag vill inte bli gammal och hamna på hem, detta har bara blivit en förvaring. Man har inte tid att sitta ner med dom gamla, jag har som uska dom senaste 30-åren sett våran välfärd nermonteras. Vi som arbetar i vård och omsorg är inte värda något. Vi kostar samhället och arbetsgivarna pengar för långtidssjukskrivningar. såsom belastningsskador, onda ryggar, och STRESS! Det som behöver göras är att rätt personal till antal boende, MER TID TILL UMGÄNGE!! mindre administrativt arbeta. Halva min dag går åt till dokumentation. Att göra listan är längre än vår arbetstid är skrämmande. tex 3 olika datasystem, dokumentation via papper såsom HSL= Hälso och sjukvårdslagen , tillbud/skador avvikelser, kontakt med Ssk, övrig personal, och att alla får rätt info. Och framför allt att CHEFER ska lyssna på personalen. (undersköterska 25-30 år inom äldreomsorg)

> ”I will be sure to write down what I want and what I don’t want. With the slim workforce today it is a utopia it will work.”[82]

Concerns about the amount of administrative work is repeated in many answers, stating that this takes away time from actual care work.

> “The big question is, I think, how much the municipalities let elderly care is cost? It is not only about money but that we need more people to be able to fulfill wishes, so it seems. Some things one can always do but how much should existing staff be able to clone themselves to be able to be at all the place at the same time and have enough time with all the responsibilities lying on our shoulders. It is our residents whom are most important for us but there is so much time one must reserve for sitting in front of a computer, with all the registers we have to write in, documentation of different sorts and many more papers to read take part in”[83]

One respondent states the right to self-determination for people living with dementia is ambiguous, and that as a staff member one should be decisive and make decisions on the residents behalf, strongly stating a preference towards a person-centered care approach:

> ”when it comes to people with dementia the right to self-determination is ambiguous. Should one go according to their will all the time, although they refuse and are suspicious, or talk in a determined way and make decisions for them for their own best. never ask a resident with dementia but rather say: now we are going to do this..!”[84]

Some respondents propose softer approaches, such as increasing communication and empathy, endorsing again a more person-centered approach:

> ”The staff should always have an open dialogue between them on how we encounter and discuss our tenants and their needs and how it is possible to do it as employees. We want to avoid force.”[85]
>
> ”Encounter your residents like you yourself would like to be encountered”[86]

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[82] ” Jag kommer att vara noga med att skriva ner vad jag vill och inte vill. Med den slimmade personalstyrkan idag är det en utopi att det fungerar.”

[83] ” Den stora frågan är tror jag, hur mycket kommunerna tillåter att deras äldrevård får lov att kosta? Det handlar inte bara om pengar men om vi behöver vara fler människor för att uppfylla önskemålen så ser det nog ut så. Vissa saker går alltid att göra men hur mycket ska befintlig personal orka klona sig för att vara på alla ställen samtidigt och hinna med alla måsten som ligger på våra axlar. Det är våra boende som är viktigast för oss men det är så mycket tid som ska avvaras framför dator, alla register som vi ska skriva i, dokumentation av olika slag och ännumer papper att läsa och ta del i.”

[84] ” när det gäller de dementa är självbestämmande defusa.skall man gå efter deras vilja jämt ,trots att de jämt nekar o är misstänka ,eller tala om i bestämd form och ta beslut åt dem för deras eget bästa.fråga aldrig en dement boende utan hellre säga att: nu gör vi det här.."!”

[85] ” Personalen bör ständigt ha dialogen öppen mellan sig om hur vi bemöter och diskuterar med hyresgästerna om deras behov och hur det är möjligt att göra som personal. Vi vill undvika tvång.”

