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ATTITUDES OF FORMAL AND INFORMAL CARE PROVIDERS IN ESTONIA TOWARDS USING GPS TRACKERS TO MANAGE WANDERING BEHAVIOUR IN PERSONS LIVING WITH DEMENTIA

Master’ s thesis

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GPS SEADMETE KASUTAMINE DEMENTSUSSÜNDROOMIGA INIMESTE UITAMISEGA TOIMETULEMISEKS: HOIAKUD FORMAALSES JA MITTEFORMAALSES HOOLDUSES EESTIS

Magistritöö

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Author’s declaration of originality

I hereby certify that I am the sole author of this thesis. All the used materials, references to the literature and the work of others have been referred to. This thesis has not been presented for examination anywhere else.

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Abstract

This thesis is written in English and is 64 pages long, including two chapters, nine figures and one table.

The aim of this thesis is to study the attitudes of informal and formal care providers regarding the use of GPS tracking devices to manage wandering in people with dementia syndrome. To investigate the care providers´ opinions, semi-structured, in-depth interviews were carried out by using snowball sampling method. Altogether, five informal caregivers and seven care home managers were interviewed. The interview guide was based on literature overview and the questions were validated by test participants.

Most of the interviewees had experienced episodes of wandering. It causes disturbance, extra stress and pressure to informal caregivers, heightened levels of stress and fear to formal care providers. According to informal and formal care providers wandering episodes range between those lasting for a couple of hours to more serious cases, where the person is missing for 1-4 days.

None of the care providers had previously used GPS trackers, but the majority of them agreed that they would be ready to do so. The application of GPS trackers can be successful if the person with dementia syndrome is willing to wear the device and does not take it off. To ensure that, the design and size of the device has to be acceptable to the person with dementia syndrome. The main benefit of the device for informal and formal care providers is the possibility to track the person in real time and quickly determine their exact location.

Overall, care providers are not aware of the rules and regulations to be taken account, when using GPS trackers to manage wandering. Therefore, clear guidelines regarding data privacy, basic human rights and provision of consent are needed.

Annotatsioon

GPS SEADMETE KASUTAMINE DEMENTSUSSÜNDROOMIGA INIMESTE UITAMISEGA TOIMETULEMISEKS: HOIAKUD FORMAALSES JA MITTEFORMAALSES HOOLDUSES EESTIS

Lõputöö on kirjutatud inglise keeles ning sisaldab teksti 64 leheküljel, kaht peatükki, üheksat joonist ja üht tabelit.

Magistritöö eesmärgiks oli uurida hoiakuid GPS seadmete kasutamise võimalikkusest dementsussündroomiga inimeste uitamisega toimetulemiseks formaalses ja mitteformaalses hoolduses Eestis. Mitteformaalsete hooldajate ja hooldusteenuste pakkujate hoiakute uurimiseks kasutati semistruktureeritud intervjuusid. Kasutades lumepalli meetodit, viidi läbi intervjuud viie mitteformaalse hooldaja ja seitsme hooldekodu juhatajaga. Intervjuude küsimustikud koostati kirjanduse ülevaate põhjal ning küsimused valideeriti eelnevalt testosalejatega.

Enamik intervjueeritavatest olid eelnevalt kogenud uitamise episoode. Mitteformaalsed hooldajad leidsid, et uitamine on häiriv ning põhjustab lisastressi ja pingeid. Hooldusteenuste pakkujad tundsid samuti, et uitamine põhjustab stressitaseme tõusu ning tekitab töötajates hirmu.

Ükski intervjuus osalejatest ei olnud varasemalt GPS seadmeid kasutanud, kuid sellegipoolest oli enamik vastanutest valmis neid tulevikus kasutama. Sealjuures rõhutati, et seadmete kasutusele võtmiseks tuleb esmalt veenduda nende kasulikkuses. Oluline on olla kindel, et seade ei oleks liiga lihtsasti eemaldatav ning dementsussündroomiga inimene on valmis seda kandma. Siinkohal oleks vajalik läbi mõelda, milline on sobiv GPS seadmete disain ja suurus.

Suurimaks kasuteguriks GPS tehnoloogia evitamisel nimetasid intervjueeritavad võimalust inimest reaalajas jälgida ning kiiresti täpset asukohta määrata. Lisaks selgus intervjuude põhjal, et teadlikkus GPS seadmete kasutamist reguleerivatest seadustest ja nõuetest on madal, mistõttu on oluline selgete juhiste olemasolu.

List of abbreviations and terms

AD	*Alzheimer’s Disease*
GPS	*Global Positioning System*
OECD	*Organization for Economic Co-operation and Development*
RDFI	*Radio Frequency Identification*
WHO	*World Health Organization*

Definitions

Dementia	*A set of symptoms associated with the decline in cognitive functions and resulting in reduction of a person's ability to perform daily activities.*
Formal care	*Paid care provided by professional health care staff at care homes, hospitals or at home.*
GPS	*Satellite-based radio navigation system that provides location and time information anywhere in the World with any weather conditions.*
Informal care	*Unpaid care, mostly provided by a member of the family, a relative or a friend that has an existing social tie to the person they provide the care to.*
Wandering	*A set of behaviours that may result in the person living with dementia getting lost. It is characterized by repeated, extended and sometimes compulsive need to walk without a specific aim.*

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Introduction

Dementia is a set of symptoms, characterised by any decline in cognitive functions, including memory, learning, orientation, language, comprehension and judgment. Dementia syndrome can be progressive or have a sudden onset due to a head trauma, stroke or brain damage. [1] Diseases causing progressive dementia mainly affect the older population from the age of 65 and above, doubling in prevalence with every five years. It is estimated that in 2030, there will be 82 million people living with dementia worldwide. The number will more than triple by 2050. [2]

Due to the cognitive decline and behavioural changes of people living with dementia, the risk of wandering and getting lost increases and consequently the need for daily assistance and supervision also grows. To increase the autonomy of the person with dementia syndrome, decrease care burden and concern regarding safety, technological solutions such as GPS trackers can be used. [3]

In 2018, the Ministry of Social Affairs initiated an expert analysis on the current condition of physical environments of Estonian care homes to determine what kind of improvements should be done to support everyday living, ensure safety and quality of life of people living with dementia. In each category (everyday living, safety, quality of life) a list of priorities was given, declaring the adoption of GPS trackers in care homes as priority number 2. [3] Nevertheless, at the moment, it is not clear whether care providers would be willing to use GPS trackers and no research concentrating on the use of GPS devices to manage wandering has been carried out in Estonia.

Besides formal care providers, most of dementia care is provided by informal caregivers, therefore the thesis focuses on investigating both - the attitudes of informal and formal care providers. Also, in most cases, informal care providers act as the legal representatives of the person with dementia syndrome, hence their viewpoints have been included in this research.

The aim of this thesis is to investigate whether GPS trackers are applicable in managing wandering among people with dementia in Estonia, based on opinions of formal and informal care providers.

The thesis concentrates on the following research questions:

1. What are the challenges of care providers in managing wandering?
2. What kind of strategies are used to prevent wandering and locate the person?
3. Are care providers willing to use GPS trackers to manage wandering?
4. What are the benefits of GPS trackers?
5. What are the barriers in using GPS trackers?

1 Literature overview and methodology

The following chapter is based on a literature overview, concentrating on the background of dementia. Furthermore, an overview of wandering and its management possibilities are provided.

The final part of this chapter concentrates on the use of GPS trackers to manage wandering behaviour in people with dementia syndrome.

