Assistive technology for the elderly population with Dementia in Norway

An approach for a more dementia friendly society

Submitted by

MONZUR MORSHED SAIKAT
s320830

OSLOMET

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Faculty of Social Sciences
Oslo Metropolitan University
Oslo, Norway

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Abstract

In an aging society like Norway, the incidence of dementia is very high. For proper integration into society, It is essential to promote assistance to Persons with Dementia (PWD) and to promote help to their wellbeing and independent living. This research aims to explore the potential of available Assistive Technology (AT) in the everyday life of PWD and find out the barriers of using them. The study have been conducted in Different municipalities in Norway involving both healthcare and technology professionals who are providing these technologies to PWD. The data were collected in semi-structured questions concerning caregivers and family member's experiences.

Two main type categories have been discussed: Satisfied and Unsatisfied users and the reason behind this have been described. The qualitative results showed that most of the PWD use ATs for independence and autonomy of life. Challenges concerning AT assess for PWD from different immigrant background have also reviewed. GPS devices helped independent travel and Medicine dispenser provided scope for self-medication for PWD. The results of the study support the idea to create dementia-friendly communities at all levels, which is a cost-effective and reliable solution for this particular aging group.

List of Contents

CHAPTER FOUR

CHAPTER FIVE

Glossary of Terms Used

Term	Meaning
ADI	Alzheimer's Disease International
ADL	Assisted Daily Living
AI	Artifical Intelligence
AT	Assistive Technology
EMA	Electronic Memory Aid
GPS	Global Positioning System
HCI	Human Computer Interaction
ICT	Information and Communication Technology
PDA	Personal Digital Assistant
PWD	Person with Dementia
SAR	Socially Assistive Robot

Acknowledgements

Chapter 1. Introduction:

1.1 The relevance of the study:

According to The sustainable development goals (SDGs) announced by the United Nations in 2015, propose the new target for global health. SDG aims to "ensure healthy lives and promote well-being for all at all ages" (UN, 2015). This research proposal addresses the role of assistive technology in helping to achieve this goal of SDG. This research aims to focus on how assistive technologies can help improve the well-being of elderly people living with dementia and finding out challenges faced by the caregivers and family members for implications of these technologies.

There are several reasons for choosing this research topic. First of all, although assistive technologies can play a vital role in supporting the well-being of people with disabilities especially in Dementia, there is a substantial unmet need for access to these technologies. According to World Health Organization (WHO) estimates, there are possibilities for more than a billion people globally to be benefited from assistive technologies, yet only one in 10 has access to them (Bennett et al., 2017). Scientific Research on how assistive technologies can improve an individual's lifestyle suffering from dementia will help raise awareness of this need. Secondly, although assistive technological support can benefit a wide range of disabilities a more focus on care for older adults is relevant because the population is aging in many countries like Norway. According to the global priority research agenda by WHO, due to aging populations and increases in non-communicable diseases, more than 2 billion people will need at least one assistive technology by 2050 (Bennett et al., 2017). WHO concluded in 2012 that "Dementia poses one of the greatest societal challenges for the 21st century" (WHO, 2012). In Norway, an aging population will be associated with an imbalanced large rise in the number of people with dementia and the number may increase from 78,000 people in 2017 to an estimated 150,000 by 2050, with substantial implications for health-care costs (Norwegian Institute of Public Health, 2015). Though there is no appropriate data for Norway, the total worldwide cost of dementia in 2018 could be 1 trillion United States dollars (Prince, 2015). Without research and development into assistive technologies and greater global awareness of the unmet need for these technologies, it would be difficult to overcome the disease burden due to Dementia. And further research is essential to ensure that, technologies should be introduced in ways that are supportive

of and respect the rights consider ethical issues of vulnerable elderly people who have dementia (Belinda Bennett et al.,2017).

1.2 Background and the status of the knowledge:

Dementia is one of the most common and most devastating conditions of late age; approximately 4.6 million new cases of dementia are occurring worldwide every year, and the number of people affected is predicted to be doubled every 20 years, to 81.1 million by 2040 and 131.5 million in 2050 (Ferri et al.,2006, Report: Alzheimer's Disease International 2015). People with mild cognitive impairment are at increased risk of developing dementia, although the conversion rates reported range from 1% to 25% or more per year(Ferri et al., 2005).

Every 3 second, someone develops dementia around the world and most of the incidence will be in developing countries. At present 58% of people with dementia live in low and middle-income countries and expected to rise 68% by 2050. The fastest growth in the elderly population is taking place in mostly China, India, and their south Asian and western Pacific neighbors (Report: Alzheimer's Disease International, 2015).

Worldwide prevalence of dementia is around 46 million; a figure predicted to be treble to 131.5 million by 2050, with current healthcare costs recently estimated at the US $818 billion (Prince M, Wimo A, Guerchet M, 2015). Among all other chronic diseases, dementia is one of the most critical contributors to dependence, disability, and care home placement (Prince M, Prina M, Guerchet M,2013). Despite a global policy push towards a more timely diagnosis and earlier intervention, considerable geographical differences in the provision of post-diagnostic care and support services exist (Prince M, Bryce R, & C., 2011). One aspect of post-diagnostic support, which may enable persons with dementia to live independently for a longer time that is potentially leading to cost effectiveness by delaying entry into care and nursing homes (Prince M, Wimo A, Guerchet M, 2015), is assistive technology. According to (Marshall M,1997) "Any item, piece of equipment, product or system is driven by electronics, whether acquired commercially, off-the-shelf, modified or customized, that is used to help persons with dementia in dealing with the consequences of dementia is assistive technology". The technology does not necessarily need to be "purposely designed" (Andrich, Mathiassen, Hoogerwerf, & Gelderblom, 2013)for persons with dementia because many mainstream technologies can be adapted to their

changing needs. Essential need areas in dementia are memory support, information, company, reducing psychological distress, and engaging in daytime activities (van der Roest et al., 2009). Various technologies have been introduced to address these needs, such as electronic calendars, Web-based information systems, video-calling, and automated activity support systems, GPS, etc.(Lauriks et al., 2007).

Evaluation studies have identified that persons with dementia are positive about using electronic devices to facilitate their independence and reduce family stress (Topo, 2008). Furthermore, small-scale studies have proved that assistive technologies improve independence, behavioral symptoms in persons with dementia, and quality of life, and stress in carers (Gitlin, Winter, & Dennis, 2010).

Despite the promising assistance of technological support systems of Assistive technology, several issues remain before they can make a difference in the field of elderly dementia care. According to (Richard & Shima, 2014), "the predominant use of technical solutions for safety and security and carer reassurance rather than for lifestyle modification in general; the lack of high-quality scientific study into the effectiveness and cost-effectiveness of ATs in dementia care; the slow uptake and implementation of assistive technologies; the lack of successful commercialization of prototype ATs; and the limited attention to aesthetics, which can make many technological support systems feel stigmatizing". Furthermore, professionals and society also seem to lack an applied understanding of the potential of assistive technology in dementia because it is not being integrated into mainstream dementia care practice (Bowes A, Dawson A, & C., 2013)

Calculations based on a big number of studies in Western Europe on Dementia show a prevalence of 6.9 percent among people over 59 years (Sosa-Ortiz, Acosta-Castillo, & Prince, 2012).The incidence rises from 1.6 percent in the age group 60-64 years to 43 percent in the group over 89 years.(Norwegian Institute of Public Health, 2015:online)
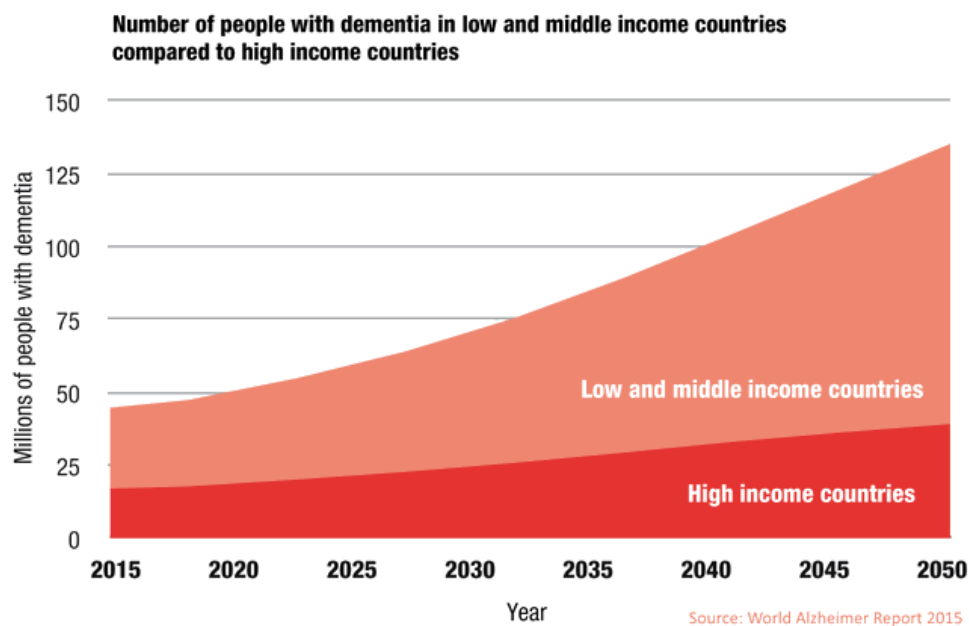
Fig 1: Number of people with Dementia globally according to the economical status (World Alzheimer Report 2015)

When these figures are compared with statistics available for the age distribution in Norway, they show that about 1.5 percent of the entire population has dementia. Almost every fifth person will develop dementia during their lifetime (Seshadri et al., 1997, report, Norwegian Directorate of Health, 2007). almost 78,000 people, or 1.4 percent of the population, have dementia in Norway (report, Norwegian Directorate of Health, 2007). A recent report from the Department of Mental Health and FHI of Norway shows the actual number of Dementia is between 84,000 and 104,000 that is alarmingly higher than previously assumed (Norway Today, 2018). Calculations reveal that "the expected increase in life expectancy in Norway will lead to over a doubling in the incidence of PWD from 2006 to 2050 if age-specific prevalence remains at current levels" (Norwegian Directorate of Health, 2007).

Society all over the world is aging fast especially in developed countries. In Norway, almost 16.71% of people are aged 65 years or more, which constitutes about one million people in total (Statistics Norway, 2018). That is nearly 2% higher than ten years before. Senior citizens especially who have dementia have been seen to be at risk of becoming marginalized because of difficulties in communication and lack of proper knowledge in benefit of assistive technology.

Findings of surveys made in the USA suggest challenges in learning and using computer-mediated Assistive information and technology in the age group of 75 years of age and older (Lee, Chen, & Hewitt, 2011).

As life expectancy is increasing, the socioeconomic burden due to disease is also increasing. It is imperative to focus on the quality of life of patients who have Dementia. Proper use of assistive technology, medicine, and social support especially sympathetic attitude towards them can help a dementia patient to lead a healthy and normal daily life and reduces the consequences and complication of the Disease burden.

Technology may be used to support chronic diseases like Dementia self-management. Both mobile phone apps and Internet-based technological interventions have been found to support self-management behaviors of people living with dementia. Technology can extend the reach of self-management to patient's communities and homes, provide for the individualized care, and provide just-in-time information.

Using technology to facilitate dementia self-management is not a new idea, but as patients become more technologically savvy, devices become more available, and new technologies emerge, the variety of technological self-management strategies increases. New assistive technology and customized mobile apps are not only about technology. Instead, it is about enhancing a person's quality of life through improved outcomes in safeguarding, living standards, social interaction, and greater independence. According to the Social Care for Excellence's Assistive Technology for Older People research briefing, some of the critical benefits of the assistive technology include (Roger 2008):

- increased choice, safety, independence and sense of control
- improved quality of life
- maintenance of ability to remain at home
- the reduced burden placed on careers
- improved support for people with long-term health conditions like Dementia
- decreasing accidents and falls in the house.

1.3 Dementia situation in Norway:

Like other wealthy countries, Norway is experiencing two opposite demographic trends, a high number of the elderly population who needs different types of age-related care and a decreasing workforce of younger people, resulting in shrinking of workforces. This gap might cause both economic and organizational challenge for the government, so the government has taken initiatives to bridge this gap by proper implementation of Assistive technologies as a part of welfare. The challenges call for a broad and integrated approach for political, social and economic measures, and there are high possibilities to the transforming potential of assistive welfare technology in care services. In 2011, a Norwegian green paper pointed out four categories of care and welfare technologies (Ministry of Health and Care Services, 2011) that will be of importance in the years ahead:

• Safety technologies, such as safety alarms, sensors, and GPS applications

• Compensation (assistive) technologies, such as robots

• Social contact technologies, such as social media for maintaining relations with family and friends

• Treatment technologies, such as devices and sensors for measuring health status.

All of these assistive technological interventions had vast potential for innovation and higher quality of life and believed to be significantly reduce public expenses for care and welfare services for the elderly population. The field is, however, in its very infancy, and there are many unsolved issues (Molka-Danielsen et al., 2013).

1.4 Research plan and collaboration:

The thesis is based on Oslo Metropolitan University under WATT Welfare Access Through Technology) project. WATT is an interdisciplinary research group at OsloMet, anchored in the Faculty of Social Sciences; Department of Social Studies. The research group also includes representatives from SIFO, TKD, and LUI, as well as representatives from the grid company No Isolation and Oslo municipality.

1.5 Theoretical perspective for the study:

The focus of this study is to understand the experience of caregivers and family members of dementia patients using assistive technology. However, the aim is not only to unravel the

descriptive accounts of advantages and barriers of assistive technology but also understand such experiences within the cultural, economic, social and political contexts. Few of the objectives are to find out and investigate different ATs available in the literature for the PWD, different ATs available commercially ,their respective advantages and limitation, categorize them based on the systematic mapping study results and finally to explore the state of AT based research for the PWD in different countries comparing with Norway.