[86] ”Bemöt dina boende som du själv vill bli bemött”

One respondent brings up the current contradictions in law and practices, and states that although the right to self-determination is important and good, there are situations where the individual is not able to make decisions deemed as socially acceptable:

> ”We have had discussion/ reflections in discussion groups about socialstyrelsens (Authors note: The National Board on Health and Welfare) guidelines on self-determination. About how people living with dementia lack insight on their needs or maybe can’t speak at all and (that) naturally creates difficult situations. It is also important that relatives are included in conversations about self-determination. I have been in contact with socialstyrelsen about this question because we have had a few residents that never want to take care of their hygiene and the staff have tried everything but are still unsuccessful. There is for example Lex Sarah if one takes care of hygiene against the one with dementia will but there is also a Lex Sarah if you don’t tend to hygiene. It’s a catch 22! Usually one finds a solution. Because we constantly talk about the individuals wishes and needs we have an individual focus that favors self-determination. There are many things people living with dementia can decide by themselves which alone is good. It is on those occasions that those living with dementia lack insight in what is needed when problems arise.”[87]

As the response above shows, the right to self-determination in dementia care homes is a difficult question that is acknowledged as a challenge. The purpose of this survey was to explore how issues related to the right to self-determination in dementia care homes is actualized in practice. All in all, the answers of this survey show that there are different approaches to daily care situations in dementia care homes. Some respondents show an incline towards a human-rights based approach in matters that can be seen as more trivial, such as keeping dentures in at night, while matters such as hygiene are seen as issues that are more important than the right to self-determination. In these matters deemed as more essential, a person-centered approach is chosen. This corresponds with the presented analytical framework that showed that there are two different approaches in relation the right to self-determination. The results also show that these two approaches are used interchangeably, depending on the perceived significance of the situation.

Many respondents’ list time and resources as restrictions to the right to self-determination of residents in dementia care homes, and several responses express criticism and frustration towards dementia care home organizations. The responses show insecurity as to whom the responsibility of questions related to self-determination fall upon- while one responds they take a role of a leader, another responds they are not anybody’s mother. One respondent

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[87] ”Vi har haft diskussion/reflektion i samtalscirklar utifrån socialstyrelsens värdegrund bl.a. om självbestämmande. Just att den demente saknar insikt om sina behov eller kanske inte alls kan tala skapar naturligtvis svåra situationer. Viktigt också att anhöriga tas med i samtalet omkring självbestämmande. Jag har varit i kontakt med socialstyrelsen ang. denna fråga p.g.a. att vi haft enstaka boende som aldrig velat sköta hygien och personalen har försökt allt, men ändå inte lyckats. Det är lex Sarah om man sköter hygienen mot den dementes vilja, men det är också en lex Sarah om man inte sköter hygienen. Det är ett moment 22! Oftast brukar man hitta lösningar. Genom att vi ständigt pratar om individens önskemål och behov så får vi ett individfokus som gynnar självbestämmandet. Det är ju många saker som de dementa kan bestämma över och som enbart är av godo. Det är vid de tillfällen som de dementa saknar insikt om vad som behövs som problemen uppstår.”

outsources their responsibility by referring to guidelines. Despite all these factors, respondents felt that residents are able, at least to some extent, effect matters of their everyday life, but were restricted either by organizational matters such as resources and time, or the care takers approach to laws, guidelines and practices that rate the “greater good” as more important than the right to self-determination. Although both a person-centered approach and a human-rights based approach is visible as an approach used by the respondents in this survey, there is a preference towards a person-centered approach, in which decisions are made in co-operation or in the behalf of the resident.

7. Conclusions

The survey responses presented above corresponded with the analytical framework, and indicated that there are drastically different solutions to the daily situations in care homes when it comes to the residents' right to self-determination. In general many responses show a preference towards a person-centered approach that, at least to some extent, outsources decision making to a secondary party. Depending on the perceived importance of the situation staff members favor either a human-rights based approach, respecting the residents ultimate right to personal decision making, or a person-centered approach, that promotes decision making in co-operation with, or by, a secondary party. Such results were to be expected, as currently the laws and guidelines concerning the right to self-determination are inconsistent.