1.1 Impact and prevalence of dementia

The development of medical care and improvement in living conditions have created a situation, where people in the world live longer and therefore the number of older people in the population has increased remarkably. As a result, aging societies and health care systems have to face new challenges, for example the rising prevalence of age-related conditions like dementia syndrome. [1]

According to the World Alzheimer Report 2018, 50 million people live with dementia worldwide. Due to the aging population, this number will increase to more than 152 million by 2050. [2] The total number of new cases of dementia each year worldwide is about 9,9 million, which means that there is a new case in every 3 seconds. [4] Globally, dementia is the second largest cause of disability among those over the age of 70 and is considered to be the 7th leading cause of death in the world. [4], [5] The total estimated worldwide cost of dementia care in 2018 was US$ 1 trillion, which is said to rise to US$ 2 trillion by 2030. [2]

Dementia syndrome is not a specific disease, but a syndrome that affects the everyday life of a person by having an impact on his/her cognitive skills and day-to day activities.[6] The most widely known diseases causing dementia are Alzheimer’ s disease, frontotemporal dementia, vascular dementia and dementia with Lewy bodies. [1] The most common cause of dementia is Alzheimer’s disease, representing approximately 60-80% of all patients [6]. Dementia is more prominent among women, as their average life expectancy at birth is higher than the life expectancy of men. [2]

The risk of developing dementia is strongly associated with age. Only between 2% and 10% of patients develop their first symptoms before the age of 65. The prevalence of dementia increases rapidly with every 5 years, after the age of 65 as depicted on figure 1. Almost 50% of all the Europeans over the age of 95 have dementia. [5]

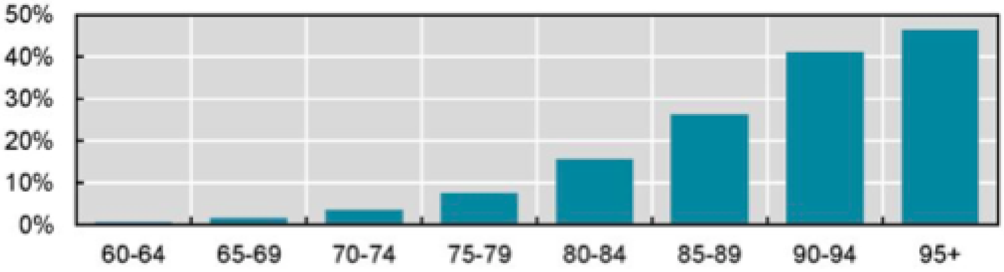

Figure 1 Dementia prevalence in Europe by age group.

(OECD, 2015, p.21). [5]

Age specific prevalence rate of dementia is estimated to remain the same over the years. The highest prevalence is demonstrated in age groups 80-84 and 85-89 (figure 2). The number of people living with dementia in these age groups is likely to increase from 3 million in 2015 to 4 million in 2035. [5]

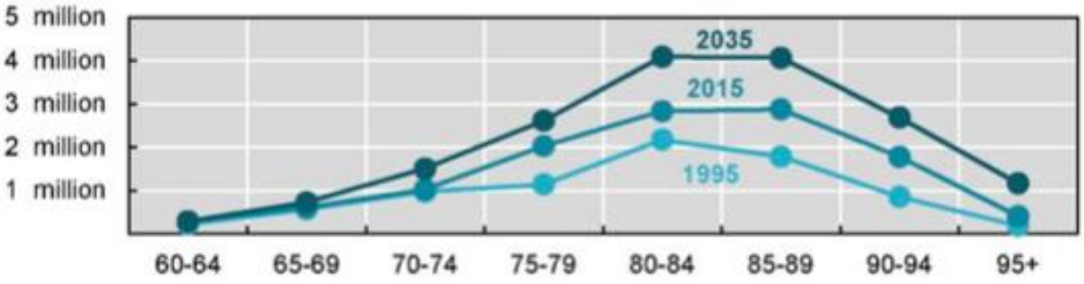

Figure 2 The number of people with dementia in Europe by age group in different years (millions).

(OECD, 2015, p.21). [5]

1.1.1 Prevalence of dementia in Estonia

According to Alzheimer Europe in 2012 there were 21 720 people living with dementia in Estonia. This counted for 1.62% of the total population, which was a bit higher than the EU average. The following table gives an overview of people with dementia in Estonia by age groups. [7]

Table 1 The Number of people with dementia by age groups.

(Alzheimer Europe, 2012, p.48). [7]

Age group	Men with dementia in Estonia	Women with dementia in Estonia	Total
30-59	417	256	673
60-64	65	405	470
65-69	446	531	977
70-74	679	1457	2136
75-79	1133	2587	3721
80-84	1419	4112	5532
85-89	912	4161	5073
90-94	312	2145	2457
95+	85	597	681
Total	5469	16 252	21 720

Similarly, to the overall statistics of Europe, Estonia's dementia prevalence remains highest in the age groups 80-84 and 85-89. Moreover, the data confirms that it is more common among women as the prevalence for women in 2012 was almost three times higher than men. Evidence shows a decrease in prevalence in age groups 90-94 and 95+. This can be due to underdiagnosis, which is more common in males, those in the oldest age groups and with less severe dementia. The decline in the person's daily functioning might be attributed to the characteristics of ageing or can be less obvious due to medical co-morbidity. Additionally, underdiagnosis is more prevalent among people living at home than those staying at a nursing home. [8]

1.2 Wandering behaviour in people with dementia syndrome

One of the most common behavioural disorders connected to dementia syndrome is wandering. It is defined as a syndrome of dementia-related locomotion behaviour having a frequent, repetitive, temporally-disordered and/or spatially-disoriented nature that is manifested in lapping, random and/or pacing patterns, some of which are associated with eloping, eloping attempts or getting lost unless accompanied. [9] Wandering is a growing problem in a lot of countries. It is difficult to ascertain the prevalence of dementia-related wandering as there are differences in how it is measured and defined. According to Hogan, the prevalence of wandering among community-dwelling seniors has been reported to range between 17.4% and 63%. [10] It is mostly associated with moderate and severe stages of dementia, but can also occur in mild stages [11]. Wandering can result in life-threatening problems like malnutrition, increased falls risk, injury, exhaustion, becoming lost and death [12]. Not all people with dementia wander, but they are exposed to a greater risk to do so.

In 2012, there were 9607 cases of people with dementia going missing in Japan. [5] A year later, the number had increased to 12 322, counting as 12% of all the missing people in 2013. Most of these individuals that were reported missing, were later found and returned home. The rest were confirmed dead or remain missing. [5] A research focusing on people with dementia getting lost in Australia, reviewed 308 newspaper articles from 2011 to 2015 that reported a missing person with a diagnosis of dementia. From these articles, 130 individual cases of getting lost were identified, of which 92 included information about the outcomes of the reported events. Of the 92 people that were found after reported missing, 73 (79%) were found alive and 19 (21%) deceased. The amount of time needed to find the missing person ranged from >6 hours to more than one week. It usually took more time (over three days) to find those that were deceased. In majority of the cases people went missing from their homes, were on foot and were found in the rage of 5 km of the place they went missing from. [12]

A similar research based on media reports in the United States, declares that the majority the average age of the entire group of 93 cases was 78. In 61% of the cases the people lived at home, 16% in nursing homes and 21% in community based assisted-living facilities. A significant number of people with dementia became lost when eloping by foot and were found within the radius of 2 km. Even if significant efforts were made to find the person, in most of these cases, formal search parties were able to find the missing individuals only in 50% of the cases. [13]

Based on the data retrieved from the Estonian Police and Boarder Guard Board, there were 82 people reported missing in Estonia in 2018. This means that it was not possible to locate the person within 10 days from the moment he/she was reported missing and consequently a file in the database for the missing person was opened. From these 82 people, 17 were aged 65 and above. As of 13.02.2019, 7 of these 17 elderlies have been found and 10 remain missing. 5 of the seven people were reported dead, when found.