The epistemology of this study is to frame out how assistive technology as being continually negotiated and transformed by embodied and socially situated individuals interacting in everyday life. Perspectives on coping as an ongoing interactive process is believed to give more understanding of the experiences with assistive technology. Lazarus and Folkman, have provided a classic definition of coping: "Coping is the constantly changing cognitive and behavioral efforts to manage external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus,1984). Coping in this theoretical perspective refers to the processes of coping, underlining efforts to manage, irrespective of the results of the efforts. On the other hand, Managing can include minimizing, avoiding, tolerating, and accepting the stressful conditions, as well as attempting to master the situation within specific contexts. Coping is an example of embodied and interacting efforts: people handle challenges through interaction, cognition, and emotion. In the early stages of coping the efforts are more conscious, but in later stages, the reaction patterns can be "automatized" as embodied habitual practice (Arntzen,2016), related to the phenomenological concept of the "lived body" (Merleau, 2002). However, coping is also a social endeavor (Lazarud,1984) developed in social interactions, and is often – especially initially – dependent on social instructions, advice, demonstrations, and continual support. In other words, technical challenges occur when there is poor congruence between the person's capacity, occupational demands, and environmental support and barriers (Townsend, 2007).

Chapter 2. The literature review – findings

This thesis investigates the impacts of ATs in supporting the PWD during their daily activities. An extensive literature review has been performed on ATs and their applications in the daily activities of the PWD to identify the research gaps for this specific field. This chapter presents a review of the existing state of the art for the topic under investigation. The literature and qualitative questioners are then linked to analyze how existing ATs are helping the PWD in their daily lives. And find out the barriers to these technologies.

The chapter is discussed in two major sections. The 1st section named "Literature Review" presents important definitions, background, and classifications of ATs, summaries of the existing empirical studies available within the research domain and enlists open research areas.

On the 2nd section "AT Bibliometric Analysis" presents an overview of AT research activities among top research countries and contribute to further open research areas.

This chapter is focused on achieving the following research objectives:

1. What are the different ATs available in the literature for the PWD?

2. What are the different ATs available commercially for the PWD?

3. What are the advantages and limitations of different ATs available in Norway?

4. How can we categorize ATs based on the systematic mapping study results?

5. What are the state of AT based research for the PWD in different countries comparing with Norway?

2.1 Important Definitions Used in the Thesis

Assistive Technology: AT is a comprehensive term used to describe "any item, object, device or system that enables a person to perform tasks that they would otherwise be unable to do by themselves, or increase the safety by which desired tasks can be performed". Simply, the purpose of AT is to provide any aid that can assist the frailest and vulnerable members of our society to live well and safe at their own home or in a care home environment (Au et al. 2015b).

The federal Individuals with Disabilities Education Act (IDEA) define AT as "any item, piece of equipment, or any product system, whether acquired commercially off-the-shelf, modified, or customized, that is used or intended to be used to increase, maintain, modify or improve the functional capabilities of individuals with disabilities" (Marino et al. 2006).

The Convention on the Rights of Persons with Disabilities (CRPD) defines AT as "the technology designed or adapted to enhance the performance and quality of life for an individual with disabilities" (Assembly 2007).

Dementia: The term dementia is quite versatile in different fields of research. This is defined as "Variety of brain diseases that include any condition that causes loss of cognitive ability (the ability to think and correlate clearly) that is severe enough to affect a person's daily functioning" (Draper et al. 2010). In easy words, dementia is a continuing mental processing disorder due to some injury or disease which result in personality change, forgetting things, mental confusion, and reduced ability to the response.

Wellbeing: This terminology has been describing in a few areas of this thesis. The term wellbeing describes "the state of being comfortable, healthy, or happy and able to function normally." (Kinney and Rentz 2005).

Assistive Technology Impact: As one of the focus of this thesis is how assistive technology influence the lifestyle of Person With Dementia (PWD), so understanding the impact of AT is important. The term AT impact means "the marked effect or influence" of AT according to the behavior of the users (Chaudhry et al. 2006).

2.2 Background of Assistive Technology

Using of AT for the PWD is a modern concept. Although some research related to AT has been started at the late '90s, those we mainly based on hypothesis. Research related to the history of Assistive technology indicates that the most comprehensive studies conducted on this topic came after 2010. That study distributed AT development into three eras. They named the first era as "The Foundation Period," the second era as "The Establishment Period" and the third era as "The Empowerment Period" (Bryant and Bryant 2011).

The Foundation Period (Stone Age to 19th Century):

The first era is known as "The Foundation Period" started in the Stone Age when people from that time attempted to use a 'stick' as a cane to assist another person with an injured leg (Bryant and Bryant2011). During the 17th and 18th centuries, the pirates used their functional capabilities by using a 'metal hook' and 'wooden legs.' In 1829 'Braille method' of reading and writing was invented for blind or partial sighted people as a helping tool. In this method, people perform reading and writing through touch. Within a few years in 1836 'phonograph' was invented by Edison to help his mother and other people with hearing problems to enable them to listen to recordings (Cook and Polgar 2014).

The Establishment Period (1900 to 1972): The second era for AT development is known as "The Establishment Period" which spans from 1900 to 1972. This period is known for the establishment of different laws, policies, and litigation. The famous law established during this era is 'The Soldier Rehabilitation Act 1918' which was extended in 1920 for the nonveterans as well. During this period many notable inventions were made like in 1937 the 'Xframe-folding wheelchair' was invented and later on in 1947 the 'Hoover Cane' was invented. Another interesting aspect of this period is the establishment of various organizations to help people with disabilities and their family members.(Asghar et al. 2017) Examples include organizations like 'Council for Exceptional Children-CEC' established in 1922 and the Learning Disabilities Association-LDA' established in 1963 (Cook and Polgar 2014).

The Empowerment Period (1973 till now): According to (Asghar et al. 2017a) The third era for AT development is known as "The Empowerment Period" which spans from 1973 till now. This era started with the 'Education for All Handicapped Children Act – EAHCA' in 1974. A few years later in 1988 'The Related Technology Assistance for Individuals with Disabilities Act (Tech Act)' law was established to support AT development and implementation financially. In 1998 'The AT Act (ATA)' was established which resultantly increased the access and availability of AT services and devices (Alkahtani 2013). During Empowerment period the demand and development of ATs have increased exceptionally. Another proof of empowering people with disabilities through AT is the statement by IBM which describes that "For most people, technology makes things easier, but for persons with disabilities, technology makes things possible" (Bryant and Seok 2016).

2.3 Assistive Technology Classification:

According to existing literature related to ATs till now, it can be classified into three major groups named as: (i) Low-Tech Assistive Technologies, (ii) Mid-Tech Assistive Technologies and (iii) High-Tech Assistive Technologies (Ganschow et al. 2001).

Low-Tech Assistive Technologies: They are usually non-electric simple devices. They need little or no training at all for using them. These devices are commonly available everywhere at low cost. These devices either need little or no maintenance at all and anyone can easily use it. The examples of low-tech ATs include adapted furniture, highlighter tape or pens, pencil grips, etc. (Ganschow et al. 2001).

Mid-Tech Assistive Technologies: Mid-tech ATs are mostly electronic based devices. These electronics can be easily operated with a small training. These electronic devices require a basic level of maintenance, so the cost is not too high for such devices. These electronic devices are widely available in markets on reasonable price (Asghar et al. 2017). The examples for Mid-tech ATs include electronic calendar, dictionaries, digital recorders, adapted keyboards, etc. (Ganschow et al. 2001).

High-Tech Assistive Technologies: High-tech ATs are sophisticated electronics and mostly contain microcomputer components for storing and retrieving data and information. Most of the time they are connected with a remote server. Mostly these ATs are of higher cost, and these also require continuous maintenance which increases its price even more. Since these are complex technologies, these require extensive training for operating them properly (Asghar et al. 2017). The examples of high-tech ATs include talking Medicine dispenser, motion detector, Integrated health monitoring devices, software, hearing and vision devices, robotics, monitoring systems, prompting devices adapted keyboards, etc. (Ganschow et al. 2001).

Cook and Hussey described that "yesterday's high tech is tomorrow's low tech." They further recognized that "as the field advances, there will be new considerations that will further stretch our concepts and force new ways of categorizing and describing ATs" (Hussey et al. 2002).

2.4 Popular Assistive Technologies from Literature:

The ATs offer various types of functionalities for the PWD like socialization, cognitive help, activity monitoring, health conditions monitoring, safe walking, medication on time, leisure activities, rehabilitation, etc. For eliciting popular ATs from literature (Asghar et al. 2017) have developed an AT evaluation criteria (based on their definitions) to understand the ATs in details better.

Assistive Technology Evaluation Criteria: The AT evaluation criteria include basic functionality, operations, advantages of AT usage and limitations associated with existing AT. The criterion is followed as:

As evident from the definition, the assistive robot (Device) should be able to help the PWD in their daily living activities like mobility, transportation, social assistance, disability rehabilitation exercises, climbing stairs, physical support, etc.

The monitoring systems assist in activities like supervision of the PWD while living at their homes or care homes. These systems should provide continuous monitoring concerning a person's health, safety, wellbeing, etc. Furthermore, these systems should provide help in deviations from routine daily activities, tracking location, detecting falls, wondering at night, etc.

The prompts and reminder systems should provide support especially to persons with cognitive disabilities. It should be able to perform activities like generating prompts and reminders for taking medicine, prompts for performing daily activities in a proper sequence, reminds people to perform various tasks on a predetermined time, prompts for executing a plan, etc.

Assistive technology includes mobile devices tailored to the specific needs of the PWD. These devices should provide support in making calls, video messages as reminders, etc. Further, these devices can also be used for monitoring patient's physiological data like weight, blood glucose, blood pressure, etc.

Assistive software applications are specially designed applications for the PWD. These applications should fulfill the needs of the PWD like organizing activity calendar, leisure, storing patient information, etc. Additionally these applications can be used in combination with other ATs for the wellbeing of the PWD.

2.5 Empirical Studies on Assistive Technology Support for the People with Dementia:

Empirical studies are conducted by using empirical evidence. These studies are used to gaining direct knowledge through observations of experiences. Empirical studies can be conducted through qualitative, quantitative or multi-methods research approaches. Research approaches used for empirical studies depend on the nature of research questions and research domain. Empirical studies are prevalent in almost all research fields. The literature review shows that there are also few empirical studies on ATs with focus on the PWD.

From the meta-analysis of Asghar et al., An empirical study effort the researchers investigated the opinion of the relatives of the PWD regarding AT support. They used 22 PWD relatives for the experiments. Two questionnaires were filled from the participants. The results show that the PWD relatives have a favorable view about the AT use for the wellbeing of the PWD (Engström et al. 2006). Another study investigated the staff members' satisfaction with AT usage for the welfare of the PWD. The study used a questionnaire-based method to collect data from 33 staff members. Data were collected before, during and six months after the implementation of the AT support at the nursing home. The ATs used include activity monitoring, alarms, internet and fall detectors. The overall results showed that the use of AT significantly improved the job satisfaction of workers with their work (Engström et al. 2005).

In another similar study, the researchers investigated staff members' perception of Information and Communication Technology (ICT) use for the PWD. They conducted interviews with 14 members of staff before, during and after ICT implementation. This ICT include communication technology, fall detector, alarms, and computers. The staff members have diverse perceptions. After the ICT implementation mostly the perceptions were on the positive side (Engström et al. 2009).

The use of computer technology is explored in another research effort. The computer technology focused in this study is an automated prompt system. A total of eight participants participated in 60 trials. The results show that the PWD was able to complete more steps with the help of prompt system. Such ATs can help reduce the number of interaction required between the PWD and their caregivers (Labelle and Mihailidis 2006).

Another empirical study investigated the use of assistive prompter during the hand washing activity. Six PWD participated in the study. The results showed that the PWD completed 11% more steps independently with the help of prompter AT. Additionally, the number of interactions with the caregivers also reduced by 60% (Mihailidis et al. 2008).

Wondering is another critical problem for the PWD which also creates a lot of stress for the caregivers as well. This problem is investigated by testing a GPS device with the PWD and asking their future needs through a case study. The results show that although the participants appreciated the use of GPS but their concerns were related to the shape and volume of the device. This empirical study further concludes to use 'user-centric' approach during the development of AT for the PWD (Faucounau et al. 2009).

In an interesting research study, the researchers used an entertainment robot for therapy of the PWD. The robot was made of metal and can respond to commands. The researchers conducted a case study at a care home. Although the patients recognized the robot, still the results show increased communication between the PWD and the robot. The robots can be a useful tool in the rehabilitation of the PWD (Tamura et al. 2004).

The most comprehensive work on this field in recent years came from the Australian researchers who used a systematic review to identify empirical studies on AT for the PWD (Fleming and Sum 2014). Their extensive search efforts enabled them to identify 178 potentially relevant studies. The evaluation criteria excluded 142 studies. The remaining 32 reviews received validity assessment using the approach from (Forbes 1997). The results show only eight studies as strongly relevant, nine studies as moderately and 19 studies as weakly relevant. However in-depth analysis of these shortlisted studies further indicates that only little empirical evidence of supporting the PWD through AT exist. The researchers concluded:

#There is a high rate of non-acceptance of AT,

#The studied AT is often unreliable.

#The AT should be tailored to the individual needs.

#There is a critical need for better designed AT empirical studies based on large samples

#The existing AT makes little difference to practical outcomes

#The ability of AT for enabling the PWD outside their home is rather weak

#The best use of AT is face to face communication

These empirical studies not only evaluate existing AT but also point towards many research areas still open for future research (Asghar et al. 2017).

2.6 Literature Open Areas

Although there have been some empirical research on ATs but unmet needs for PWD for using AT is still not fulfilled. Asghar et al. mentioned a few open areas in the research areas. There are many researchers of the view that although there is a lot of AT available for the PWD, these AT are not thoroughly evaluated. The lack of AT evaluation for the PWD may result in their lack of trust in AT and reluctance in its use (Fischer et al. 2014). In another study, the authors emphasized the need to conduct trials for analyzing the AT impacts and its effectiveness in supporting the PWD (Leroi et al. 2013).