The analytical framework for this thesis presented documents relevant to the issue of right to self-determination for those living in dementia care homes in Sweden: the International Human Rights Instruments, Swedish Law, and Guidelines and Principles published by the Swedish National Board on Health and Welfare. These were chosen as the basis for the analytical framework, as this subject lacks previous research from the distinct perspective of the rights of the residents, and these listed documents are currently the basis for elder care services in Sweden. From these documents, two different approaches to the right to self-determination in dementia care work were identified: a human-rights based approach and a person-centered care approach, which were used as the basis for analysis of the survey, to identify how the instructions in these documents regarding issues related to self-determination in dementia care homes are actualized in actual care work. The ethical aspects and considerations of these two approaches, as well as other ethical considerations in regard to the right to self-determination, were also discussed.

The content analysis of the documents relevant to the right to self-determination for those living in dementia care homes in Sweden showed that current legislation in Sweden is in line with International Human Right Instruments, emphasizing every individual's right to self-determination. Guidelines and principles in relation to dementia care work published by the Swedish National Board on Health and Welfare as well as Swedish law, in addition to acknowledging the right to self-determination, also recommend a person-centered approach be adapted to dementia care work. Currently the definition of a person-centered approach carries many different interpretations, being at its simplest providing opportunities, to at its most extensive version being an extensive and intrinsic care model that actively involves care takers. The model the Swedish National Board on Health and Welfare presents of a person-centered approach is one that encourages the care taker to reflect what is best for the individual living with dementia from their perspective, which also can be seen as this approach endorsing shared decision making. This gives the care taker the opportunity- or responsibility- to act according to their own moral convictions.

The issue of self-determination for those living with dementia is a complex question that requires the attention of society at large, as such complex moral questions being solved on a local level inevitably leads to inequality in the treatment of those living with dementia- while one staff member may respect the residents right to refuse the other may feel taking forceful measures is more ethical. Leaving ethical questions up to the personal preference of care home staff is a questionable solution for all parties involved, especially as there is no consensus as to how these issues should be dealt with; everyone has their own distinct views on how important the right to self-determination is when speaking of people with an illness such as dementia. With the number of older people increasing in society, the right to self-determination for those living in care homes will undoubtedly be an important issue our society must tackle in the future, as the current system enables the care staff to influence many important, and personal, medical and social questions related to the right to self-determination. To begin this discussion, many questions will need to be discussed: how valuable is the right to self-determination? If the right to self-determination is to be infringed upon, who should be making the decisions? Who has the responsibility in these questions- the resident, the worker, the relative or society?

The World Health Organization and the United Nations have proposed a human-rights based approach for care work in dementia care homes, which would place precedence over the individual’s right to decide what to do despite their illness. The approach proposed emphasizes the individual’s right to self-determination, but does not address how one should act in situations where the individual living with dementia cannot make informed decisions. On the other hand a person-centered approach, endorsed by Swedish law as well as in guidelines and principles, promotes shared decision making, but currently lacks clarification as to in what extent and who should be helping in decision making on behalf of the individual living with dementia. These aspects make it apparent that the right to self-determination for those living with dementia carries many ethical questions that need to be addressed and discussed before either approach could be implemented as a reasonable method of care work among those living with dementia.

Finding solutions to the ambiguous situation of the right to self-determination for those living in dementia care homes is undeniably a complex process that would require the co-operation of not only care home staff or state, but residents’ and their loved ones input. To find answers to these questions, policy makers and those involved in dementia care- residents, staff and loved ones -need to communicate their wishes and needs, and find consensus in the difficult questions- for example should medication or showers be forced if the individual does not realize what is in their own best interest? This would require identifying if there are situations where residents need to be restricted or forced for their own wellbeing, and investigation into if there are moral grounds for implementing such forceful actions. This would require both further research into these questions, as well as clarification of the approaches that currently exist. Based on these questions it could be discussed if the current approaches can be clarified or combined to a viable approach; one could even discuss the possibility of creating a completely new approach to the right to self-determination for those living in dementia care homes.