1.2.1 Challenges of care providers in managing wandering behaviour

Dementia care is mostly provided by informal family carers but also in formal care institutions by paid care workers. Informal caregiver usually provide similar care that formal caregivers do, but have an existing social tie to the person they provide care to.[1]

As wandering episodes are very difficult to predict, it is a concern for both – formal and informal care providers. [14] The behavioural and psychological symptoms of dementia are strongly associated with the psychological burden of the caregiver. [15], [16] Caregivers of persons with dementia dedicate more time on care than other caregivers.[17] Compared with other long-term care users, individuals with dementia need more personal care and more supervision. [18]

In a research on perceptions of risks of institutionalization of people with dementia, based on eight European countries, including Estonia, informal carers and health professionals name caregiver burden, caregiver unable to provide care and neuropsychiatric symptoms (including wandering) as the most prominent reasons for institutionalization. [19] The informal carer providing the care, is often forced to combine paid work and care activities, which eventually might become too burdensome, thereby causing the person to continue with part time work or drop out of the labour market entirely. 40% of informal carers report having emotional stress and 74% report concern about maintaining their own health since becoming caregivers. [20] Consequently, the person might end up in institutional care earlier than actually necessary, because it becomes difficult to keep the individual safe at all times. About 70% of nursing home residents have some form of cognitive impairment. [15] Additionally, caregivers are concerned about the lack of safety at home, assuming that formal care is 100% safe and care is provided 365 days per year, 24 hours a day. [21], [22], [23]

Dealing with wandering is a challenging task also for care facilities. Nursing homes need to direct their resources towards training personnel, introducing emergency procedures and reducing overall risks of wandering. [24] Providing constant supervision and ensuring safety to those who are physically healthy and able to move independently has proven to be very challenging. [3] Additionally, quite a lot of care homes are not able to provide enough personnel to provide a high-quality service. [25]

1.2.2 Preventing wandering behaviour

Care providers have reported that they sometimes have been forced to take up extreme measures to keep the person with dementia safe. Described methods include locking the person indoors, use of pharmacological interventions like sedation, and physical restraints such as tying the person up to prevent him/her from wandering. [26], [27] Initially, these methods might be seen as safety ensuring, but in reality over sedation can cause higher falls risk and decrease in mobility may result in pressure injury or death. [28] Therefore, the use of nonpharmacological, person-centred strategies are recommended. [28], [29]

In special dementia ward facilities several constructive intervention measures are used, for example, heavy doors that require more effort to open than regular doors. Additionally, doors can be hidden or camouflaged with non-transparent material (e.g. frosted glass, mirrors) so the activities outside will not distract and attract the person inside. Exits, fire escapes and rooms that are not meant to be accessed by patients, can be covered with curtains, murals or screens. [30], [26], [23] Some care homes have created endless corridors that are built in a circular form with a public shared activity area in the middle. This way the person with dementia can have continuous walks around the hallway but will never reach an exit. [26]

Formal caregivers have indicated that if they are busy doing their care routines in the wards, they keep the doors open to be aware of the movements in the corridor. Sometimes they put barriers in the form of nursing carts and toilet chairs in the hallway, so they can hear the noise and react when someone is trying to move them. Some formal care providers have a requirement that when the patient enters the facility, a photo has to be taken. It can even be part of the patient's record. This helps the caregivers to search for the patient, if he/she has wandered off. [23]

Additionally, technological solutions like surveillance cameras can be used. Wandering detection devices like door safety systems, sensors and alarms are able to notify the caregiver, when someone is trying to leave a certain area or pass the front door. [28], [23] Some institutions use sensor mats that are put in front of beds to know, when the patient is trying to leave his/her bed, especially at night. [23]

Moreover, methods of human intervention like reading, eating together, chatting with the caregiver and going for walks to distract the person with dementia, have been used. [26] Other interventions that involve external stimulation are for example playing cards, quizzes, colouring, listening to music, massage therapy and aromatherapy. [28] Keeping the person with dementia active during the day might help to prevent wandering, as it enables him/her to sleep better at night and can potentially keep the individual from leaving the room. Nevertheless, human interventions are very time consuming and strenuous on the caregiver and therefore might not be considered a priority in most care facilities. [26]

1.2.3 Locating the person with dementia syndrome

Based on Müller et al. interview, the informal caregivers state that if a person with dementia gets lost, often other relatives and even neighbours are involved in the search process. [22] The procedure is very similar in formal care, where professional caregivers are gathered and arranged to look for the missing person. The process usually is as follows: looking inside the building, call the patient's relatives, look outside and finally call the police. [22] Therefore, wandering also places a significant burden on law enforcement institutions. Incidents of wandering may initially turn into cases of missing persons to which law enforcement representatives are obliged to react. What makes it difficult to resolve such cases, is the person's tendency to seclude themselves. Often, they follow an incoherent path, avoid searchers and are unwilling to respond when called for. The usual cost for locating and rescuing a person with dementia is about $1500 an hour. It is said to take approximately 9 hours for the law enforcement to solve a case of wandering. [24] The safety of missing elderly persons may be seriously jeopardized if caretakers cannot locate them within the "golden 24 hours". [14] If a person with dementia is lost for more than 12 hours, there is a 50% chance of finding him/her injured or dead. [31]

Radio-frequency identification (RDFI) and global positioning system (GPS) devices present an opportunity to determine the wanderer's location. The latter being reported more time effective than radio frequency devices. [30]

GPS devices use satellites at high altitude. The system can easily ascertain the location and track the transmitter appliance carried by the individual with considerable accuracy.[32] There are exceptions to some locations like underground car parks, shopping malls, railway tunnels and public transport, where it is difficult to receive an exact signal. Apart from that, the person can be positioned whenever they are outside.[27]

RFID tracking devices consist of reader and a transponder tag that can be worn on the wrist, ankle, clothing or implanted under the skin. The tags are inactive until the reader activates them, enabling the tag to retrieve data. An RFID device operates at a lower range than GPS devices do, therefore RFID is better for locating objects inside the house. RFID devices are not too good at directly communicating their location outside. [33], [34] Similarly, to RFID, Bluetooth trackers use tags paired with a Bluetooth enabled device to use a two-way communication to locate the person. Bluetooth also works at a lower frequency, making it good to use inside the building. [35], [36]

Overall, GPS trackers enable to identify the person's location rather accurately as they are not tied to a specific location through tags. GPS trackers can directly notify the user where the device is located, whereas RFID and Bluetooth take time to search where the tag is located. Additionally, GPS devices can be used in large, outdoor areas. [30], [37]

1.3 Application of GPS tracking devices to manage wandering

Family caregivers of people with Alzheimer's disease have reported that from the 14 suggested innovative technologies, one that was most appreciated was a tracking device (53.3%). Female and younger caregivers valued the devices significantly more than older and male caregivers. [31] Nevertheless, even if such technologies are available, the uptake is not necessarily high. [15]

GPS trackers can be in the form of wristbands, watches, bracelets, even shoes that are equipped with the tracking technology. [27], [28] GPS trackers can provide the caregiver with real-time and historical information about the wearer's location through a cloud platform. [38], [39] Most devices can give position alerts, if the person with dementia has gone outside a specific perimeter. Some enable communication and emergency calls between the caregiver and the wanderer, so it is possible to provide recommendations and directions to guide the person to a safe location. [40], [41]

The easiest and low-cost solution to use is a mobile device that most people already have and use. Mobile phones already have a built in GPS functionality and the person just has to carry the device so he/she can be monitored and positioned through an application by the caregiver. [40], [41]

For example, in Estonia, a GPS tracker in the form of a watch is available. The device shows the location of the person within a radius of 8 meters and enables to determine a specific zone, so the caregiver would be alarmed, when the person leaves the area. The watch can be connected to a mobile phone or computer application and worn on the wrist with a regular strap, a strap that cannot be removed or a belt clip. The price for the watch starts from 430 €. [42]

1.3.1 Legal considerations

When using GPS trackers, it is essential to involve the person with dementia syndrome or his/her legal representative to the decision-making process, to ensure that the needs of the care recipient have been taken into account. Currently, no legal basis exists regarding the processing of personal data in the context of general care and restriction of the person's freedom of movement. Additionally, it has to be assured that the fundamental rights of the person are guaranteed (dignity, autonomy, privacy etc). [3]

When using GPS trackers, a consent has to be given by the person using the device. When providing a consent, the person must be legally competent. The consent has to be written, voluntary, specific, informed and unambiguous declaration of intent. It should cover all operations performed on personal data or sets of personal data. The specific conditions for consent are laid out in Article 7 of the General Data Protection Regulation. [3]

In case the person is not able to consent or does not understand the purpose of the usage of a monitoring device, the employment of such devices should be prohibited. GPS trackers can then only be used, when they really are seen as necessary and are requested by the person with dementia syndrome or his/her legal representative. [3]