Another study describes user satisfaction with AT as the essential factor for AT long term use and adaptation. User satisfaction for AT is driven by their needs, preferences, personal values and attitudes (Carvalho et al. 2014). Another study is also of the view that usability is a critical challenge for technology adaptation and AT usability can be increased through interaction with the PWD (Carrillo et al. 2009). Additionally, human-centered design and development of AT can yield better results as compared to training them on the use of AT (Schikhof et al. 2010). Another study emphasized the need to involve the PWD at the early stage of AT development. The AT users usually face anxiety, lack of socialization and aggression. They further recommended using an integrated approach for AT development for the PWD (Okoro et al. 2010).

Although there have been few empirical studies already performed in this research field, those studies have many limitations associated with them. One of the major limitations of the existing empirical study is a small sample size used in studies (Labelle and Mihailidis 2006). Most of these studies collected data from caregivers and staff workers from care homes rather than the PWD themselves (Engström et al. 2009). Furthermore, the PWD can explain their requirements for future AT better, as they know better what they need (Wherton and Monk 2008). Some researchers especially emphasize the need to involve the PWD in empirical AT studies to

analyze the impact of these AT on their lives (Topo 2009). The literature review also reveals the importance of AT in reducing the symptoms of cognitive impairment related to Dementia.

2.7 AT compensation for cognitive impairment:

To provide a routined lifestyle people with dementia undertake specific types of time-related tasks (e.g., keeping appointments, taking medication, or following a daily schedule) various possibilities of pre-programmed automatic reminders via Electronic Memory Aids (EMAs) are available since the late '90s. (Hart et al., 2004). A study was done by (Kim et al., 2013) where the mentally and some functionally impaired people use a palmtop computer-based memory aid. The study found this technology to be useful in a percentage of patients for assisting memory dependent functions. A customer conducted the study was mentioned in (Hart et al.,2004), where AT was used to achieve experiences and attitudes regarding the use of portable AT devices as memory and organizational aids. The study indicates that these devices are acceptable or desirable for use as compensatory memory and functional aids by a person with moderate to severe brain injury. Although some of the research differs in approach, the study confirms the usability of memory aids for persons with cognitive impairment, the importance of using their own reminders and of giving them and their informal health carers controlled access over the reminders. Most researchers indicate the importance of involving caregivers in the implementation of ATs as carers motivate and sometimes train the person with dementia to use the ATs which also benefit themselves, as use of AT by a person with dementia reduces feelings of worry in the caregivers and family members (Szymkowiak et al., 2004).

There is only a few research that focuses on the effect of ATs for people with dementia (Van den Broek et al., 2010; Zanetti et al., 2010; Wilson et al., 2011.). Most studies are uncontrolled, not randomized and based on a small sample, but justify hope for future development. Van den Broek et al. (2010) studied the use of the Voice recorded Organizer, a device on which the PWD records a message, and that plays it back on a pre-scheduled specified date and time. The PWDs that participated in the study the prospective memory improved surprisingly after the device was taken into use.

Zanetti et al. (2000) focused on five patients with Alzheimer's Disease to conduct seven prospective cognitive tasks on particular times with the help of an electronic agenda and compared the output with a controlled trial in which the same functions had to be done without

the electronic agenda. All participants showed a significantly better result on the memory tasks when using the electronic agenda.

Wilson et al. (2001) focused on the effectiveness and usability of the 'NeuroPage' system, a pager system which is used for a large number of reminders and notifies for various activities. Within a mixed memory disorder diagnostic group, including people with dementia, NeuropPage, and pocket-computer memory enhancement system were introduced and found to be working although remembering and motivation to enter relevant information did limit overall usefulness. ATs seems to be particularly suited to support memory and, although they are generally more expensive than non-electronic memory aids, require little training. The" Forget-Me-Not" device which is an electronic calendar to aid persons with memory problems or cognitive impairment, designed within the European Technology, Ethics and Dementia project and could be useful for persons who are confused about day and date. An AT informing the person verbally, using vocal recordings, of specific appointments or tasks, also showed promising effects (Szymkowiak et al., 2004) utilized a Personal Digital Assistant to remind patients daily tasks, telephone numbers, appointments and birthdays. A high percentage of the Users have appreciated these ATs, although some visually or hearing impaired users recommended a reminder in the form of touch and sound vibration. Baruch et al. (2004) mentioned beneficial effects of computer systems on orientation, feelings of anxiety and independence in a patient who has Alzheimer's disease. Using Computer screens in the bedroom and living room lowes the needed support and the number of nighttime calls to the healthcare givers.

A cross collaboration project called ENABLE project (Enabling technologies for people with dementia) mentioned about 12 different ATs effectiveness to improve quality of life, support memory, and reduce the burden of caregivers. These assistive technologies proved to facilitate independent living, giving autonomy to PWD and some devices were able to reduce anxiety in PWD as well as their caregivers (Gilliard and Hagen, 2004). Cognitive intervention is an added benefit to support people with dementia in their memory function and can be presented utilizing video conference, computer-based, or Internet-based systems.

2.8. Need for GPS, health monitoring and perceived safety:

Different types of monitoring technologies and detection devices such as GPS or alarm systems inside and outside the home of PWD is found to be useful in various research. It provides both safety and security of the person who has dementia as well as their carers. Over the last few years, detection devices such as GPS tracking system and alarm systems for health issues and safety have been developed for persons with Dementia.

Research on four different biomechanical activity devices to index wandering, Algase et al. (2001) found the Step Watch particularly useful to assess the amount and daily course of wandering behavior in people with dementia. In this study, Boundary alarms (activated by a wristband) or tagging patients electronically and monitoring stations were found to be effective, reliable, less time consuming, successful and economically beneficial. The study also indicates the use of these tracking devices to reduce both patients and caregivers stress (Miskelly, 2004). A bedside tracking device system was tested in a memory clinic with Dementia patients who frequently immobilized from the room at night, additionally provides floor motion sensor lights and alert the carer by alarm so that they can perform the necessary intervention (Masuda et al., 2002).

Fig 2.1: A modern Insole GPS tracking system.

A new AT system was mentioned in Lin et al. (2006) which consists of indoor and outdoor activity monitoring, emergency rescue service through security alarm and remote monitoring that can be accessed via several mobile devices. The indoor monitor detects motions between certain

areas of the PWD at their homes. Outdoor activities, accompanied or unaccompanied, are recorded in a pre-set activity area, that can be activated by pressing a button on the position tracking device. Messages or alarms are generated by the monitoring devices and sent to a remote server and inform responsible persons to take immediate action where necessary. In an emergency situation, the person with dementia can activate an emergency button by himself and it sends a message to the server which is linked with a call center. The person's location, situation, and geographical information are analyzed and sends a holistic response to care providers, search teams and family members (Lin et al. 2006).

On the other hand, the secure remote monitoring facility embedded in the system allows family members or care providers can access a patient's location information at any time by logging onto the system with a secure password. Even though, the system was expected to be beneficial in helping locate persons with dementia by 11 volunteers who reviewed the system. Paavilainen et al. (2005) tested an active social alarm system, IST Vivago1 WristCare, which provides continuous telemetric monitoring of the user's regular activity. This study result indicates the use of 'telemetric actigraphy' in long-term screening and follow-up of cognitively impaired persons for circadian rhythm and other sleep-related problems associated with dementia and cognitive impairment.

Global Positioning Systems (GPS) is among the most popular tracking devices used in Norway and some other developed countries for monitoring the PWD. Miskelly (2005) describes in his research about testing a mobile phone with GPS to help families of PWD. The PWD always carry a mobile phone when he leaves the house, and his family members can locate him very precisely around the clock. The software of the phone can pinpoint the person's location with an accuracy of 5 meters and allows to send help in the shortest possible time.

Using GPS as a tool for tracking PWD was highlighted by Shimizu et al. (2000) who developed a system that finds out the wandering individual to a range of 100–200 m. This device was examined in various conditions such as Inside thick wall, rough weather, and near tall structures. Surprisingly the result indicates, The GPS tracking devices can work perfectly even though the working environment is not suitable.

The European Commission is aiming to create an 'intelligent environment' under the ' Telemedicine and eHealth strategic Objective' program that allows the management of the health

status of every person, which will further allow both patients and health professionals in coping with major health challenges and overcome the emergency issues. Target is to develop technologies, such as biosensors and secure encrypted communications in 'smart clothes' and implants, as well as software tools for monitoring and managing the ambulatory status of both physical and mental health and safety of the patients. Literature reviews do not confirm these technologies are being applied and validated for persons with dementia to date.

Chapter 3. Research Approach, theory and methods:

3.1 Approaches, Research questions:

The goal of this study is to understand how assistive welfare technology is influencing the lifestyle of the elderly population suffering from dementia and find out the barriers to using this technology. To enable an in-depth understanding, semi-structured qualitative interviews have been conducted with caregivers and family member of older adults who have dementia. As well as understanding the Challenges faced by the Healthcare personal/ Caregivers and patients with using the assistive technologies. The following research questions have been used in this qualitative research:

1.   How do Caregivers and family members experience assistive technology in elderly patients who have dementia?

a.   What are the advantages and downside of assistive technology?

b.   What Challenges do they encounter while using assistive technology?

c.   In what ways could assistive technology be provided more effectively and efficiently?

2.   What are the barriers to equitable access to assistive welfare technology for elderly dementia patients with different ethnicity in Norway?

a.   How are the family members involved in the decision-making process before starting the use of assistive technology?

b.   What are the challenges faced by the caregivers or family members of the elderly suffering from dementia from a different ethnic group?

c.   How do family members perceive communication with health professionals responsible for this service?

3.2 Choice of Method:

This chapter explains and justifies the research methodology used for the research design, data collection, and data analysis. The research methodology is used to find out the solution through a systematic process. In other words, the research methodology is defined as "the procedures by which researchers go about their work of describing, explaining and predicting phenomena are called the research methodology" (Rajasekar et al. 2006). The aim of the research methodology is to give a work plan for the study project.

The chapter starts by focusing on the methodology issues, followed by a discussion on primary and secondary research types. Then the qualitative research approach is explained along with its characteristics and advantages. The 2nd section highlights the research process used for conducting a systematic mapping study. The section starts with a research strategy used for selecting studies from the literature review. Which is followed by Assistive Technology (AT) identification from literature, available AT support by different municipalities in Norway and development of a systematic map based on the data gathered. The 3rd section briefly explains the methodology used for the bibliometric study. The 4th section focuses on the application of the qualitative method for data collection related to AT use by the Patient With Dementia (PWD) through semi-structured interviews. The ethical considerations followed throughout the research process are also explained with each section.

3.3 Methodology Issues

This thesis involves both secondary and primary research methods. Both secondary and primary research methods and their implication for this study have been described below.

3.3.1 Secondary Research

Secondary research involves "the findings from other literature reviews; it involves the gathering of results of other's research from books, journals or the Internet" (Hafner 2007). The secondary data is already published in the form of journal papers, conference papers, personal documents, newspapers, government or non-governmental organization (NGO) statistics reports, magazines, etc. (Veal 2006). The situation demands the use of secondary data at times. Sometimes this method is used as the sole research method for the complete project. In other studies like this one, this method is used to obtain a fundamental understanding of what is already done and what

to do next. Both the literature review and systematic mapping studies as the secondary research method have been used in this research.

The literature reviews provide a basic concept about the important work done in academia related to a specific area of research interest. For this study, a thorough literature review has been conducted for collecting data and for aggregating evidence from literature according to the recommendations. For secondary data collection, the search engines used for this research project include ORIA, Science Direct, Research gate, ACM Portal, Springer, Psychinfo, CINHAL, Pubmed, Cochrane, etc. The research publications from different journals and conferences are included in the literature review section. The search strategy for the literature review has been adapted and modified according to need. The details of the search strategy have been discussed briefly in the next part.

3.3.2 Primary Research

The primary research is " the research that is generated by asking questions, conducting trials and collating results from" (Hafner 2007). In this form of research, the researchers usually collect first-hand data. There are different types of primary research methodology used commonly among the research community. These methods include observations, interviews, questionnaires, case studies, ethnography, etc. Furthermore, the primary research can take the form of qualitative, quantitative or multi-methods research approaches. As this study has been conducted with Qualitative research method, For a better understanding of this research approaches, the following section will describe it in detail along with the characteristics and advantages.

3.4 Qualitative Research

The qualitative research attributes to the "meanings, concepts, definitions, characteristics, metaphors, symbols, and descriptions of things." The primary focus of qualitative research is on understanding the individual's interpretation of their environments and their own and other's behavior (Bryman 2003). Literature often describes qualitative research as exploratory research for which the research questions are developed (Guba and Lincoln 1994). The qualitative research offers several advantages including, It provides details and in-depth understanding of some situations as it focuses on behaviors, feelings, and attitude of the people rather than counts

and ranks. It creates an open environment and encourages the participants for extended responses, which can open interesting topics not considered initially. Can encourage people to share their experiences and can help to know why people act in specific ways in certain conditions. It can help to understand the feelings of the people related to the topic under investigation(Asghar, 2017).

3.4.1 Types of Qualitative Research Methods

Qualitative research traditionally tries to find out the answer to "why?" questions, as often these are based on the grounded theory practices. This method is mainly focused on cases on individual bases. Various methods can be used for qualitative data collection, such as focus groups, observations, interviews, etc. (Bryman 2003). Based on the requirements of this study, interviews are used as a qualitative method.

3.4.1.1 Interviews

An interview is usually one to one conversation where specific questions are asked on the topic and answers are given by the informants. The first person asking the questions acts as an interviewer and the replier acts as the interviewee (Gubrium and Holstein 2002). There are three major types of interviews which include: unstructured interviews, semi-structured interviews and structured interviews (Santiago 2009). Due to the nature of the thesis, semi-structured interviews are used for the data collection.