Currently, mixed practices are taking place in dementia care homes, and in some cases the resident has more opportunities to implement their right to self-determination then in others, depending on the views of the care taker. At the moment two contradicting approaches are endorsed in relevant documents related to the right to self-determination for those living in dementia homes, as well as these contradictory approaches being carried out in practice.
The rights of those living with dementia are no doubt an issue of human rights, but instead of blindly enforcing rights that may induce more harm than good, attention should be focused on dealing with the actual situations. The current situation regarding the right to self-determination in dementia care homes leaves many questions up to the care takers, whom

voice concerns over having too much work, as well as insecurity as to whom responsibility in questions of self-determination fall upon. In practice, care home staff are daily solving these complex moral situations to the best of their ability and according to their personal preference- amongst increasing demands and stress.

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Appendix 1: Survey

Rätten till självbestämmande för personer med demens

1. Vad är din yrkestitel?

2. Vad är din högsta avslutade utbildning?

3. Hur länge har du jobbat inom äldreomsorgen?

4. Hur länge har du jobbat på din nuvarande arbetsplats?

5. Hur många brukare bor på avdelningen du jobbar på?

6. Enligt socialtjänstlagen:

> "Socialtjänstens omsorg om äldre ska inriktas på att äldre personer får leva ett värdigt liv och känna välbefinnande (värdegrund) 5 kap. 4§ socialtjänstlagen (2001:453), SoL. För att uppnå det behöver äldreomsorgen bland annat värna och respektera den enskilda personens rätt till privatliv och kroppslig integritet, självbestämmande, delaktighet och individanpassning." (Socialstyrelsen 2013 http://www.socialstyrelsen.se/aldre/nationellvardegrund)"

Känner du att de rättigheter som anges ovan införlivas i dagliga arbete?

Ja Nej Delvis

➔ Nej eller delvis; Varför känner du så?

7. Känner du att de boendes rätt till självbestämmande (att få bestämma när och vad som hander under dagen) är respekterad?

Ja Nej Till viss del

➔ Om nej eller delvis: på vilket sätt anser du att de boendes rätt till självbestämmande inte respekteras?

8. Får de boende bestämma själva när de ska äta?

Ja Nej Till viss del

- ➔ Om nej eller till viss del: på vilket sätt hindras de boende från att bestämma när det gäller måltider?

9. Kan de boende påverka när de ska duscha?

Ja Nej Till viss del

10. Kan de boende påverka när de ska gå på toa?
Ja Nej Till viss del

10. Kan de boende påverka när de ska vara delta i aktiviteter?

Ja Nej Till viss del

11. Hur skulle de boende få mer möjligheter att påverka de dagliga rutiner? Vad tror du skulle krävas för att detta skulle införlivas?

Följande frågor är hypotetiska, påhittade situationer. Försök sätta dig in i situationerna och förklara hur du skulle göra om du var där:

12. En boende har vägrat att duscha under en veckas tid, trots att både du och dina kollegor, flera gånger, försökt övertala hen att duscha. När ni konfronterar boenden och berättar att hen måste duscha blir hen aggressiv men det är nu tydligt att boenden verkligen behöver duscha.

13. En av de boende vill sova med sina löständer trots att tandläkare säger att detta inte bör göras. Tandläkaren säger att om man har i löständer under natten kan man få tandköttsinflammation. Du lyckas ta ut löständerna och lägger dem på toaletten. En stund senare går boenden in och hämtar sina tänder igen. Detta upprepas många gånger varje kväll.