1.3.2 Benefits of using GPS trackers to manage wandering

GPS can potentially support people with dementia and their caregivers to manage wandering and increase the social inclusion as well as mobility of the person with dementia. [27] Using GPS trackers enables the possibility of creating virtual boundaries, geozones. Whenever the wanderer crosses the outer limits of the zone, an alert is triggered and sent to the caregiver of the person with dementia. [24]

A GPS tracker can provide the caregiver with real-time and historical information about the wearer’s location through a specific platform. Some devices enable communication and emergency calls between the caregiver and the wanderer, so it is possible to provide recommendations and directions to guide the person to a safe location. [40], [41]

Based on previous researches the most common reason mentioned by formal and informal care providers to use GPS tracking was to enhance the safety of the person living with dementia. In both settings the tracking device could provide the person with dementia syndrome with more freedom of movement, possibility to continue with outdoor activities and increase his/her autonomy. [22], [27], [29], [43] Using GPS can increase the feeling of privacy as they do not need someone to constantly supervise them. [43] It can also provide respite to caregivers as they are aware of the persons whereabouts and also have a greater feeling of freedom by using GPS technologies. [27] Formal caregivers have reported to feel more confident and in control as they have more time to concentrate and complete their tasks, consequently reducing staff burden. [29] Ultimately, reducing caregiver stress, can result in additional time spent with the person with dementia and hence in more person-centred care. [44]

Another benefit is the speed with what the person with dementia can be found. GPS has been proven highly reliable in providing a location when immediately requested. [27] Continuous tracking produces a breadcrumb trail of the person carrying the device, making it easier to track down and locate the wanderer. Based on a trial with GPS trackers, most of the participants were found within 10 minutes of searching. In more than 90% of the cases, the location matched the actual position of the person. [45] It can potentially help to reduce caregiver and law enforcement burden [24].

1.3.3 Barriers in using GPS trackers to manage wandering

GPS devices can create a false sense of security, where the carers are mostly dependant on the technology and do not provide enough attention to the person. Also, by trying to reduce the risks of wandering, new ones can be created. For example, delay in responses of care staff and ineffective use of alarm devices, in case the staff does not check the alarm. According to Alistar et al., when the emergency alarms of GPS devices do not work consistently they can potentially create an alarm fatigue. [44] As a result, the caregiver might assume that the alarm has been accidentally triggered and the person does not really need help or that someone else will respond. [29]

Another research shows that false alarms can become an unmanageable burden, when people with dementia remove their trackers and relocate to another position, leaving the staff confused, unable to find the resident from the location the tracker indicated. Sometimes, patients in care homes leave the building with their relatives, forgetting to notify the staff and generating alarms that causes them to panic as they assumed that the resident had left the building unattended. [43] GPS trackers might be ineffective when used indoors, in the mountains, under heavy clouds or in forests. The connection with the satellite has to be unobstructed. [24]

Drawbacks can also include the physicality and functionality of the GPS device. Some of the functions can prove to be unhelpful or the device itself might be too big and difficult to carry around. [27] It is important that the design of the device is flexible, because not all technologies are suitable and acceptable by everyone. Users have indicated that it should have a discrete design, for instance resembling common items like a necklace or a watch. The device should be affordable, as technologies that are too expensive will probably be inaccessible for those, who need it the most. Additionally, the battery of the device has to be charged and person needs to remember to take it with him/her. [27]

Implementation challenges like removal or refusal by the person with dementia can occur.[44] More than 95% of the location determinations failed because the user did not wear the device, as opposed to technical errors. [45] For example the person with dementia might leave without wearing the shoes that are equipped with GPS tracking devices. White et al. shows that the tracking system has been reported to be limited due to compliance and technical constraints. This means that the device needs to be comfortable to use and easily operated. Finally, the GPS is not able to prevent the wanderer from all forms of harm, like for example crossing the street. [27]

Using GPS trackers also raises the concern about harm to human rights. [27] A lot of institutions are resistant to use GPS trackers, because they are afraid of litigation problems due to privacy issues. Formal care providers are not certain, whether using GPS devices can be seen as a freedom depriving measure or not. Furthermore, the person with dementia might not be able to give their consent for being monitored, which can be seen as a violation of their privacy. [23]

1.4 Attitudes of informal and formal care providers based on previous research

There are quite a lot of researches concentrating on the use and attitudes towards GPS trackers. In most of the studies, the prevailing theme is the problem of ethics and the predicament of autonomy and safety.

A qualitative study focusing on the acceptance and adoption of location-based services in dementia revealed that, when using GPS trackers, a dilemma between safety and autonomy exists. The research was based on 21 interviews with informal and formal caregivers in Germany. When it comes to autonomy, caregivers feel that at the earlier stages of dementia it can enhance the personal freedom of the person with dementia by allowing him/her to leave home or the care facility and go outside independently. On the other hand it is seen as an invasion to the person’s privacy, which does not align with the current dementia care concepts and is rather seen as an impairment to the person’s independence. [26]

In more severe stages of the illness, the caregivers need to give up quite a lot of their own life and independence, therefore some family caregivers saw a potential benefit of the GPS system. The overall wellbeing and quality of life of the person with dementia was seen more important than the concern for privacy when using GPS trackers. Formal caregivers experienced a greater feeling of responsibility for safety. [46]

A study with client-caregiver dyads in Canada, revealed that after using a GPS device for an average of 5.8 months during a 1-year period, the acceptance of trackers was high. Informal caregivers indicated that the tracker gave them a peace of mind by providing a possibility to locate the person with dementia. Nonetheless, concerns regarding false alarms and notifications, communication problems and battery life were expressed. [47]

A study examining the viewpoints of informal and formal care providers in Israel, showed that when comparing the two, family caregivers saw GPS trackers as a means for enhancing safety and providing them with a peace of mind, whereas professional caregivers saw the value in giving more autonomy and were in favour of using the device only in severe circumstances and when there are no alternatives. In general, informal caregivers showed higher support to the use of tracking devices than formal caregivers.[37]

Additionally, a research based on a survey among Chinese family caregivers living in Canada, revealed that the respondents had an overall positive attitude towards the use of technology to assist with caregiving of people with dementia. Nevertheless, from the 12 technologies presented in the questionnaire, GPS trackers were the least used. From the 40 respondents less than 5% used GPS devices, which might be due to the stigma associated with being monitored or tagged. The most important features in regard to technology were the reliability of the device and the capacity for it to work without manual input from the user. From all of the respondents, women were significantly more open towards using technology in caregiving. [48]

1.5 Methodology

The aim of this study is to research the attitudes of formal and informal care providers towards the use of GPS trackers to manage wandering in people living with dementia. As the topic requires a more in depth understanding, a qualitative research method has been chosen to carry out the study.

Within this thesis informal care providers are defined as members of the family, relatives or friends of the person living with dementia, who act as primary care providers and are not paid for the service provided. The selection criterion also includes the requirement of the person actively being in the carer role at the time of the interview. Carers who have previously had to take care of a person with dementia, but are no longer performing care activities, are excluded from this study.

When researching the attitudes of formal care providers, the focus is on the directors and managers of care institutions in Estonia that currently provide services to people living with dementia. This is due to the fact that they are responsible for the whole care organization and have a broader overview of the possibilities and problems of the care cycle, therefore providing a wider image of the topic.

1.5.1 Methods

The necessary data was gathered by in-depth semi-structured interviews, a method that enables the author to collect detailed information about the relevant topic as well as ask additional questions and expand on the subject, if necessary [49]. The author uses a non-probability sampling method, in particular exponential discriminative snowball sampling. This method is mostly used, when dealing with representatives of a population that are difficult to find. Snowball sampling uses a chain referral method, meaning that the primary data source references to another potential participant in the research. When using exponential discriminative snowball sampling, the interviewees provide multiple referrals, from which the author can choose one new participant, based on the focus and the objectives of the study. [50]

The interviews were carried out as phone interviews. Due to the limited amount of free time the care providers have, phone interviews were considered as the easiest and most convenient method for the research participants. When face-to-face interviews are harder to schedule and require more training, phone interviews allow flexibility and are cost-effective. [51]

1.5.2 Development of the interview guides

Two separate interview guides were developed – one for formal care providers (Appendix 1) and another for informal care providers (Appendix 2). The interviews were all semi-structured, allowing asking questions not included in the original interview, enabling to be more flexible and provide the interviewees freedom to express their own views and expand on the topic. The interview guides were developed based on the theory and information gathered from the literature review. The guides were validated by conducting first interviews with test participants to determine the estimated durability of the interview and to discover whether the structure is logical and questions understandable. As a result, some of the questions were reformulated for better understanding and the interview guide restructured. Additionally, input from subject matter experts was gathered to assess and determine the relevance of the topic.