Semi-Structured Interviews: Semi-structured interviews are usually focused interviews. The semi-structured interviews are based on open-ended questions following the interest of the topic. Usually, this method involves broad questions and some hints for the interviewee to prompt response. The open-ended nature of the questions allows the researcher and the informants to discuss the research topic in detail. This method provides the freedom to the researcher to probe the informant's experiences as well (Fylan 2005). The advantages of using semi-structured qualitative interviews are: The participants can answer in details. Accurate information about opinion, attitude, and values of the interviewees can be gained. The informal environment can encourage the participants to be more honest and provide more freedom. The researcher can change direction and adjust questions according to the need of research during the discussion.

3.4.2 Research Method Used for the Systematic Mapping Studies:

In this thesis, a systematic mapping study has been performed. Which is based on general ATs that support the PWD in their daily activities.

The research process used for systematic study is divided into three parts. In part one, a thorough search strategy has been developed for eliciting AT studies from the available literature. Part two deals with listing of ATs available in literature and provided by 4 selected Municipalities in Norway. In part three the actual systematic mapping of assistive technologies available in literature and in Norway performed.

3.4.2.1 Search Strategy: The search strategy used in this study is adapted and modified from (Jalali and Wohlin 2012, Asghar 2017). The process starts by identifying the scope of the study from all aspects related to AT for the PWD. The study scope helps in the formulation of research questions formulation and selection of appropriate keywords. In the beginning, I only used the ORIA and CINHAL search engine to find the related papers and more keywords. Afterward the search extended to Web of Science, ScienceDirect and Scopus as well for collecting more research papers on the topic under investigation.

3.4.2.2 AT Identification from Literature and provided by Municipality in Norway:

Part two of the research process for mapping the study is focused on eliciting AT available in current literature and different Municipalities in Norway. Twenty-two studies have been finalized from literature. These 22 studies are based on the design, development, and implementation of ATs for the PWD. Sixteen of these studies are focused on the use of 'GPS and Medicine Dispenser' for the PWD. Others involve on reminders and prompters, robots, assistive walkers, patient monitoring, health monitoring technologies, etc.

Fig: 3.1: A modern Medicine Dispenser.

To evaluate the available ATs provided by the different municipalities health service, I visited four different municipalities health service office, one NAV office and one exhibition held at "ALMAS HUS" in Oslo for the PWD. Visited Municipalities are Oslo, Bydal, Drammen, and Lervik. This study shortlisted two such ATs that are mostly provided by all the Municipalities for PWD.

3.4.3 Systematic Mapping of ATs:

As per definition, the "Systematic mapping is a process to map out and categorize the existing literature on a particular topic"(Petersen et al. 2008). In this study systematic map has been developed mainly on AT functionalities, its advantages, and limitations. Furthermore, this study focused on if there is any barrier for equitable access to these technologies for different ethnic groups.

3.4.4 Study Context and Ethical Considerations:

Ethical Perspectives:

Ethical approval has been taken from the Regional Ethics Committee before conducting the qualitative interviews (NSD approval form Attached). Citizens health information is sensitive and personal nature. Some of the health issues are particularly stigmatizing especially mental health issues like dementia. Confidentiality has been emphasized to the patient's family member. During interviews, I was sensitive and responsive to participant's distress. My personal experience as a physician and training working with dementia patients and with their family members, I handled the interview process efficiently. On an academic front, I have undertaken courses on development theories and practices and qualitative research method. Participations were voluntary, and the participants have signed an informed consent form. Participants were made aware of their right to withdraw from the study at any time and request the interview to be deleted from the record. Care was taken during writing up the findings, so that, the participants are not directly identifiable. Pseudonyms or codes for information that is identifiable in transcription, such as name or residence have been used. All the stored data including the recording of the interviews, transcriptions will be deleted by 1st of August according to NDS(Meldeskjema for behandling av personopplysninger).

3.4.4.1 Limitations: Although there are many ATs available on the literature only GPS and Medicine Dispenser have been focused on this thesis as they are most commonly used in Norway. The data used for mapping study is gathered from reviews for the period 2000 to 2017. The study has been conducted in only four different municipalities in Norway. The result may not be generalizable to other areas, as different municipalities have their own strategy for dementia support. As dementia causes varying levels of cognitive impairment, so PWD has not been interviewed for data collection. Although many other municipalities provide various kinds of ATs, only four municipalities have been visited for interviewing.

3.5 Research Method Used for this Qualitative Study

The previous section discussed the methods available for qualitative studies, their characteristics, advantages, and limitations. In this study selected semi-structured qualitative interview have been performed. The next section shows the research process used throughout the qualitative method.

3.5.1 Semi-Structured Interviews Used for the Qualitative Study:

This study conducted semi-structured interviews for collecting qualitative data from the caregivers, family members, and professionals responsible for providing the AT services. Semi-structured interviews offer the advantages of eliciting information from respondents and explore the issues that both interviewer and the interviewee feel important (Longhurst 2003). For qualitative data, seven semi-structured interviews have been carried out with the participants who work closely with persons with dementia and provides assistive technology support to them. The whole process can be subdivided into:

(i) interviews template design and validation,

(ii) Interview participants, data collection and analysis and

(iii) study context and ethical considerations.

3.5.2 Interview Template Design and Validation :

Previous studies conducted before show that both focus groups and interviews are popular methods for research which involve the PWD (Fukuda et al. 2015; Lykkeslet et al. 2014). As the informants of this study have been selected from four different municipalities in Norway, therefore the study adopted the semi-structured interviews method in which "the interviewer sets up a general interview structure by deciding in advance the ground to be covered and the main questions to be asked"(Drever 1995). This method gives both the researcher and informants a chance to explore issues they feel important in a structured way. This technique is famous for small scale research like this due to its flexibility.

The interview template design was a critical task as usual because the outcome was dependent on the quality of the interview template. Guidelines for designing the semi-structured interview template were followed from (Jones 2004).

The structure of the questionnaire was simple and the number of questions was kept limited based on the recommendations by (Beuscher and Grando 2009b). As the informants allowed maximum one hour time for each interview; therefore sometimes a shorter template has served the purpose better.

3.5.3 Interview Participants, Data Collection and Analysis:

After design, development, and validation of the template, data was collected by interviewing seven informants. Although some researchers have different arguments on the number of interviews in qualitative research, yet there are no specific criteria regarding the number of interviews. All the informants of the study were professional and somehow associated with PWD and providing AT. For the interview process, I contacted 11 people to participate in this study and seven informants showed their willingness. Others could not participate because of their tight schedule. As mentioned earlier, In total seven interviews were done with the participants from Oslo, Bydal, Drammen, and Lervik. The distribution of informants is Four from Oslo, One from Bydal, One from Drammen and One from Lervik. Among the seven participants, Five participants were Nurses who have further education in Geriatric diseases. All five of them work at local "Helsetjenesten" in the municipalities and responsible for AT support to PWD. Three of them have family members who have dementia and using Assistive technology. Two of the informants are Third generation immigrants in Norway. One of the participants is Assistive technology product designer working at NAV and responsible for providing support to more than 300 PWD. One of the informants is a Senior Researcher of SINTEF, who is working for the development of Assistive technology in Norway since 2012.

Table 3.1: Information of the participants:

Number	Gender	Age (Years)	Area	Years involved with AT	Description
ATD1	Female	38	Drammen	6	Nurse, AT advisor at Drammen Helsetjeneste with 120 PWD.
ATD2	Female	57	Lervik	7	Nurse, AT advisor at Lervik Helsetjeneste with 120 PWD
ATD3	Male	46	Oslo	6	Nurse, Immigrant background, Family members with dementia
ATD4	Female	42	Oslo	7	Nurse, Immigrant background, Family members with dementia
ATD5	Female	35	Oslo	3	Nurse, works in Nursing home with PWD
ATD6	Female	29	Bydal	3	AT Product designer, works at NAV with 300 PWD
ATD7	Female	59	Oslo	9	Senior Scientist of SINTEF, Engineer and education in public health.

For data analysis, as the 1st step, the verbal recorded data was transcribed. Each interview was interpreted by listening to the recordings to develop an overall understanding of the interview. After documentation of the interviews, cross-validation was done by listening to recordings again. The complete data was read twice, and key information for initial ideas was taken at this stage.

On step 2, the 'NVivo 12' software was used for initial data codes. After coding all the data, the data having the same codes was collated together. The 3rd step was all about working with a long list of different codes. After that, the mind maps were used to sort out different codes into potential themes. Most of the codes were used which resulted in themes and sub-themes, the other codes were deleted. The 4th step involved the filtering of themes. Some of the themes were collapsed into other themes, while one theme had a small fragment. The coherence of data extracts into each theme was tested. Additionally, the relationships of the themes with each other were also cross-checked through thematic mapping. At the 5th step, the working titles of the themes and sub-themes were replaced by the suitable names that fit the topics. After many revisions of themes in relation to the collected data, the final thematic map has been generated. As of a 6th and final step, the analysis was transcribed as a report with sufficient evidence related to each theme and sub-theme with the interviews data and existing literature.

Chapter 4 The interview: Study and Findings:

This chapter focuses on the qualitative study conducted for this thesis paper. The data collected through semi-structured qualitative interviews are interpreted through thematic analysis. The thematic analysis resulted in three themes and fifteen sub-themes, which are discussed with appropriate examples. This section further highlights the findings of the qualitative study, suggestions for the institutions responsible for AT support and future requirements of the PWD.

The qualitative study has been performed to achieve the following research objectives:

OB1:" How do Caregivers and family members experience assistive technology in elderly patients who have dementia?"

OB2:" What are the barriers to equitable access to assistive technology for elderly who have dementia with a different ethnic background in Norway."

4.1 The Qualitative Study

The main goal for the different Municipalities in Norway is to assure the quality of life to their citizens. Some municipalities are providing assistive technology to the older adults having different kinds of disease and disabilities including dementia. AT services are highly subsidized by the health service departments of municipalities in Norway, but In most cases, the patients pay a small monthly subscription. So to gain customer satisfaction by providing them with quality services are one of the prerequisites for the service provider. AT usability evaluation studies can serve significantly in achieving this goal by highlighting the likes and dislikes of the PWD for existing ATs. Moreover, such studies can also serve as the basis for requirements elicitation from the PWD for future ATs.

Because of the increasing demand for AT in the health sector, there is a trend in academia for research regarding AT design, development, and implementation for the PWD nowadays. The health sectors are also transforming ideas into reality for betterment and wellbeing of the PWD (Doukas et al. 2011). Many studies are available in literature which present some new ideas and AT devices for the welfare of the PWD (Hoey et al. 2010). It is a fact that Assistive technology success depends heavily on its end-user perspectives and satisfactions specifically the patients. Therefore a good understanding of the point of view of the PWD regarding the usability of

existing AT becomes more critical. There are only a few studies carried out in this domain (Span et al. 2013). Such as (Rowe et al. 2009) in the USA (Demers et al. 2001) in Canada, (Jedeloo et al. 2002) in the Netherlands conducted some studies for testing AT satisfaction from the patients.

There have been very few AT usability evaluation studies conducted in Norway with focus on the PWD. The importance of this study becomes even more significant as about 1.5-2% of the whole population of Norway already having some degree of Dementia. (report, Norwegian Directorate of Health, 2007). And due to the increased number of the aging population, This steady rate of dementia population increase will create challenges for the government. I, therefore, conducted this study in Norway by involving the target population who are associated with implementing these Assistive technologies to People with dementia. And to know their point of view regarding current ATs and their future needs.

This study highlights the experiences of the Caregivers, Service providers and family members of PWD who use different ATs for performing their daily activities. As the first step, the properties of the participants have already discussed in Research Method to understand the participants and their characteristics. As the second step thematic analysis is done on data collected to achieve study objectives.

4.1.1 Themes and Sub-Themes of the study:

The thematic mapping analysis has been designed to distribute data into three major themes and fifteen sub-themes (see table 4.1), which depicts the experiences of the PWD with ATs. The experiences reflect three major spheres: the person in the society (public sphere), the person in the family (private sphere) and the person herself/himself (personal sphere). The themes comprise of the satisfied and continuing users because of improved autonomy of life, and scope for better communication with others (public sphere); the Unsatisfied and not continuing users due to lack of privacy and social isolation (private sphere) and the user desired to have a balance between technology and human care (personal sphere). (Asghar et al. 2017)

Table 4.1: Themes and Subthemes through Qualitative Content Analysis

Satisfied and continuing users	Freedom of life
	Facilitated Communication
	Facilitated travel
	Relieving stress
	Facilitated medications
	Longer staying at home due to facilitated safety
	Socio-Economic benefit
Unsatisfied and abandoned users	Late administration
	Lack of customizations
	Technological Failure
	Social isolation
	Lack of product availability
	Barriers associated with different ethnic background.
Human technology interaction for medical and social care	Introduction into curriculums
	Special training needed

4.1.1.1 Theme 1: Satisfied Users who are continuing:

In general most of the informant said AT users felt 'comfortable' using ATs for their daily functioning. While discussing the advantages and limitations of the ATs, the informants were mainly positive with the AT assistance. According to them, the main challenge was related to functional difficulties that PWD have to face during daily activities and ATs were helping them to minimize these barriers. An informant ATD1 who is responsible for providing AT to almost 120 PWD in Drammen Municipality expressed her delight by saying:

"The ATs help its users to do many activities easily and independently without depending on others. They can make a one-touch call by clicking on the pictures and go outside independently without any fear and minimizing the risk by the GPS support."

The satisfied users termed facilitated communication, travel and appropriate medication and activities support as significant contributions of AT support in their lives.

Subtheme 1: Freedom of life:

Assistive technology has offered freedom and independence for the PWD. Helped them to overcome the barriers set by Dementia itself. According to ATD7 who is a senior scientist of SINTEF and developing ATs for PWD for the last nine years:

" AT helps the PWD to do the things they like to do, given them more freedom, offered a safer life. Most of the PWD associate AT with safety."