14. En av de boende vill inte tvätta sina kläder, utan vill använda samma, smutsiga kläder varje dag. När du försöker hämta de smutsiga kläderna blir den boende arg och förbjuder dig från att tvätta dem. Hen anser att kläderna är rena och vill därför fortsätta använda dem. Hen säger att du ljuger när du säger att kläderna är smutsiga.

15. En av de boende vägrar att ta sin medicin och spottar ut alla tabletter. Detta händer varje gång du eller dina kollegor ska ge hen medicin.

17. Har du några reflektioner eller tankar kring självbestämmande (rätten att bestämma när och vad som görs) och hur detta skulle kunna förbättras i allmänhet?

Appendix 2: English translation of the Survey

Survey on the right to self-determination for those living in dementia care homes

1. What is your job title?
2. What is your highest education?
3. How long have you worked in elderly care?
4. How long have you worked at your current workplace?
5. How many residents reside in the unit you work in?

6. According to the law on social services:

   > *" Social services care for the elderly should be aimed so that older people can live in dignity and endorse well-being (values) Chapter 5, Section 4 of the Social Services Act (2001: 453) SOL. In order to achieve this elderly care needs to, among other things, protect and respect the individual's right to privacy and bodily integrity, autonomy, participation and personalized care". " (Socialstyrelsen 2013 http://www.socialstyrelsen.se/aldre/nationellvardegrund)*

   Do you feel that the rights stated above are implemented in daily work?

   Yes No Partly

7. Do you feel that the residents right to self-determination (decide what is done and when) is respected?

   Yes No Partially

   ➔ if no or partially; How do you feel that the right to self-determination is not being respected?

8. Are the residents able to decide themselves when to eat?

   Ja Nej To some extent

   ➔ If no or partially; How are the residents restricted when it comes to meal times?

9. Are the residents able to influence when they shower?

   Yes No To some extent

10. Are the resident able to influence when they can use the bathroom?

11. Are the residents able to influence when they can take part in activities?

12. How could residents be involved more in daily decision making? What do you think would be required for this be implemented?

The following questions feature hypothetical situations. Imagine yourself in these situations and describe what would you do:

13. A resident has refused to shower for a week, despite you and your co-workers efforts to try to convince the resident to shower. The resident becomes aggressive when confronted about the need to shower. The need to shower the resident has become apparent, but the resident simply refuses.

14. A resident wants to sleep with their dentures in their mouth, despite doctors' orders. Having dentures in during the night will cause gum disease according to the doctor. You successfully remove the dentures, and place them in the bathroom but the resident goes to get the teeth and puts them back in their mouth, and does this every time you take out the dentures. You have the same struggle every night.

15. A resident does not want their clothes washed and wants to wear the same, dirty, clothes continuously. When you try to go collect laundry, the resident forbids you. The resident feels that the clothes are clean and they want to continue wearing them.

16. A resident refuses to take their medication and spits out the pills given to them. This happens continuously at every attempt to provide medication.

17. Do you have thoughts as to how self-determination (right to decide when and what is done) of the residents could be improved in general?

Appendix 3: Introduction E-mail

Hej,

Mitt namn är Laura Balash och jag studerar en master i internationellt socialt arbete och mänskliga rättigheter på Göteborgs univeristet. Jag ska nu skriva min D-uppsats och därmed ska jag genomföra en internet undersöking på ämnet självbestämmande och rätten till självbestämmande för personer med demens och som bor på ett särskilt boende. Jag har själv jobbat på flera särskilda boenden och därigenom blivit intresserad av huruvida personer med demens har möjlighet att påverka sin vardag och livssituation.

Målet med studien är att undersöka hur mycket de boende kan påverka sina dagliga rutiner, det vill säga, när och hur saker ska bli gjorda. Informationen från denna undersökning kan förhoppningsvis ge insikt om hur man kan öka patienttillfredsställelse och delaktighet och hur man kan jobba så att boendens vardag blir mer förgylld.