Both interview guides were constructed in Estonian. The first part of the interview for informal care providers concentrated on the demographic information of the participant, including gender, age and county of residence. The interview consisted of 20 closed and open-ended questions. The first part of the interview guide for formal care providers focused on gathering information on general background of care homes, including questions about the county of practice, number of care places, average age of care recipients, number of caregivers and the estimated waiting time for the care services. The interview consisted of 19 closed and open-ended questions.

Both interview guides were divided into 3 main topics. The first part concentrated on the background of care provision and preparedness to provide services to people with dementia syndrome. The second topic consisted of questions focusing on wandering, more specifically the strategies used to manage wandering and the impact of it. The third topic aimed to gain insight of the care providers´ readiness to use GPS trackers to manage wandering as well as their attitudes towards using these devices.

1.5.3 Interview participants

For both, informal and formal care providers´ interviews discriminative snowball sampling was used [50]. Altogether interviews with 7 care home managers and 5 informal caregivers were done. The initial contact with informal care providers was achieved through MTÜ Elu Dementsusega. [52] For formal care, the first contact was established based on the list of care institutions provided by the Ministry of Social Affairs. Recruitment of new participants was stopped, when no substantial new information was revealed. Additionally, no geographical limitations were set during the recruitment process of the interview participants. In case of formal care providers, the participants were limited to managers and directors of care homes. For informal care providers the criterion of being actively performing care responsibilities at the time of the interview, was set.

Interviews with informal care providers were held on 01.04., 02.04., 23.04. and 06.05. in 2019. Interviews with formal care providers were held on 22.04., 30.04. and 03.05. in 2019. All interviews were carried out as phone interviews, lasting approximately 20-30 minutes. All interviews started with an introduction about the interviewer and the overall topic and aim of the interview. All participants were asked for their consent to be interviewed and assured that they will remain anonymous. Then, demographic and general background information was asked. Next, based on the interview guide, the main part of the interview was completed. All the participants´ answers were transcribed during the interview. Furthermore, the answers were translated into English. Finally, the interviews were analysed by using thematic analysis method. At first, open coding was used to break the text into more specific and shorter concepts. Then, the codes were grouped and organized under broader themes relevant to the research questions. [53]

2 Results

The next chapter describes the results of in-depth interviews carried out with five informal and seven formal care providers in Estonia.

The first part concentrates on interview results, whereas the second part follows a discussion on the most important observations and outcomes. The last section of the results chapter focuses on the limitations of the research, also gives suggestions on further studies of the topic.

2.1 Interview results

The following sections give an overview of the answers received through interviews with informal and formal care providers in Estonia.

The overview of the results is divided into nine parts. The first two parts concentrate on the description and background of informal and formal care providers. The remaining parts focus on interview results divided by relevant topics of the research.

2.1.1 Description of informal care providers

The interviews were carried out with five informal care providers. Four of the interviewees were women and one was a man. The average age of interview participants was 57, the youngest being 44 and the oldest 75. Three of the participants were from Harju county, one was from Võru and one from Ida-Viru county.

The average age of the people with dementia syndrome the caregivers were taking care of, was 81. Two of the five persons living with dementia were men and three were women, the youngest of them being 68 and the oldest 92. One of the caregivers was taking care of his father, three of their mothers and one of her husband. All, but one caregiver, who was caring for her husband, shared their care responsibilities with someone else. Two out of four interview participants were sharing care responsibilities with their siblings, one with her mother and one with his wife. Only the caregiver taking care of her husband lived together with the person with dementia syndrome. Three caregivers lived in the same city but in different districts and one caregiver lived 35 km from the person she provided care to.

Three out of five caregivers had been caring for the person for three years, one for four years and one for five years. All respondents said they perform their care responsibilities in parallel with everyday work. Three of the five caregivers explained that they work full-time. Furthermore, one caregiver worked with a workload of 1,5 and another with 0,5. The caregiver that works with a workload of 0,5, previously worked full-time, but due to the decline in health of the person living with dementia, she was forced to decrease her workload in the last six months.

All but one caregiver had thought of admitting the person with dementia syndrome to a care home. Reasons like caregiver burden, declining health and health conditions that the caregiver is not able to manage independently, were mentioned. One of the caregivers said: "I submitted my mother to a care home for a month last summer, because I wanted to have some time for myself. It was becoming too stressful. At the moment, we are in a waiting list, but overall, I would like to keep my mother at home as long as possible, so she could be in a familiar environment and not with strangers." The caregiver that had not thought of admitting the person to a care home claimed that as long as the person does not pose a threat to herself or to others, he saw no reason to admit the person to an institution.

Four of the five caregivers spent an average of three hours a day on care activities. Additional time is spent on traveling to the person and back home. One of the caregivers explained: "Sometimes I stay overnight, because I have to come again in the morning. There is no point in going back home, because I will lose too much time." One caregiver, who also lived with the person she was taking care of, spent an average of seven hours on care provision.

2.1.2 Description of formal care providers

The interviews with formal care providers were carried out with seven care home managers. Two institutions were situated in Saare country and from each of the following counties - Järva, Jõgeva, Põlva, Tartu and Võru, one manager was interviewed. The number of places in the care homes ranged between 25 and 215, the number of care workers between 11 and 38. For approximately every 12-15 care recipient, the care home had one caregiver. The average age of care recipients in the care facilities was 79.

From the seven interviewed care home managers, five said that they have waiting times for general services provided in the care home. Furthermore, the person can be registered into several care homes, which makes it difficult to determine the exact length of the waiting time. On average, the care homes had 15-20 people in the waiting line. Two care homes did not specify waiting times. One of those care homes claimed that they do not pre-register people due to lack of resources. The other care home explained that they accept new residents only, when a place becomes available.

Only one of the interviewed care homes said that they had a separate department for people with dementia syndrome. The department had 30 places, but even so there were 6-7 undiagnosed residents in the other departments. One of the care homes described that if possible, they try to keep people with dementia syndrome in the same room. Another care home, which was located in two separate buildings, said that they place people with dementia syndrome one of the buildings surrounded by a yard and a fence. One care home manager said that she did not believe separate departments for people with dementia syndrome are necessary. She explained that based on her experience, they adapt very well with the environment of the care home, when the people are able to communicate, interact and are daily actively engaged. She emphasized that caregivers have to have time to focus on the person. To do that, caregivers in that particular care home do not perform any activities related to hygiene.

Three out of seven care institutions said that they have no criterion in providing services to the people living with dementia. Two care homes stated that they accept only those that are in the mild stadium of dementia and two explained that they will not take a person with a tendency to violence. Additionally, other criterions like “diagnosis”, “calmness” and “no tendency to wander” were mentioned. Moreover, one of the care institutions said: “We accept people based on their suitability. Meaning, we accept them, when they are suitable for us. They cannot be aggressive or wander. We accept people with dementia syndrome, but only the ones who have difficulty with remembering or sometimes feel disoriented. We cannot take people, who are violent, because we do not have separate rooms for them. In case the person is not able to adapt in the care home environment, the service provision will be cancelled.”

All care homes allow their care workers to take part in specific trainings that are focused on taking care and providing services to people living with dementia syndrome.

2.1.3 Wandering behaviour in people with dementia syndrome

All but one informal caregiver had experienced wandering episodes. During the years of care provision two caregivers had had two more difficult episodes of wandering, one caregiver had experienced one and one had three. One of the caregivers added that in proportion to the time that he had performed his care activities, the episodes of wandering were not that frequent. Additionally, in most cases the person wandering was found by someone on the street, which was then reported to the caregiver or to the police. Cases, where the person got lost and went missing were less frequent.