She mentioned a success story:

"We have a success story regarding GPS. Mr. X, aged 78 who lives in a nursing home for the last five years who have been diagnosed with dementia for the last seven years. The municipality has provided him GPS. He does not even know what GPS is, but he said before his family restricted him from going out due to safety and there was always an argument with him and his family members, now after using GPS he is happy because his family allows him to travel independently."

Subtheme 2: Facilitated Communication:

As the disease progress, PWD becomes more vulnerable to communicate. Proper communication support is critical for helping them. The literature also supports this argument that the ATs have the potential to increase the number of communication opportunities for the PWD and decrease their loneliness (Meiland et al. 2014). The informants have almost similar views regarding the communication help they were able to get through the support of ATs.

The ATD2 described that AT usage helped to decrease the loneliness of its users and resulted in more frequent contacts by their friends and families. She pointed out that:

"The PWD who are using AT can talk to their family members and friends with an easier and convenient way. Moreover, it helped them to communicate with the health-care service providers when they need help with a single button click."

Subtheme 3: Facilitated Travel: Travel without any assistance is often highlighted as another challenge for the PWD as they face constraints like cognitive impairment, loss of memory, physical mobility, and forgetfulness. Most of the informants of this study shared their positive experiences about facilitated travel using GPS. The ATD5 pointed out that:

"Most of the PWD are unable to go out alone because of the fear of getting lost. Due to the application of GPS, the family members can easily track them when they are outside. Which gave the PDW higher level of independence, autonomy, and safety.".

An informant of the research ATD2 who is a Nurse and team leader working at Lervik termed the AT support during travel from one place to another as a life-changing experience and expressed her feeling as:

"After using GPS, PWD at my hospital now can wander outside independently by themselves. It was quite difficult for them before because of the fear of getting lost, which happened so many times."

The literature review also indicates the importance and contribution of independent travel for rehabilitation. The systems like the Opportunity Knocks support the PWD in using public transport. It uses context-aware information, and whenever user deviates from their selected plans, it notifies them and guides them the correct way to return home (Patterson et al. 2004).

Apart from the carrying GPS devices, The use of a different form of ATs for travel is also evident in real life places these days. There are many advanced travel facilitated technologies available and provided by some municipalities as a pilot project, and the disabled people are seen using smart walkers at markets and public places. From the study participants, the ATD4 mentioned the experience of his mother. Such smart walker which helped his mother to travel independently and perform her daily activities.

He described this situation as:

"My mom's walker has GPS and navigation system which helped her move independently from one place to another. She goes shopping every morning and meets her friends at a nearby club every evening. She is 74 years old now and having Dementia for the last 6 years. My mom is more confident, and smart navigation has given her much autonomy than before."

A systematic literature review aggregated knowledge about the GPS enabled smart walkers available for the PWD and highlighted the importance of this AT. They are cost-effective solutions and can quickly increase the self-confidence of the PWD (Martins et al. 2012b).

Subtheme 4: Relieving Stress:

Assistive technology helps to reduce stress and tension both in family and PWD themselves. It is a solution of multidimensional problems related to cognitive impairment for a person and his family. According to informant ATD3:

"AT has been proved as Taking off the stress from the family members. The burden of care has also been reduced from family members. Family members continue being at work; they don't need to stay home and take care of their PWD."

By using AT, PWD got more chance for outdoor activities, which has a very positive impact on both physical and mental health.

Subtheme 5: **Timely Medication and Activities:**

Dementia causes gradual cognitive impairment. PWD often experiences problems associated with forgetfulness. The weakening cognition creates issues like forgetting to take medicine, overdosing of medication, performing activities on time, and remembering about their health conditions. ATs has been successfully used to avoid such situations. ATs like Medicine dispenser solved issues like this. The assistance of ATs in this regard is highly appreciated by the ATD6 who expressed herself as:

"The reminders help PWD to do activities on time which otherwise forgotten most often. The main advantage of using reminders is to take medicine on prescribed time".

The literature supports this statement by going one step ahead through the use of context-aware reminders. These reminders not only help the PWD in daily tasks but also manages conflicts between pre-defined plans and real-time destructive activities (Du et al. 2008a).

Apart from this, The ATs like the HomePod help the PWD to monitor their physiological data for weight, blood glucose, blood pressure, etc. at home. The medical information provided by such ATs can be transferred to a doctor instantly and securely for analysis as well (Medvivo 2015).

There has been researching for using ATs in medical services. Informant ATD5 who is a nurse and working with PWD mentioned:

"Some of my PWD have high blood pressure and diabetes issues which need continuous monitoring. We offered them smart devices that record ambulatory blood pressure and monitor blood glucose level and sent signals to us when the reading is abnormal. It also detects the accidental fall of the patient's, and we can take a prompt response. But this support is only for hospital settings now. We have the plan to provide this service for the patients who are not hospitalized so that we can take care of the patients from their home."

She also mentioned AT is the future of remote monitoring and medications.

In two similar talks the ATD4 and ATD1showed their satisfaction with the health monitoring devices that they used by describing:

"My mother is using a health monitoring device for a few years, and she is happy using it,"

"We are not afraid of hypoglycemia any more. The health monitoring device keeps my grandmother updated throughout the day".

Subtheme 6: Can remain at home for longer period:

AT has helped PWD to stay at their home for longer period than before. Informant ATD7 emphasis on the importance of staying longer period with the family for such patients.

"Due to regular use of AT, PWD are remaining at home even 7-8 years longer than before. They are going to the nursing home at a later age. Which has a huge socio-economic benefit for the local municipality."

More people with dementia are living longer with complex conditions and needs. Assistive Technology can help PWD to stay living well and safely at their home as they get older.

The literature also suggests that using household technology devices including ATs, People with dementia had less visit to the hospital and could speed up hospital discharge by providing added support in their own home (Blackburn, 2006). The respondents in their study said that the devices gave peace of mind to their family members.

Subtheme 7: Socio-economic benefit:

AT has been proved to reduce the costs of care for the elderly and their families. Even though some PWD may need to make monthly payments according to their income, but in most of the cases, ATs are distributed free of cost. And the total cost is obviously much less than the price of home-health or nursing-home care. ATD2 from Lervik mentioned:

"We are providing GPS support to around 180 PWDs. They are living independently in their homes now. They perform a daily outdoor activity, especially during summer. If we had to provide a personal assistant for each of them for everyday support, economically it was challenging for us. We can satisfy our PWDs within our budget using ATs."

First of all 'assistive technology' is a broad term, covering a wide range of possible devices and arrangements for PWD. Our focus is limited and concentrating on particular subsets of technology. The intended impacts of technology may concern cost reduction, improved services, quality of life for people with dementia, improvements in caregiver support or any other possible outcomes for different municipalities. As for example telecare to keep people at home, therefore saving costs of institutional care; activity and reminiscence focused materials which aim to improve quality of life; telemedicine has improved outcomes in terms of QALYs (quality-adjusted life years). The number of people with dementia are varied in different areas, and people with the condition experience a range of challenges which change over time that impact the overall cost. Finally, there are issues regarding stakeholder interests, and the extent to which assistive technology has costs and benefits for people with dementia and their families, care service providers and society as a whole.

4.1.1.2 Theme 2: Unsatisfied and not continuing users:

During the interviews (2 out of 7) participants also discussed the downside of these ATs. The downside was mainly associated with the availability, Usability, adaptation, and failure of the AT. Participant ATD1 mentioned:

"we are unable to promote an adequate number of ATs according to the demand. Some customers are not happy with the delay, as they really need it now."

Other informant ATD5 told:

"10-15 % of ATs users don't like to use it anymore. Few of them complained it's not useful for them. Some find it hard to use and some complained about the failure of the device."

The existing literature also suggests that some PWD don't like to adopt ATs as they believe these do not fulfill their requirements, compromise their privacy and result in the reduced social circle.

Subtheme 1: **Late administration:**

One of the most important reasons behind the Failure of ATs implementation is late administration. As dementia is a progressive degenerative disease of the brain, as the disease progress, PWD tends to forget more than before. After a specific time, it is challenging for the PWD to learn about new technology. In spite of repeated training, the success rate of a todapting technology is very low. According to ATD7:

"One of the reasons behind this ATs failure is late administration. Most of our ATs users starts when they are more than 65 years old. Some of them are diagnosed dementia at a very late stage, and when we try to implement ATs into them, most of them could not learn using it because of their reduced cognition level."

This is why it is imperative to implement ATs as soon as the person is diagnosed with dementia. Now a day's Modern medical technologies allow us to diagnose dementia in the early stage of the disease. So as soon as someone is diagnosed both the patient and their family members need counseling about the importance of ATs.

Subtheme 2: Lack of customizations:

One of the downsides of these ATs are, they are not tailored according to the need of its users. As every PWD are individual and level of cognition is different for every patient, each of the PWD expects customized services from ATs. The informant ATD6 raised the similar concern that most of the ATs are not tailored according to her patient's needs who are old and cognitively challenged; but most cases they are more appropriate for the young people, she mentioned that:

"Most of the modern ATs are designed in a way that cognitively challenged patients cannot learn and use it easily. Even after repeated training and counseling most of the advanced stage dementia patients show a little response to the medicine dispenser. On the other hand, the response rate is quite high for the relatively younger PWDs".

She further recommends the research and development of ATs that are tailored to the needs of the elderly in general and the PWD in particular.

Subtheme 3: Technological Failure:

Technological failure is one of the major drawbacks of current ATs available for the PWD. 5 ouy of 7 informants of this study have mentioned about their experience regarding the technological issues. ATD6 said:

"About 10-15% of cases ATs failed because of the failure of the technology itself. In the case of GPS, It can fail inside because the device is designed to work outside, Sometimes the battery drains unexpectedly, and when the PWD forget to charge the device, it switches off or gives the wrong reading." ATD6 also added:

"ATs always depend on a network connection to be connected with a remote or terminal server. If the network connection or SIM card fails, the system does not work at all."

The literature also admits the failure of ATs in some cases. No matter how much effort is put in the implementation, ambient systems can be prone to crashes. This is partly due to the reliance on several wireless communication protocols. Among others, thick walls, temporary interferences or inadequate coverage are factors that affect the system's reliability. We have also met problems related to the use of sensors, being battery issues or merely a curious user pulling off the new "object" in his environment. (Aloulou et al., 2013)

Subtheme 4: Social Isolation:

Social isolation is other critical issues associated with the PWD. It has been an ethical discussion if the ATs and lower human interaction causing social isolation for the PWD. Though the literature review does not strongly suggest the implementation of ATs are an only aggregating factor for social isolation among PWD, but some believe less human interaction due to

Technologies aggression plays some role behind it. The literature also indicates that in some cases the PWD who use ATs feel more isolated than others(Asghar, 2017).

The ATD3 raised a similar concern as she described the situation as:

"Even though the monitoring devices and medicine dispenser helps family members to monitor the health conditions, but in some cases, PWD believes family members pay less attention and visiting less than before. Some claims the amount of time spent with them has decreased since they started using assistive technology".

Subtheme 5: Lack of product availability:

Two informants from two different commune have mentioned about the scarcity of the product availability. In some cases, the municipality is unable to supply required ATs in time. Though most of the time it is due to manufacture or supply chain fault, sometimes it is due to lack of proper coordination in between organizations. In this regard ATD1 said,

"Sometimes we have to wait for a particular product (AT) for quite a long time. The municipalities do not have the reserve of these emergency ATs. When a patient applies for a particular AT, we have to order it to a manufacturer company, and sometimes it takes up to 3 months to supply the product. PWD and their family becomes impatient most of the time, and gives us a negative feedback."

So it is essential to reserve some ATs in municipalities all the time so that PWD can have it on an emergency basis.

Subtheme 6: Inadequate follow up due to workforce deficiency:

Three different informants have mentioned about the improper follow up after administration of ATs at their municipalities. Some PWD has complained to them that they have to wait too long for customer support regarding the failure of the ATs. ATD6 admitted:

" I am the only person to provide technical support following administration of ATs in this municipality. I am responsible for almost 300 PWD using AT. Sometimes it is quite impossible for me to ensure proper follow-up due to workforce deficiency."

Recently the municipality has started training sessions for the users of ATs. According to her, they are receiving positive feedback from the PWD following training.

4.1.1.3 Theme 3: Human- technology interaction for medical and social care:

In spite of the success regarding ATs in dementia, two informants emphasized on the Human-Technology interaction for a future welfare model. The ATD4 who is a psychiatric care Nurse emphasized this point as:

*"If we depend entirely on technologies and reduce the human interaction significantly, it will create a silent gap in the patient welfare system. PWD will be too much dependent on technology which might cause psychological instability for the PWDs."*ATD3 added:

"Complete absence of human touch to managing PWD will create loneliness among the user of PWD."

The literature also supports this argument that the use of technology in combination with balanced human care can yield better results for the wellbeing of the PWD.

Subtheme 1: Introduction ATs into the curriculum:

It has been discussed for the last few years to introduce Assistive technology into the Nursing curriculum. To provide better support through assistive technology, healthcare professionals need a solid foundation on it. Learning about ATs from a bachelor level will allow them to work more confidently with dementia patients. According to ATD2 who is in charge of a Nursing home for older people:

" It is essential for healthcare professionals to be familiar with Assistive technology before they start working with the PWD. If they learn the use of ATs from academic levels, it will build up confidence among them when they will practically implement those."

Subtheme 2: Providing specialized training:

Training on AT is a must especially for the PWD as they are often not familiar with the use of modern technologies due to a different level of cognition. The ATD6 emphasized this point as:

"Modern ATs like Medicine dispenser is highly complicated for mentally challenged PWD. They need proper training before start using this machine. They should also be trained on what should they do if the machine fails. Double dosing or a missed dose might be fatal for some patients ".

A monthly follow up after training will help the service providers to solve the challenges regarding the technological issues of AT. A group discussion will also allow them to know each other and reduce social isolation.

4.2 Barriers for equitable access to AT for PWD from the different ethnic background:

In this section, we will try to find out if there is any barrier for equal access for PWD from diverse ethnic background. Two of our informants are from different ethnicity who are also working with PWD with immigrant backgrounds.