Jag skulle vilja fråga om ni skulle vara intresserade av att delta i projektet? Undersökningen är en internetundersökning som tar ca 5 minuter. Alla svar är anonyma. Frågorna är för alla som jobbar i demensboenden, och ni skulle bara behöva skicka en länk till enkäten till anställda e-post.

Jag kommer att lägga en lista med frågor och en länk till enkäten till denna e - post. Om ni har några frågor avseende detta projekt, jag skulle gärna komma och presentera projektet, eller så kan ni svara till detta e-postmeddelande eller ringa mig. Vill slutligen tillägga att om ni enbart vill kolla igenom enkäten innan ni fyller i den, avsluta då inte med att trycka på ”submit” för då registreras det som ett svar.
Länk till enkät: https://surveyplanet.com/57014e86493d480c1bf1699f

Tack så mycket på förhand!

Med vänlig hälsning,
Laura Balash
laura_balash@hotmail.com
076 4260449

Handledare Magnus Nilsson
magnus.nilsson.2@socwork.gu.se
031-786 3889

Appendix 4: English Translation of the Introduction E-mail

Hello,

My name is Laura Balash and I am studying a Master's program in Social Work and Human Rights at the University of Gothenburg. I am now in the process of writing my Master's thesis and for my thesis I will investigate the right to self-determination for those living in dementia care homes by means of an online-based survey. I have myself worked in dementia care for several years, which sparked an interest in me to research how people living with dementia can influence their daily life and life situation in general.

The aim of this study is to research to what extent residents can affect their daily lives, in other words, influence when and how things are being done. Information collected from this survey will hopefully provide insight on how to increase patient satisfaction and participation, as well as how one can work to make the residents lives more enriched.

I would now like to ask if you are interested in taking part in this project? The survey is online-based and takes approximately 5 minutes to complete. All answers are anonymous. This survey is aimed for all staff in dementia care homes, and you only need to send this link to the e-mail addresses of your staff.

I am going to attach a copy of the questions to this survey to this e-mail. If you have any questions concerning this study, I would be more than happy to come present this project, or you may also e-mail or call me. Finally I would like to remind you that if you wish to view the survey before forwarding it, please avoid pressing "submit" for otherwise your answers will be registered.

Link to survey: https://surveyplanet.com/57014e86493d480c1bf1699f

Thank you in advance!

Kindly,

Laura Balash
laura_balash@hotmail.com
076 4260449

Supervisor Magnus Nilsson
magnus.nilsson.2@socwork.gu.se
031-786 3889

Appendix 5: Introduction to the Survey

Mitt namn är Laura Balash och jag studerar en master i internationellt socialt arbete och mänskliga rättigheter på Göteborgs univeristet. Jag ska nu skriva min D-uppsats och därmed ska jag genomföra denna studie på ämnet självbestämmande och rätten till självbestämmande för personer med demens och som bor på ett särskilt boende.

Målet med studien är att observera hur mycket de boende kan påverka sina dagliga rutiner, det vill säga, när och hur saker ska bli gjorda.

Alla svar är anonyma.

Om Ni har några frågor får ni gärna kontakta mig eller min handledare.

Med vänliga hälsningar,
Laura Balash
laura_balash@hotmail.com
076 4260449

Handledare Magnus Nilsson
magnus.nilsson.2@socwork.gu.se
031-786 3889

Appendix 6: English Translation to the Introduction to the Survey

My name is Laura Balash and I am studying an International Master's Program in Social Work and Human Rights at the University of Gothenburg. I am now writing my Master's thesis and for this I am conducting this online-based study on the right to self-determination for those living in dementia care homes.

The aim of this survey is to investigate to what extent can residents influence their daily routines, in other words, when and how things are being done.

All answers are anonymous.

If you have any questions please feel free to contact me or my supervisor.

Kindly, Laura Balash
laura_balash@hotmail.com
076 4260449

Supervisor Magnus Nilsson
magnus.nilsson.2@socwork.gu.se
031-786 3889