In general, all care homes have experienced wandering episodes outside the care institution at some time. Three of the care homes explained that they have not had such cases in recent years. Two care homes said that they experience wandering events rather rarely. The remaining two care facilities claimed that they encounter wandering attempts quite often. One of them mentioned that they have wandering attempts almost daily.

2.1.4 Challenges of care providers in managing wandering behaviour

The most frequently mentioned impact that wandering had on caregivers, was extra load of stress. This was indicated by three respondents. Two caregivers said that wandering was rather disturbing. Other impacts included were extra burden, fear, feeling of powerlessness and hopelessness. One of the caregivers pointed out that he felt powerless because there was no good way to manage wandering. On the other hand, he claimed that it happened rather rarely to take up any extreme measures. Another caregiver described her experience: "I had to change the locks, because I was afraid that when he had the keys and the address with him, someone would use them and break in. This was really stressful."

Three out of seven care home managers think that wandering increases stress and caregiver burden. Two care homes said that it causes fear and caregivers are afraid that something has happened to their client. Additionally, one care provider explained: “The caregivers are not allowed to leave their positions in the department, when someone gets lost. If they cannot leave, someone else has to find the person. Therefore, I think it mostly causes stress to other employees, not the caregivers.” Furthermore, it was mentioned that wandering causes additional work and leaves less time for the caregiver to perform his/her daily duties. One care manager thought that wandering does not affect care workers at all.

2.1.5 Preventing wandering behaviour

All caregivers have used some kind of strategies to manage wandering. Methods like locking the door and taking the keys away, putting a slip of paper with a phone number and address into the pocket or bag of the person with dementia syndrome had been used. The most frequently used methods were locking the front door and keeping the contact details in the person´s pocket or bag. One of the caregivers explained: "We usually lock the front door but leave the key on the table. In reality, my mother really does not remember how to use the key, so if we come, we have to guide her through the door. We are afraid to really lock her up, because you never know what might happen." Furthermore, one of the caregivers had used an old mobile phone, which had her and her mother's phone number in it. The phone was put into her father´s pocket and when he got lost, the person that found him, could use the phone and contact the caregiver or her mother. This method had proven to be useful in most of the wandering cases. Another caregiver explained: "We bought him the phone that is meant for the elderly. The one with the emergency button…But it was of no use, because he never took it with him." One of the caregivers used a bracelet that had his phone number on it, but his mother was reluctant to wear it and it finally got lost.

Each care home had used some kind of strategies to manage wandering. The majority, six of the seven care managers, claimed that wandering is mostly prevented by care workers' attention. One of them said: “We do not have any special methods or technologies. It is mostly the eyes of the car workers and their attention.” Two care homes described that they keep some of their doors locked, so it would be more difficult to go out of the building. For example, one of the care institutions said that they have four doors in different parts of the building, making it very difficult to constantly make sure that no one exits. Therefore, they try to keep the doors locked, but as there is a general practitioner's office in the building, it is not always possible. Two care homes also mentioned that often other clients help to keep an eye on the people with dementia syndrome and report to the caregivers, when someone is trying to exit the building. One care home said that they have cameras inside and outside the building. Nevertheless, in their opinion, cameras could only help in determining the direction the person went to. Another care home manager explained: “When we see that the person is more active, we try to place him/her to a room located at the very back of the corridor. Then it takes the person a longer time to reach the door. Additionally, to get out, they have to pass the caregivers' room.” One of the care home managers mentioned that the people living in the area of the facility, are very well informed and usually report to the care institution, when they see someone wandering outside. Furthermore, one care home described: “We have two client workers, who actively engage people with dementia syndrome in different daily activities. Additionally, care workers engage them in conversations and provide constant supervision. When you really concentrate on the person, actively engage them and give them something to do, they will not wander.”

2.1.6 Locating the person with dementia syndrome

Three out of four caregivers had contacted the police, when experiencing a wandering episode. This was mostly done, when the person had been missing for a longer period of time. Usually, at first, the caregivers tried to look for the person themselves and then finally called the police. Often, the case got a solution without the involvement of the caregiver. This happened, when the caregiver was not aware that the person with dementia syndrome had gone out and was then found by someone on the street, who contacted the caregiver directly or through the police. Depending on the case, the time that was spent to locate the person ranged from two hours to four days. Two caregivers had experienced events of wandering, where the person was found in two hours, the other two had the person missing for a day. Additionally, one caregiver had experienced another episode of wandering, where the person was missing for four days. The caregiver explained: "This one time he was missing for four days. For a while I looked for him myself…I thought he had gone to Tartu. I also called my son, who lives in Tartu and asked him to look for him in the places he usually wanted to go to. His aim was to visit his parents´ grave in Tartu, but he never made it there. He got lost first. And finally, I called the police."

All of the care homes said that, if a person got lost, they would at first search for the person by themselves. Five out of seven respondents said that if necessary, they would finally call the police. One of the care homes explained they have used the help of local people to search for the person, another care home mentioned that they used, if needed. In one of the cases, the care home also involved the Boarder Guard. Furthermore, a care home manager described: “We have an agreement with the police that at first, we go through a certain area ourselves and if we cannot find the missing person, we call the police. We mostly know where to look…certain roads that lead away from the institution. We have had cases, when the person is searched for with a helicopter using infrared technology. Overall, that is very expensive and not always justified. Also, in such cases the police have to file a separate report to the prefect.” Another respondent said that most of their cases are wandering attempts and if there are twelve people working in the institution a day, there is enough staff to concentrate on the person, talk to them and have constant supervision”.

The length of time that took to find the missing varied in different cases for every care home. Sometimes the person was found immediately, at other times it took two days to locate the missing person. In most cases the person was found within two-three hours. One care home had a case, where it took a day to locate the person and another care institution had a person missing for two days. One care home could not specify how long it took them to locate a missing person.

2.1.7 Application of GPS trackers to manage wandering

All except one caregiver were aware of the possibility to use GPS trackers to manage wandering. However, no one had previously used the device. Four out of five caregivers said that they would be willing to use GPS devices. One caregiver was not sure if she would use it. She explained: “I don’t really know. So far, the mobile phone we put in his pocket has worked well. Our numbers are in the phone and if someone finds him, they can call us. We have stuck to it and it has proven to be successful.” Another caregiver commented that he would be willing to use the GPS tracker if he could be sure that it is useful and works.

Three of the five care providers thought that using GPS trackers would help to keep the person with dementia at home longer. One of them remarked that when the condition progresses and the person starts wandering more, he most likely will have to choose between admitting the person to a care home, hiring a professional caregiver or quitting his job. In this case, he saw a GPS tracker as an alternative that would give him a possibility do go on with his daily life, but in the meantime keep an eye on the person he was taking care of. Two of the caregivers were already planning to admit the person to a care institution. In their opinion, GPS trackers would not help to keep the person at home for a longer period of time. This was because both caregivers were providing care to people with dementia, who also had other health conditions, which the caregivers were not able to deal with independently. Therefore, they had decided to admit the person they were taking care of to a care home.

Five care home managers out of seven were aware of the possibility of using GPS devices to manager wandering. None of them had previously used GPS trackers in their institutions. Four care homes said that they have not used GPS technology, because it was too expensive. Two care homes mentioned that they feel that using such devices is necessary. One of them said: “I do not think it is necessary to use GPS devices in our care home. We can divide people between two houses. We can put the people with the dementia syndrome to the building that has a garden and a fence. It allows them to walk around freely and the caregivers keep an eye on them. Maybe, it would be more relevant for informal care providers at home. In a care home, it is the caregivers’ job to provide supervision and take care of the person. This is why they are here.” The other manager said that in care provision, the human factor is very important. She explained that, when the caregiver knows the person through and through, actively engages him/her into different daily activities and conversations, there will not be any need for GPS trackers. Moreover, reasons like absence of a definite set of regulations, privacy and data protection requirements were mentioned. Also, an uncertainty towards whether using a GPS device is a violation of basic human rights, was brought up as a reason for not using GPS trackers. Even so, four out of seven care homes said that they would be willing to use GPS trackers to manage wandering behaviour among people living with dementia syndrome.