4.2.1 Beliefs and values about reseasons behind Dementia:

The informants of the study have experience working with different levels of dementia with different ethnic background people. Informants mentioned about five different ethnicities. They are Vietnamese, Somali, Pakistani, Philipino and Turkish. Through the research question, I tried to find out if there are any barriers for equitable access to AT for dementia people from a different ethnic group. This study does not focus on any specific ethnic group but discusses in general.

The research finds that there are some misconceptions about dementia with people from a different ethnic background. Especially among those who are 1st generation immigrants from lower or middle-income countries. Unlike dementia, Some psychological or mental illness shows sign and symptoms or are usually present from the early age of life. These mental diseases are believed to have some biological causes from early childhood.

In some cases, severe mental illness was believed to be a danger for the patients and others. According to informants, when the situation is grave, everyone seeks professional help, but they have observed PWD with different ethnicity often comes very late or only in extreme condition. According to ATD4:

" Although the number of PWD from different ethnicity is very high in Norway, sometimes it is hard to reach them and provide ATs. We are providing ATs to almost 320 PWD in this

municipality. Only 4 of them are from a different ethnic background, which is just over 1 % of the total service recipient."

One of the informants ATD3, who is also from an Asian family and working as a Nurse mentioned about her father who has dementia. Her father showed sign symptoms of dementia at a very early age when he was only 51 years old. He was losing concentration at his work and started forgetting things. Their family thought it was due to a highly stressful job or some biological reasons. Some of the family members mentioned he got this mental problem from family and it has no care. Some said about environmental causes such as the cold and dark climate of a Norwegian winter is the reason behind this.

"My family kept the disease hidden for many years and only when my father's mental condition was terrible only then we seek help from the doctor. His disease was diagnosed too late because of some misconceptions among the seniors of my family. We are trying to help him learning ATs like GPS and medicine dispenser, but it's tough for him to remember new things at a late stage of Dementia."

The informant also mentioned, their family believes the mental health-related disease is high in Norway then their country of origin. Because in Norway, people have big houses, and in most of the cases when they become old, they live alone. Isolated lifestyle might be a reason for Dementia she mentioned.

ATD4 explained that awareness of the mental health-related disease like Dementia in the different ethnic immigrants is low and it was often not taken seriously:

'A lot of immigrants especially from lower-middle-income countries misunderstand about the mental health-related disease. Some of them think they are 'just down' and as a result, professional help was deemed unnecessary.'

At the same time, some immigrants family recognize that unaddressed cognitive impairment could have serious consequences, such as committing suicide. It was at this stage they believed professional help would be beneficial.

ATD3 also mentioned culturally specific beliefs about the causes of mental health problems, such as hot and cold imbalances and evil spirits. However, they only consider this to be a belief held in rural areas in their origin countries and tend not to endorse these explanations.

ATD4 indicates some families of PWD have different holistic approaches of healthcare, where they do not make any difference between body and mind regarding modern biomedicine. They believe in the vital role of social support in maintaining mental, physical and spiritual health.

From a previous study, some of the immigrant informants used religious believes and visited spiritual healer to solve the cognitive impairment and mental health issue though the outcome was not described by the informants(Straiton M,2017). ATD4 added:

"Sometimes family members of PWD from the different ethnicity mix with symptoms of depression with dementia. As they have the experience to overcome depression or another short term mental illness without any counseling or medication, feelings without professional help, family members believe they could do so again".

Usually, at First, they try to deal with the mental illness with their ways as they did before.

Because they think in a way,

"They will not go through any bad phase. As they have previous experience to deal with the situation they know how to deal with it."

Some of the immigrant family of PWD believe that they are mentally strong and adaptable:

ATD3explained:

'My father always says Turkish are very tough. He means even though we are sad, we still have a smile and we can still keep happy'.

They have gained this confidence in having developed a high threshold for problems due to having experienced difficulties throughout their lives. Immigrants sometimes compare themselves with local Norwegians, who they saw as fortunately never had any issues such as natural disasters, poverty, and inadequate health services and therefore have less experience to cope when health problems arise. Some immigrants value self-care and self-reliance and believe they can take care of themselves without professional assistance. ATD4 mentioned:

"My family is from Asia. When I was young, I have seen my family did not seek help because they think that we are capable of combat health issues. My family always faced a lot of problems before coming to Norway. So, therefore, my family believes it is easier for us to get over mental issues and move on. We don't need to consult with a doctor for this. We rather try to cope with the situation by ourselves."

Some immigrant family believes that their family ties and social networks are stronger than Norwegian ones. So they experience less mental health problems and well prepared to overcome without professional help. According to ATD3:

"Our family comes forward all the times as a backup system, and we live closely. If someone is in a problem, it is such as everyone's problems. in this way, they help each other, and as we have an excellent backup system, we are being uplifted."

4.2.2 Stigma:

Three informants discussed the stigma about mental health problems and dementia in immigrant background. It is especially common for PWD from southeast Asian immigrants in Norway. An informant from Southeast Asian origin mentioned different aspects of stigma, each of which can help explain their reluctance to seek help.

A study (Straiton et al. 2018) on mental health for immigrants shows,

Firstly, mental health problems are often associated with madness, and people are afraid of the affected person. They ask questions like:

"Hey! Are you crazy? What happened? Or are you hallucinating? Are you having delusions? Are you sick? Does someone in your family have the same condition? Is it curable? I think you are dangerous" etc.

Secondly, asking help for mental health problems like cognitive impairment means the person cannot cope with the situation. It is, of course, stigmatizing because an individual is not only be labeled as crazy, but also he cannot handle his problems, undermining their sense of resilience and strength. ATD4 said:

"It's very important to go to the doctor and check what actually happened. But not so many people from my culture will do that. Also, it's kind of showing like mental weakness, if you admit that you have mental issues, it's kind of like saying: you can't deal with this, so you are weak."

Thirdly, stigma related to cognitive impairment extends beyond the individual and threatens to affect the family's reputation (Straiton et al. 2018).

An Asian informant ATD3 explained:

'Reputation is essential for my family. Especially, as my family tries to maintain a high class. and people will start talking about the mental illness present in my family, which is not a good thing for family reputation."

Due to multidimensional stigma to the immigrant society, some families with PWD may be prone to keep their problems hidden. The judgment that mental illness reflects poorly on family lineage is not infrequent even in modern Asian cultures. Preserving the social appearance of oneself and family, or 'Saving face' can lead to the covering of mental health problems like Dementia (Kramer EJ, 2002).

On the other hand, some of the immigrant family are very positive for seeking help from doctors when their family members have some kind of mental health problems related to age. They have been able to distance themselves from these stigmatizing opinions.

Some families have previous experience of cognitive impairment among the elderly in their family. They have learned that seeking professional help always ease the tension of the family and limit the health problems.

Many health care providers who are second or third generation immigrants are working in the health sector in Norway especially in big cities like Oslo. Even though they have a different ethnic background, they have an education in healthcare or otherwise increased awareness of mental health problems. They can at least distinguish between 'Insanity' and 'Dementia.'

Some informant families have witnessed others seeking care from a GP for mental health issues for elders, and this familiarity helped to reduce the stigma associated with help-seeking (Straiton et al.2018).

4.2.3 Inadequate knowledge about mental health services:

In most of the low-income countries, citizens are deprived of mental health services (Saraceno B,2007). Which might be due to a lack of available resources. One of the informants indicated that mental health services in her homeland are not included in the primary health care system. They usually have to travel a long way to go to a tertiary level hospital for seeking help for mental issues.

It is also costly in most cases. As cognitive impairment is not a life-threatening acute problem for the elderly, like a heart attack or Stroke, family members often don't show any interest to invest money on it.

A good number of immigrants living in Norway are therefore not familiar with the theme of primary mental healthcare. Which might be a reason for not seeking help from the GP for uncomplicated mental health problems like the early stage of Dementia. According to ATD3 :

"Many immigrant family members of PWD believes, that has not occurred to them before, to see a doctor for that kind of mental issues."

Instead of that family member usually, associated mental health care is reserved only for severe cases where, for example, the PWD is a potential danger to themselves or others. She emphasizes

"If that PWD is hurting other people, only then family members call a professional or send them to a tertiary mental hospital.'

However, many immigrants are unaware of how their GP can help them. But sometimes they believe that the GP might give them advice, therapy, medication, or refer them to a mental hospital.

In some cases, PWDs consider medication acceptable 'if it's really necessary for them'. If there's some, nervous breakdown,' Sometimes they are worried about addiction and side effects of drugs due to preconception. Such ideas might also increase reluctance to visit a GP (Straiton et al.2017):

"Because of the misconception, Some mild onset of PWD thinks that before they meet the doctor for the cognitive impairment or memory loss issue maybe they can wait and observe if you can make it without taking any medication, because it is really hard to take pills at elderly age, they

have to rely on the Nurse for the lifetime, and because in the future, without regular pills, they will not be able to control themselves."

Moreover, some immigrant families travel back to their origin countries for alternative care (based on folk beliefs, herbal medicines, and traditional healers) [43] instead of Western medicine for general health problems. Besides, because the cost of private healthcare in their homeland can be high (WHO, 2012) Sometimes they refrain from or make delay seeking general healthcare. ATD4 said,

"It takes a very long time to decide for us if the mental health condition is serious. My family doesn't want to use our money right away if they are not sure about something serious."

Thus, lack of familiarity with doctors, in general, might be a reason why the PWD with different ethnic background tend not to visit GPs in Norway as a source of initial consultation unless all other options are exhausted.

4.2.4 New Healthcare system in a new country:

The idea and experience of the Norwegian healthcare system among immigrants are diverse. As only 1-2% of the total ATs users are from different ethnic background informants were asked about if they know about perceptions and experience of consulting a GP in general by the family of PWD from different ethnicity.

Few Factors can be highlighted that may affect perceptions of help-seeking for immigrants. We can categorize them into access, language, and GP-patient relationship.

4.2.4.1 Inaccessibility of healthcare information

It is usually challenging for immigrants to learn about a new health service in a new county right away. Most of the immigrants of lower or middle-income countries are used to a health system where they usually don't go to a GP or when they need emergency care; they visit the hospital or specialist directly.

When they are assigned to a new GP in Norway, they find information in Norwegian language and take assistance from others which reduce their autonomy. They know, every time they need to visit a GP, they need help from the surrounding friends or families. Dependency on others sometimes stops them from going to GP when they have the disease at the primary stage.

Further, most of the time PWDs are dependent on their family members when it concerns the economy. Dependence on a partner may leave immigrant PWD with less control over their health, may cause delays in mental health seeking.

4.2.4.2 Language

All the participants have mentioned about varying levels of Norwegian language skills among the PWD with different ethnic background. Different immigrants have different language skills, Such as Arabic, Urdu, Vietnamese, Turkish, etc. Most of the first generation immigrants do not have good English language skill. So when they consult with the GP, they try to explain a blend of both Norwegian and English. Which sometimes actually lead to confusion with both GPs and patients.

And when it concerns the impaired cognitive level of the Dementia person, understanding each other becomes more important. PWD with narrow language skills, therefore, feels difficulty to express themselves.

One of the informants mentioned her Grandfather who has Dementia always likes to consult his GP as she speaks Arabic. When he was referred to a tertiary hospital for some serious health issue last year, he was very uncomfortable consultation with the doctor and nurses working in the hospital. ATD3 said,

"My Grandfather's GP speaks Arabic. So the GP always understand his problems clearly. If my grandfather had to express in Norwegian, it might not be accurate."

The language barrier is particularly important in cases that relate to cognitive or psychological health.

Although immigrants in Norway can request an interpreter at a consultation, not all of the PWD from different ethnicity are aware of this, and none had used the service. This supports the earlier argument that health information in Norway is not always accessible to immigrants in time.

4.2.4.3 Patient-GP relationship

Patient's personal opinion and involvement during the decision-making process by the healthcare professional is emphasized in Norway (Carlsen B, 2006). In this regard, the patients are usually

informed about alternative treatment options by, discuss their concerns with, and indicate their preferences to the GP. The family members with PWD are satisfied with this model. ATD4 said,

"My mother's GP is very willing to listen to her problem carefully. She asks some follow up questions concerning the mental and other health issues. She has a sympathetic ear and takes time while writing the prescriptions. She also gives preferences to my moms choice of food regarding diet plans. My mother is pleased with her GP."

When the GP is cordial with the PWD from a different ethnicity they can come to the solution as a team . Person with early onset of Dementia gets a chance to play an active role concerning his mental health issues.

Some informant mentioned about the dissatisfaction about her family regarding GP consultation. She talked about her previous family GP, who has been shifted by a new one two years back. Her family thought that GP is a more authoritative person regarding Dementia issues of her mother.

" When my mother was diagnosed with Dementia for the first time, the doctor just gave some pills. We asked about the consequences of the diseases but did not get any proper answer. The doctor also mentioned his time limitation. As the doctor could not answer our questions, we thought he is not competent in dealing with mental health issues of my father. So we changed his GP because we did not want to take any risk."

4.3 Assistive Technology Scope and Categorization:

Based on the result of the questionnaire, this study offers insights into the usability of the current ATs based on the real-life experiences of the PWD. The study further reveals that the PWD can discuss the uses of ATs and its impacts on their lives. Based on the findings of the interviews, ATs are categorized for further analysis. AT categorization helped to analyze the benefits and limitations of existing ATs and the requirements of the PWD for future ATs in Norway.

Literature review reveals that there are many types of ATs which provide different kinds of support for the PWD. These ATs include: mobile multimedia technologies help the PWD to communicate with others (Donnelly et al. 2010), prompt technologies generate reminders to let the PWD know about doing some activity (Seelye et al. 2012), leisure technologies help in enjoyment activities (Torrington 2009) and automatic task assistance technologies help in the

completion of tasks in the right order (Peters et al. 2014). However, the scope of AT support for this study is limited to the ATs provided by the participants. Based on the study results, the ATs used by the participants are classified into two major categories:

1- Monitoring and ensure safety

2.- Timely Medication.