2.1.8 Benefits of using GPS trackers to manage wandering

When the caregivers were asked, what could be the main benefits of using GPS trackers to manage wandering, four participants said that they could help to track the person with dementia in real time. Three caregivers expressed that the GPS could potentially help to find the person faster and determine the specific location. Furthermore, two caregivers thought that using GPS technology could help reduce stress. Only one caregiver said that the device could enhance sense of safety.

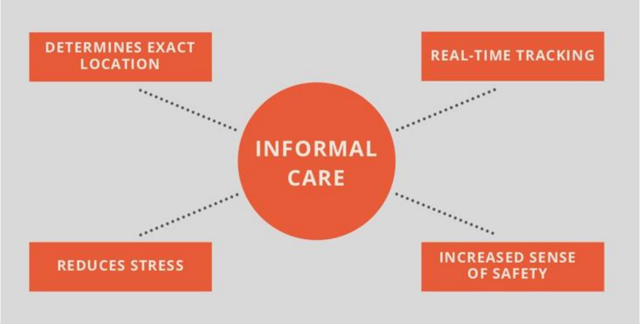

Figure 3 Benefits of GPS trackers in managing wandering in informal care.

In the opinion of four care home managers, one of the main benefits of GPS trackers, is the possibility to quickly locate the missing person. Two care homes mentioned the opportunity to determine the exact location of the person as well as use real-time tracking.

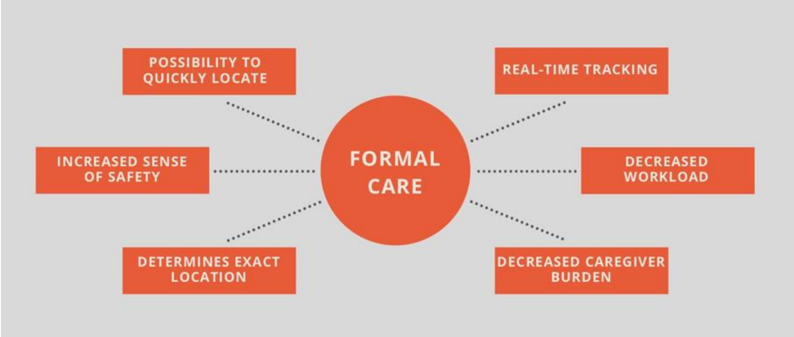

Figure 4 Benefits of GPS trackers in managing wandering in formal care.

Other benefits mentioned by the care homes were decreased caregiver burden and workload, increased sense of safety and autonomy of the person with dementia syndrome, possibility to prevent the person from going too far and to use geozones. One care home manager saw that GPS trackers would be more beneficial to informal carers in home care.

2.1.9 Barriers in using GPS trackers to manage wandering

Three out of five interview respondents could not name any limitations regarding the use of GPS trackers. Two caregivers were concerned that the GPS device can easily be removed and then it would be of no use. Additionally, they mentioned the possibility that the person with dementia syndrome would not be willing to wear the device and the risk that using GPS technology might be taken as violation of privacy. One of the caregivers clarified: “I think that in this context, there will not be any conflicts concerning the violation of the person’s privacy, right? In our experience, the main problem is that the person is not willing to wear the device. I mean, she did not even want to wear the bracelet. If this issue was solved, and she would be happy to wear the tracker…then I do not see that it would cause any inconvenience to us or to her.”

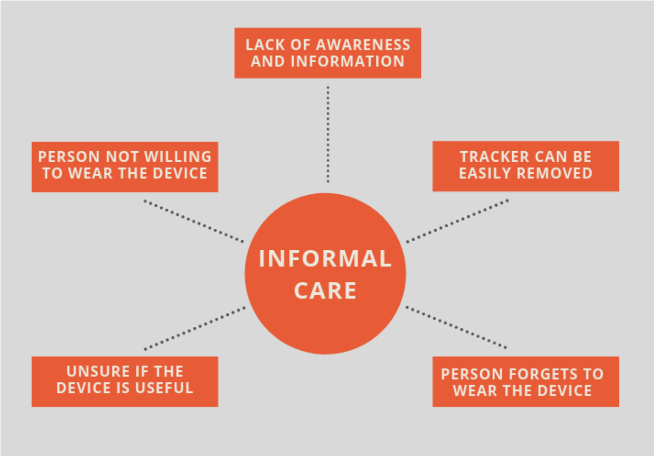

Figure 5 Barriers in using GPS trackers to manage wandering in informal care.

Two out of seven care homes mentioned that the limitations of GPS devices are that they are too expensive, the person with dementia is not able to give a consent to use the GPS tracker, it is too easy to take off, the device associates with a prisoner and it is uncertain whether using the device is a violation of basic human rights.

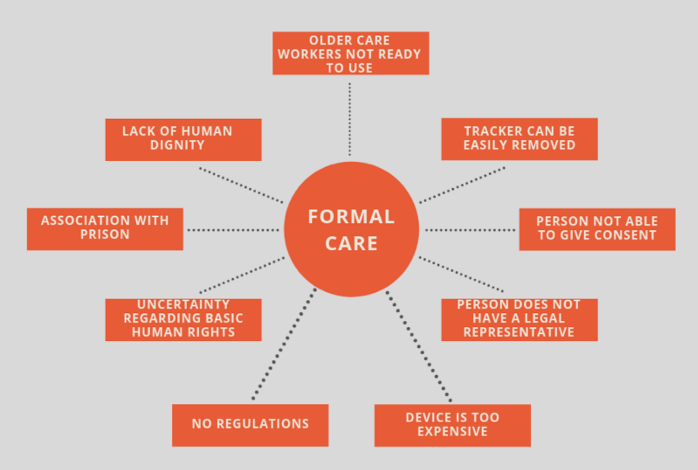

Figure 6 Barriers in using GPS trackers to manage wandering in formal care.

Other limitations mentioned were lack of human dignity, older caregivers not being prepared to use the technology, a person with dementia syndrome does not understand the necessity of the device, the person does not have a legal representative and uncertainty about the regulations regarding data protection. One of the care home managers thought that using GPS trackers might make the person with dementia syndrome feel harassed. Another manager did not know what the limitations could be.

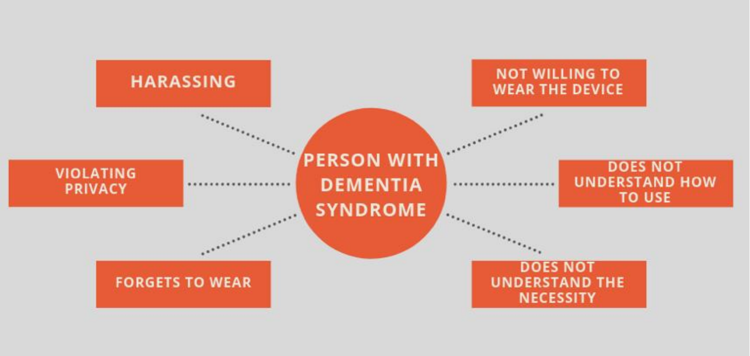

Figure 7 Barriers of using GPS devices from the point of view of the person living with dementia syndrome as indicated by care providers.

2.1.10 Recommendations for requirements for GPS trackers

Based on the answers of formal and informal care providers the following requirements play a considerable role in the successful application of GPS trackers. Care providers emphasize that in order for the GPS tracker to be functional, the person with dementia syndrome should not be able to take it off. The device should be worn by the person at all times, otherwise it loses its purpose and care providers are not able to locate the person, when needed.

Figure 8 Recommendations for requirements for GPS trackers.

People with dementia syndrome should be willing to wear the device. Based on caregivers’ previous experiences people with dementia syndrome might be reluctant to wear unfamiliar objects. Therefore, the design and size of the device should be acceptable to the person with dementia syndrome. Finally, to increase the adoption of GPS trackers the device should be affordable to all, otherwise those, who need it the most might not be able to purchase the device.