4.3.1: Monitoring and ensure safety:

All seven participants of the study are somehow providing or responsible for Monitoring and safety for the PWD through the municipality. It is mainly included GPS and fall sensors and some cases health reading devices.

4.3.1.1 The Benefits for Monitoring: Almost all the participants provide ATs for ensuring patients location and safety through monitoring purposes. These devices helped them to monitor their daily movement and in small cases physical conditions like blood pressure, heartbeat rate, diabetes level, etc. regularly. This continuous health monitoring enabled them to adopt a healthier lifestyle (Schikhof et al. 2010).

The GPS assisted users in traveling outside their homes through GPS functionalities. Furthermore, some GPS enabled smartwatches can monitor a person's physical health conditions as well as generating alerts at detection of abnormal health conditions (McCabe and Innes 2013). The use of ATs for monitoring should be encouraged among the PWD as it will promote self-monitoring of their health by themselves.

4.3.1.2 Challenges for Monitoring:

 Due to the reduced cognitive level, some patients forget to carry the GPS with them sometimes. On the other hand, as GPS consumes a lot of battery, it needs to be charged every day before use. Sometimes the wearing and un-wearing health monitoring devices also proved rather disturbing. The negative impacts of bulky and heavy devices are evidenced in literature as well (Lyons 2015). Therefore there is a need for lightweight and small smart ATs specially designed for the PWD.

4.3.1.3 Privacy Concern:

Although the participants understood that monitoring systems were there for their safety, but they did not like being monitored all the time at home or outside as it affected their privacy. The privacy concerns related to monitoring are also raised (Zhou et al. 2009). Some new GPS enabled health monitoring ATs monitor only positions and health conditions but did not offer intelligent recommendations based on the health conditions. Addition of intelligent recommendations can yield better results of AT use for the PWD (Asghar et al. 2017a).

4.3.2 Timely Medication:

Five out of Seven informants have provided information about Medicine Dispenser for proper and timely medication for PWD. As it is easy to use Medicine dispenser has been trendy among PWDs nowadays.

4.3.2.1 The Benefits of Medicine dispenser: The reminders set in the Medicine dispenser helped the PWD to take medication by themselves in time. These ATs(Medicine Dispenser) were also capable of recording audio messages and can deliver these messages as prompts on the pre-specified times. Such ATs are considered useful especially for the PWD as they often face cognitive challenges (Boger et al. 2006). Using Medicine dispenser provide PWDs independence from waiting for a nurse coming home for medication every time. PWD can take an appropriate dose of medicine every time through Medicine Dispenser.

4.3.2.2 Challenges for using ATs for Medication: It is sometimes challenging to learn the operations of medicine dispenser for the person with an advanced stage of dementia. In a few cases, the medicine dispenser showed technical errors, and the PWDs or the family members were not well trained what to do. Furthermore, the PWD often find the noise created by the motors as rather disturbing. More language options were also a demand.

Chapter 5. Discussion and conclusions:

5.1 The Met and Unmet Needs of the People with Dementia in Norway:

At the end of each interview, the participants were asked about their specific recommendations for the future ATs, which can help the municipalities to provide better ATs in the future. After analyzing the information, against the ATs available in the literature and provided by the municipalities, tried to find out whether these requirements have been already implemented or not and scope for further improvement.

Most participants anticipated more user-friendly interfaces from the future ATs and also requested the AT producers to make simple and easy to use functionalities according to the patient's cognitive levels. Also, the participants further recommended tailoring the next ATs to the elderly needs.

The participants providing monitoring ATs advised that the future monitoring ATs should also provide smart recommendations when they detect some abnormal issues and health conditions. These ATs can use red alerts for making the users aware of their critical health conditions. In addition to this, future ATs should speak the health readings for older adults to be mindful of their health conditions. The AT developers should use machine learning approaches, Artificial Intelligence(AI), and smart algorithms to achieve these functionalities. To the best knowledge of the authors, these requirements are yet to be implemented within the discipline of ATs for the PWD and require further efforts from academia and industry. Implementation of these requirements can significantly help the PWD towards self-management of their health. (Asghar et al. 2017a)

Some of the participants recommend more prominent texts and larger fonts will help PWD in reading and following instructions quickly. These requirements are partially implemented in ATs like Nourish Carer Dashboard (Nourish Care 2015) and True-Kare revolutionary telecare service (True Kare 2015).

A new recommendation coming from the participants was related to the development of specialized games by focusing on the needs of the PWD. These dedicated games can help PWD in learning activities and adopting a healthy lifestyle. These recommendations are partially

implemented as currently there are few games available for the PWD like Lumosity, Dakim, Clevermind, Fit Brain Trainers, Cognifit Brain Fitness, Brain Trainer, Brain Metrix and Eidetic, etc. (Nouchi et al. 2012; Huntsman 2014). Similarly, GPS with long-lasting battery recommendation is already full filled by some providers.

Understanding language is also a barrier to accepting ATs for different ethnic groups. Therefore the participants suggested the development of ATs in different languages. The participants also advised using the ATs in combination with human care as this combination can promote the wellbeing of the PWD. This recommendation is well supported in recent literature as it is believed that AT usage with balanced human contact can yield more significant results (Asghar et al. 2017a). Other functions like voice-based calling and video-based training on how to operate ATs by the device itself need the attention of the future researchers as well.

5.2 The Impact of Assistive Technology for People with Dementia in Norway:

The main findings of this study and the relative impacts of ATs on the lives of the PWD are discussed here. The medication ATs helps in proper and timely medications. The communication ATs provide improved chances of socialization through social contacts and more natural interactions with other people (Doukas et al. 2011). The social interaction through ATs is considered as good as real care from the family members and caregivers (Mordoch et al. 2013). The monitoring ATs contribute to the improved safety of the PWD through decreased fear of being lost and continuous monitoring of the health conditions (Meiland et al. 2014). Finally, the reminders assist in the improved cognition of the PWD through decreased memory and cognition barriers (Imbeault et al. 2014).

The feeling of freedom and Autonomy, feeling of safety and enhanced cognition results into improved confidence and self-esteem of the PWD (Torrington 2009). It is also evident in recent literature that these supports also contribute to the quality of life for the PWD (Teipel et al. 2016).

The combination of improved confidence, self-esteem, and life quality motivate the PWD towards performing their daily functioning independently and contribute towards their rehabilitation (Martins et al. 2012b). In short, ATs can be useful for prolonging the stay of the

PWD at their own homes rather than relocating them to care homes and can save money for their families, care organizations and the Governments (Asghar et al. 2017).

5.3 Suggestions for Assistive Technology Providers:

The findings of this study have established that PWD can use ATs for some of their daily activities. However, the PWD has few concerns which need attention to maximizing the usability of the ATs. The key highlights of this study including interface effectiveness, pure functions, tailoring elderly needs, technology, and human care combination are consistent with the current literature as often these challenges are emphasized by other researchers as well (Boman et al. 2014, Asghar et al. 2017).

The AT providers may accommodate the limitations identified in this study. It will help them in providing better quality ATs for the elderly in general and the PWD in particular. The study recommends them to use to focus on user-centered approaches for AT development by involving the PWD throughout the development process. It is believed that the involvement of real users will yield their functional requirements and actual requirements will result in better ATs (Qadir et al. 2009). The PWD can also contribute their views during the design and development of ATs.

Moreover, the municipalities do not have any plan for an empirical study on provided ATs for its functionality. The ATs should be tested through case studies by involving the PWD. The result of the empirical research will help to analyze the support and impacts of ATs on the daily activities of the PWD. These user-centered approaches will help to gain better acceptability from the PWD along with producing capable ATs (Asghar et al. 2017). The AT effectiveness will promote AT retention for a more extended period and ultimately the high rate of AT abandonment can be decreased.

5.4 Actualization of Assistive Technology in "Real World Scenario" :

Different kinds of assistive technology are available that may help to compensate for the cognitive impairment of Person with Dementia. Some assistive technology is used in facilitating communication, provide company during loneliness, used during exercise, provide entertainment, and relaxation, which is proved to be beneficial to decrease behavioral symptoms related to Dementia and other mental health problems. First and foremost, a wide range of

monitoring technologies like GPS is available to relieve caregivers and family members from the strain of constant supervisory attentiveness. They include technologies to alert caregivers and family members when an individual gets out of bed during the night or attempts to leave home at unexpected or inappropriate times and to help ensure safer walking and address wandering problems. The availability of wireless mobile technology has increased the range of affordable products available and reduced the price of many (O'Keeffe, Maier, & Freeman, 2010).

If we think about usability, an assistive technology device need to be both practical, beneficial and should also pass the ethical issues. If a substance or product has efficacy, serve the purpose but causes distress, cannot be treated as helpful. Every person demands different needs, abilities, and preferences; no assistive technology can be generalized as to be perfectly useful for everyone with dementia (O'Keeffe, Maier, & Freeman, 2010). Even if an assistive technology product is useful in a research setting, its usefulness may be limited when used in practical fields such as the home of a person with dementia or when used in a wrong way.

The aspect of Dementia that can influence the acceptance, use, and effectiveness of assistive technology include a person's:

• Quality of cognitive abilities and deficits,

• Different emotional and behavioral changes,

• Personality characteristics and attitudes toward technology,

• Attitude and motivations regarding assistive technology that appears to exert "external control," and

• The physical and social environment surrounding the person. (LoPresti, Mihailidis, & Kirsch, 2004).

Any mismatch of these factors can result in an assistive technology product not being used effectively or a complete failure, even if it has been proven to be useful in a controlled trial setting. A person with dementia must be both willing and able to use a product and comfortable with its use even with impaired cognitive levels. Many research confirmed that the use and acceptance of an assistive technology device might also depend on individuals' personality, motivation, and insight into their deficits and previous experience(Jones, 2004).

Every municipality needs a thorough assessment of its PWDs Before introducing an assistive technology product or monitoring system. It can include evaluation of the individual condition, their physical and social environment to determine if the person can use it and will get benefit from the assistive technology. Evaluation or empirical study will ensure that an AT matches a person's deficits, abilities, and preferences, as dementia is characterized by a progressive cognitive decline (O'Keeffe, Maier, & Freeman, 2010).

Even though there are some conventional assistive technologies such as GPS and Medicine dispenser supplied by the municipalities, but they need to introduce such ATs on a trial basis to evaluate for themselves whether they are useful in both effectiveness and beneficial. Monitoring AT to ensure efficacy and safety can be of benefit to caregivers, but its use needs to be carefully implemented, and the patient's friendly so that it does not cause any stress to a person with dementia. For example, When a PWD miss a dose of medication from medicine dispenser, the sound of an alarm or a voice recording of Medicine dispenser that warns the person to take medication could be frightening or disorienting, especially if the person is mentally challenged.

There are different types of research on Assistive technologies for patients with many kinds of disabilities. This research is quite specific as this study recognizes the persons with Dementia population for AT assisted autonomy of life. The study tried to focus on how AT has given independence for organizing personal daily routine and outdoor activity without any human help. Literature reviews indicate this specific group of the population requires more community attention and easy access to use AT functionalities, which makes this population different from the other typical AT users. Moreover, the interest of the PWD for AT assisted living and their resulting impacts are worth investigating. This study further emphasis on the demand of the PWD should be considered while developing AT for this population as research based on general population cannot provide the fundamental requirements of the PWD. This study tried to give a better insight into the needs, expectations, feedback, experiences, suggestions, and impacts of AT assisted medication, travel and overall living for the target population in Norway.

Since the literature review has a deficit on theoretical and practical knowledge regarding AT assisted medication, outdoor activity and access to AT for the PWD with different ethnicity in Norway, the findings of this study should add some values to the present research. The data and

recommendations of the study can be used to develop even a more Dementia friendly assistive technology guideline in Norwegian perspective.

5.5 Motivations for using Assistive Technology for medications and outdoor activity by PWD:

The use of assistive technology as a part of Outdoor activities, independent travel, and Medication motivations are deeply dependent on the factors that are internally oriented and influence the PWD to use ATs. Through the interview and analysis data from literature reviews, we can classify four motivational dimensions among the PWD. These motivations uncover the level of needs of the PWD. The 'Independent outdoor activity and medication' appeared as the primary motivation as available ATs offer various facilities to them in Norway. These facilities include Safety during outdoor activity, mobility support, Independence, and hassle-free self - medication.

Other motivation includes 'easier and safer communication' which is linked to the ease and frequency of communication offered by the ATs for PWD who likes outdoor activities. These opportunities include 'One-touch emergency calls, Navigation to homes over GPS and call center support, develop social networks and help in interaction with other people.

The next level of motivation is involved with 'needs compatibility' that focuses on the compatibility of the ATs with the needs and requirements of the PWD with different cognitive levels, which is the core to success and retentions of those ATs in use. This level is based on variables like 'the AT functions as claimed by the providers', 'the AT is adaptable to my personality' and 'the AT is adaptable to patients lifestyle'(Asghar et al. 2017).

The 4th level of motivation is related to 'cost-effectiveness' among both for the Municipality and the patient's perspective. Which means the ATs should provide desired support at reasonable and affordable prices. This level revolves around the variables 'the AT is dependable,' 'warranties with the AT,' 'easy to handle AT maintenance' and 'the price and maintenance is affordable' (Asghar et al. 2017).

5.6 Achievements related to AT support in Medication and outdoor activity:

The achievements are linked to the outcomes, improvements, and benefits of using AT support for outdoor activity and medication. The results of this study designate that there are a lot of positive effects of AT assisted outdoor activity and medication for the PWD which can resultantly help them in overcoming their limitations and increase the feeling of independence. The results can be summarised three different achievement dimensions for the PWD. The 'improved achievements' is the most important output among all, which focuses on the accomplishments of the PWD through the use of ATs. The achievements of the PWD fulfilled due to 'the AT helps to meet their needs,' 'improved successes through AT use,' 'the interface effectiveness of the AT' and 'decreased the complexity of tasks'.

The 2nd level of achievements belongs to 'improved independence' which indicate that the use of ATs for the stress-free outdoor activity and self- medication enhances the independence of the PWD as they don't have to depend so much on the external help from others(Asghar et al. 2017). The contribution of different variables towards improved independence is based on the 'help to get formal support through interaction with others,' 'environmental control,' and 'sensorial support,' 'reduced dependence' and 'doing daily activities independently and taking self-medication without external physical support.'

The 3rd level of achievement is related to the feeling of 'improved safety' through the use of ATs. This achievement indicates that the PWD feel safer and secure while doing outdoor activities and self- medication when they use ATs for this purpose. The main reasons behind this factor are the 'improved sense of security,' 'help to decrease fear of loss,' 'sense of feeling safer in carrying out routine activities' (Asghar et al. 2017) and 'the appropriate safety measures' offered by the ATs.

AT facilitated medication and outdoor activity is highlighted as outstanding service for the PWD by many researchers (Innes et al. 2015). The achievement outcomes through the use of ATs in independent outdoor activity and self-medication increase the confidence, self-esteem, and sense of belonging for the PWD. All the evidence lead towards better rehabilitation opportunities for the PWD as they feel themselves to be the part of this Norwegian society as before. The results are well supported by literature as well as research shows that physical support and mental

satisfactions provided by ATs has excellent contribution towards the rehabilitation of the PWD with disabilities (Martins et al. 2012b, Asghar et al. 2017).

Psychological support is one of the crucial areas of AT assistance for the PWD by providing them psychological support through increasing their self-esteem and confidence. According to (Torrington 2009), the psychological support plays an essential role in perusing the PWD to use ATs for performing different daily tasks which otherwise they are reluctant to perform.

The AT assistance in outdoor activity and self-medication contributes to the wellbeing of the PWD (McCabe and Innes 2013; Cortés et al. 2008). Active participation in outdoor activities along with appropriate medication would help in their rehabilitation and in adopting a healthy lifestyle (Kamel Boulos et al. 2009). Therefore, we can conclude that AT assisted independent outdoor activity and medication contribute towards the rehabilitation and independent living of the PWD.

5.7 Implications:

This study provides an understanding of the needs, motivations, and achievements of the PWD who use ATs for outdoor activities and self-medication. The research leading to this study suggests that the PWD should be studied as a distinct group for independent activities. It is also evident that people aged 65 and above are the fastest growing risk group of Dementia. Therefore this distinct group should be on focus for increase awareness on AT. Since this group has different motivations and accessibility needs, their outdoor activity and self-medication related behaviors might also differ from the people not identified as having dementia. Therefore municipalities and AT providers need further understanding of the PWD attitudes, behavior and psychology which would benefit the vast dementia society in Norway.

The AT facilitated independent living, outdoor activity, self-medication, AT cost-effectiveness, AT supported more accessible communication and needs compatibility are identified as motivational factors the PWD should be focused during the development of dementia-specific ATs. These factors will allow the PWD to better plan their daily activities without the help of their caregivers or family members. The ATs provide communication and socialization opportunities for the PWD as well, which will help them to eliminate the feeling of social isolation from rest of the community (Gössling et al. 2016, Asghar et al. 2017).

Additionally, this study points out that AT supported autonomy among PWD results in the sense of improved achievements, improved independence, and improved safety. Simultaneously they feel more motivated to do activities which otherwise they might be reluctant to perform. The feeling of security, achievements, and freedom impact the PWD psychologically and would help them towards rehabilitation. The result of this study potentially offer the assistive technology providers from the municipalities a better means of understanding the needs of the PWD for AT supported independent living and associated challenges. Timely administration of AT is economically efficient, as it saves the costs of caregivers and other human resources. Despite so many benefits, the research on AT is still primitive and needs more efforts from the academic researchers.

5.8 Conclusion:

The data obtained from the study provides information about Current state of ATs in Norway, and this knowledge can be used for planning and implementation of Assistive technology for proper medication and locate the persons with dementia as integrated health care services. The study confirms that using ATs for PWD provide increased safety for both patients and their family- and professional caregivers. Furthermore, it confirms that by using ATs persons with dementia can maintain their autonomy and continue their outdoor activities despite of the disease progression. This means that they can thereby enjoy their freedom and independence. By increasing autonomy, self-confidence, mobility, increasing or maintaining health and functional capacity, and promoting active lifestyles, assistive technologies are proved to reduce the risk of disability and hospitalization, prevent social isolation, enhance security, and maintain support networks, thus enabling older adults to age at home. It is further experienced that early intervention and close collaboration between persons with dementia, family caregivers and professional caregivers are vital factors for success. PWD from different ethnicity needs more attention so that they can get easy access to ATs. More research is needed in order to explore possible long term effects, consequences and overcoming the challenges of implementing technology for persons with dementia as integrated health care services.

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OsloMet - Storbyuniversitetet
Att: Ardis Storm-Mathisen/Monzur Morshed Saikat (student)
ardist@oslomet.no/dr.monzurmorshed@gmail.com

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VURDERING AV BEHANDLING AV ALMINNELIGE PERSONOPPLYSNINGER I PROSJEKTET "ASSISTIVE WELFARE TECHNOLOGY FOR THE ELDERLY POPULATION SUFFERING FROM CHRONIC DISEASE AND DISABILITY IN NORWAY: AN APPROACH FOR A MORE DEMENTIA FRIENDLY SOCIETY"

Norsk senter for forskningsdata AS (NSD) viser til meldeskjema innsendt 01.07.2018. Meldingen gjelder behandling av personopplysninger til forskningsformål.

Etter avtale med den behandlingsansvarlige, OsloMet - Storbyuniversitetet, har NSD foretatt en vurdering av om den planlagte behandlingen er i samsvar med personvernlovgivningen.

Resultat av NSDs vurdering

NSD vurderer at det vil bli behandlet alminnelige personopplysninger (navn, epost, telefonnummer og bakgrunnsopplysninger) frem til 28.12.2018.

NSDs vurdering er at behandlingen vil være i samsvar med personvernlovgivingen, og at lovlig grunnlag for behandlingen er samtykke.

Vår vurdering forutsetter at prosjektansvarlig behandler personopplysninger i tråd med:
- opplysninger gitt i meldeskjema og øvrig dokumentasjon
- dialog med NSD, og vår vurdering (se under)
- OsloMet - Storbyuniversitetet sine retningslinjer for datasikkerhet, herunder regler om hvilke tekniske hjelpemidler det er tillatt å bruke

Nærmere begrunnelse for NSDs vurdering:

1. Beskrivelse av den planlagte behandlingen av personopplysninger

Formålet med prosjektet er å undersøke hvordan assisterende velferdsteknologi påvirker livsstilen til eldre som er rammet av dementia, og mulige barrierer til bruken av velferdsteknologi for denne brukergruppen.

Utvalget vil bestå av 8-10 helsepersoner som arbeider med personer som anvender velferdsteknologi. Datamaterialet skal samles inn ved personlige intervjuer som skal utføres over telefon. Det skal samles inn opplysninger om hvordan helsepersonell opplever bruken av velferdsteknologi. De personlige opplysningene som samles inn vil omfatte direkte identifiserende informasjon (kontaktinformasjon), og som indirekte identifiserende informasjon ved at informantene snakker om egne erfaringer i intervjuet.

All behandling av personopplysninger i prosjektet er basert på utvalgets informerte samtykke.

Ifølge meldeskjema skal personopplysninger behandles frem til 28.12.2018.

2. Personvernprinsipper

NSDs vurdering er at behandlingen følger personvernprinsippene, ved at personopplysninger;
- skal behandles på en lovlig, rettferdig og åpen måte med hensyn til den registrerte (se punkt 3 og 4)
- skal samles inn for spesifikke, uttrykkelig angitte og berettigede formål og der personopplysningene ikke viderebehandles på en måte som er uforenelig med formålet (se punkt 1 og 3)
- vil være adekvate, relevante og begrenset til det som er nødvendig for formålet de behandles for (se punkt 10)
- skal lagres slik måte at det ikke er mulig å identifisere de registrerte lengre enn det som er nødvendig for formålet (se punkt 6 og 10)

3. Lovlig grunnlag for å behandle personopplysninger

NSD vurderer at den planlagte behandlingen av personopplysninger er lovlig fordi det skal innhentes samtykke fra de registrerte.

Personvernforordningen art. 7 stiller krav om at et samtykke skal være dokumenterbart. Dette medfører at du enten må motta en underskrevet samtykkeerklæring fra hver deltager, eller deltager må bekrefte på lydopptaket at de har lest igjennom informasjonsskrivet og samtykker til deltagelse før intervjuet starter.

4. De registrertes rettigheter

NSD vurderer at den registrerte har krav på å benytte seg av følgende rettigheter; informasjon, innsyn, retting og sletting av personopplysninger, begrensning, dataportabilitet.

Behandlingen er basert på samtykke fra den registrerte, og vedkommende kan utøve sine rettigheter, herunder trekke tilbake samtykket, ved å ta kontakt med prosjektansvarlig.

NSD finner at informasjonsskrivet datert 01.07.2018 er noe mangelfullt, og ikke gir de registrerte god nok informasjon om hva behandlingen innebærer og om hvilke rettigheter de har. *Vi forutsetter derfor at følgende tilføyes før det gis til utvalget;*

- det må beskrives hvordan konfidensialitet ivaretas og i hvilken form opplysningene oppbevares; direkte personidentifiserbart eller avidentifisert
- hva som skal skje med personopplysningene ved prosjektslutt: sletting eller anonymisering
- retten til å be om innsyn, retting, sletting, begrensning og dataportabilitet

- retten til å klage til Datatilsynet
- kontaktopplysninger til veileder
- kontaktopplysninger til institusjonens personvernombud

For forslag til formuleringer, henviser vi til vår mal til informasjonsskriv, som nå er oppdatert i henhold til nytt personvernregelverk. Denne kan finnes på våre nettsider: http://www.nsd.uib.no/personvernombud/hjelp/informasjon_samtykke/informere_om.html

Vi forutsetter at det reviderte informasjonsskrivet sendes til personvernombudet@nsd.no innen det opprettes kontakt med utvalget. Husk å oppgi prosjektnummer.

Vi minner om at hvis en registrert tar kontakt om sine rettigheter, har OsloMet - Storbyuniversitetet plikt til å svare innen en måned. Vi forutsetter at prosjektansvarlig informerer institusjonen så fort som mulig og at (institusjonen) har rutiner for hvordan henvendelser fra registrerte skal følges opp.

5. Informasjonssikkerhet

Lydopptak av intervjuene og transkripsjoner vil bli lagret på en personlig bærbar datamaskin. Datamaskinen vil være passordbeskyttet og innelåst i en skuff. Det er kun studenten som skal ha tilgang til denne.

I meldeskjema har du ikke oppgitt hvorvidt eller hvordan du skal oppbevare navneliste/koblingsnøkkel. Vi anbefaler at denne også oppbevares i et låsbart skap eller i en passordbeskyttet mappe.

NSD forutsetter at personopplysningene behandles i tråd med personvernforordningens krav og institusjonens retningslinjer for informasjonssikkerhet.

6. Varighet

Ifølge meldeskjema skal personopplysninger behandles frem til 28.12.2018. Opplysninger som kan knyttes til en enkeltperson skal da slettes/anonymiseres.

Anonymisering innebærer å bearbeide datamaterialet slik at ingen enkeltpersoner kan bli identifisert. Det gjøres ved å:
- Slette navn, adresse, telefonnummer, epostadresse, IP-adresse og andre nettidentifikatorer
- Slette eller grovkategorisere arbeidssted, institusjon og andre bakgrunnsopplysninger-
- Slette eventuell navneliste/koblingsnøkkel

OsloMet - Storbyuniversitetet må kunne dokumentere at datamaterialet er anonymisert.

Meld fra om endringer
Dersom behandlingen av personopplysninger endrer seg, kan det være nødvending å melde dette til NSD via Min side. På våre nettsider informerer vi om hvilke endringer som må meldes. Vent på svar før endringen gjennomføres.

Informasjon om behandlingen publiseres på Min side, Meldingsarkivet og nettsider
Alle relevante saksopplysninger og dokumenter er tilgjengelig:
- via Min side for forskere, veiledere og studenter
- via Meldingsarkivet for ansatte med internkontrolloppgaver ved (Institusjon).

NSD tar kontakt om status for behandling av personopplysninger
Etter avtale med OsloMet - Storbyuniversitetet vil NSD følge opp behandlingen av personopplysninger ved planlagt avslutning.

Vi sender da en skriftlig henvendelse til prosjektansvarlig og ber om skriftlig svar på status for behandling av personopplysninger.

Se våre nettsider eller ta kontakt ved spørsmål. Vi ønsker lykke til med behandlingen av personopplysninger.

Med vennlig hilsen

Marianne Høgetveit Myhren
seksjonsleder

Hanne J. Pekovic
rådgiver

Lovhenvisninger

NSD vurdering er at den planlagte behandlingen av personopplysninger:
- er regulert av personopplysingsloven, jf. § 2.
- oppfyller prinsippene i personvernforordningen om:
  - lovlighet, rettferdighet og åpenhet jf. art. 5.1 a)
  - formålsbegrensning jf. art. 5.1 b)
  - dataminimering jf. art. 5.1 c)
  - Lagringsbegrensning jf. art. 5.1 e).
- kan finne sted med hjemmel i personvernforordningen art. 6.1. a)
- gjennomføres på en måte som ivaretar de registrertes rettigheter personvernforordningen art. 11-21.

NSD legger til grunn at institusjonen også sørger for at behandlingen gjennomføres i samsvar med personvernforordningen:
- art. 5.1 d) og art. 5.1. f) og art. 32 om sikkerhet
- art. 26-29 ved felles behandlingsansvar med andre institusjoner eller bruk av databehandler
- kapittel 5 ved overføring av personopplysninger til tredjeland/internasjonale organisasjoner