2.2 Discussion

During the course of dementia, the person experiences deterioration in his/her cognitive skills. [6] The most common behavioural change that occurs, is wandering - a dementia-related locomotion behaviour, which can result in life-threatening outcomes like malnutrition, increased falls risk, injury, exhaustion, becoming lost and death. [13]

Wandering increases emotional distress end therefore amounts in greater caregiver burden, initially having a negative effect on the quality of life of the carer and the person living with dementia. [22] One of the possible solutions to help to manage wandering and reduce the risk of harm among patients with dementia, is a global positioning system (GPS) device. GPS devices enable to locate the person faster by generating a breadcrumb trail, when the person is continuously tracked. If the compliance of the device is high, the person can be located within 10 minutes of searching. [45]

2.2.1 Wandering behaviour in people with dementia syndrome

The prevalence of wandering among community-dwelling seniors ranges between 17.4% and 63%. [10] According to data based on findings in the media in Australia and the United States, in most cases people went missing from their homes and were on foot. [12], [13] The length of time taken to find the missing person ranged from >6 hours to more than one week. [12] Based on the interviews, all, but one informal caregiver had experienced episodes of wandering. In comparison, all formal care providers had had wandering events. According to informal and formal care providers, wandering episodes ranged from those lasting for 2-4 hours to more serious cases, where the person was missing for 1-4 days. None of the wandering episodes described by the care providers had ended with the person being deceased or severely injured.

In general, the majority of care providers explained that the events of wandering do not occur that frequently. Nevertheless, over time, wandering episodes may happen more often and the outcomes of such events cannot be predicted. To demonstrate the potential risks of wandering, a map depicting an area with a radius of 5 km in Nõmme, is presented. The specific range was chosen based on a research in Australia, which revealed that people with dementia syndrome were usually found in the radius of 5 km of the place they went missing from. [12]

Figure 9 An area with a radius of 5 km on Google Maps.

The map clearly demonstrates the potential risks the person with dementia syndrome might encounter, when walking in that area. The area is surrounded with several water bodies that raise a possible risk of drowning. Additionally, a large part of the region is covered with forests and roads. Furthermore, a larger highway passes through the area, potentially placing the person with dementia syndrome to a life-threatening situation and increasing the risk of getting injured. Therefore, even if the episodes of wandering are not that frequent, the risks and possible outcomes of the behaviour have to be acknowledged.

2.2.2 Challenges of care providers in managing wandering behaviour

The behavioural and psychological symptoms of dementia are strongly associated with the psychological burden of the caregiver, as a result 40% of informal carers report having emotional stress and 74% report concern about maintaining their own health since becoming caregivers. [15], [16], [20] All informal caregivers that had experienced episodes of wandering said that such cases were very disturbing, placing extra stress, pressure and burden on the caregiver. One of the caregivers emphasized that it is very difficult to handle, when the person with dementia syndrome constantly speaks about leaving. This can have an influence on the caregiver's everyday life, as constant fear that something might happen, can cause anxiety and additional stress. Another informal caregiver said that episodes of wandering were quite frightening. On the other hand, the episodes were not too frequent that they would have required any extreme measures to be taken.

All informal caregivers that took part in the interviews performed their care activities in parallel with their job responsibilities, making it rather difficult to be aware when wandering episodes occur. [20] Wandering episodes are very difficult to predict, creating additional stress as the caregiver cannot be certain whether the person with dementia syndrome is safe or not. [14] According to the Alzheimer's Association Report 2015, when care responsibilities become too burdensome, the person might have to continue with part time work or drop out of the labour market entirely. [20] Similarly, after 3,5 year of care provision and working full-time, one of the informal caregivers was forced to decrease her workload to 0,5. In reality the caregiver would have liked to continue working full-time, but as the condition of the person living with dementia syndrome worsened and the need for supervision and care increased, she was forced to continue working part-time.

Formal care providers also experienced additional stress and heightened levels of fear towards their clients. The feeling of uncertainty, whether something has happened to the person with dementia syndrome, causes anxiety and stress. Wandering episodes cause extra tension, as the caregivers constantly have to be alert to make sure that no one leaves the building and gets lost. One of the care home managers indicated that managing wandering is definitely an extra task for the caregiver. For example, in the morning the caregiver has to perform several tasks like washing, cleaning etc, therefore providing constant supervision is seen as an extra job. Wandering episodes are very difficult to foresee, and providing continuous supervision is rather time consuming. [14] It can prevent performing other necessary tasks and in reality, would require an additional person, who could keep an eye on the person that has a tendency to wander. Informal care providers also raise the concern that in case someone gets lost outside, caregivers are not allowed to leave their positions or departments. Therefore, someone else, whoever is able to leave, has to start looking for the missing person. Consequently, wandering does not only affect the caregivers but also other people working in the care institution. It might even have an effect on other care home residents, whose daily life is disturbed.

In conclusion, both informal and formal care providers have to deal with increased stress levels, pressure and anxiety. To reduce caregiver burden in informal care, the supportive services provided by local governments could be more attainable. This could help the caregiver to remain working full time, but enables to reduce the load of care provision, if necessary. Moreover, employers could allow caregivers flexible working hours, teleworking and increased annual leave. Additionally, taking part in dementia support groups could help reduce caregiver burden. Regarding informal care, regulations concerning the adequate number of staff and roles could be established. A better division of tasks could reduce the work load of formal caregivers.

2.2.3 Preventing wandering behaviour

Care providers have reported that to keep the person with dementia safe, they sometimes have been forced to take up extreme measures. [26] These methods include locking the person indoors, using pharmacological interventions like sedation and physical restraints such as tying the person up to prevent him/her from wandering. [27] Based on the interviews none of the care providers indicated that they have used sedation or physical restraints. In general, pharmacological interventions and physical restraints should not be used, as it is against basic human rights, therefore making it difficult for care providers to confirm the usage of such methods. Only one of the informal caregivers admitted that to avoid wandering, he has sometimes taken the person’s keys away, but was reluctant to actually lock the person up in a room, because in case something happened, the person would not able to get out. Even if interview participants did not use such methods, the problem still remains relevant. In recent years, several checks have been carried out in the Estonian care institutions, revealing in the media that these methods are still being used. To reduce the use of pharmacological interventions and physical restraints, care providers should be encouraged to use alternative preventive methods. To increase the deployment of nonpharmacological techniques focus should be on raising the awareness through relevant trainings.

Based on previous research, in some care homes several constructive intervention measures have been taken into practice, to prevent the person from wandering.[30],[26],[23] However, it appears that most buildings in Estonia, where care homes are situated, are not that suitable for housing people with dementia. Nevertheless, some care homes have been able to adapt and address the problem by coming up with a solution by themselves. One of the care homes divided their residents between two separate buildings, enabling accommodation for people with dementia syndrome in a house surrounded by a yard and a fence. This gave the residents an area, where they could safely walk outside under supervision. Another care home tried to move all people with dementia syndrome into one room, so they would be separate from regular residents and it would be easier to keep an eye on them. Based on the author’s opinion, before issuing the care institution with a licence to provide services, the suitability for people with dementia syndrome should be confirmed. If the care home does not meet the requirements, appropriate recommendations to improve the environment, should be provided.

Even if quite a lot of technological interventions are available to help manage wandering, very few care providers have used them. [28], [23] This could be due to lack of relevant information and awareness of available solutions, as the technological measures reported by the care providers, were mostly quite simple. For example, formal caregivers revealed that they have acquired alarm buttons, but people with dementia syndrome usually do not know how to use them. One care home also had cameras, but according to the manager it did not really help to prevent wandering, but only gave an indication of the direction the person went to when leaving the building. Two care homes indicated that in the future they plan to obtain technological measures like wandering detection devices such as sensors and alarms that notify the caregiver, when someone is trying to leave a certain area. Usage of similar technologies to manage wandering has also been demonstrated in previous researches. [28], [23] To increase the use of technological solutions, awareness among care providers has to be raised. This can be done through dementia support groups targeted at informal caregivers or by adding relevant subjects focusing on the use of technologies in the curricula of formal care providers. Additionally, trainings on the possible technological interventions could be provided to both – informal and formal care providers. Furthermore, to promote the implementation of preventive technologies, grants supporting the administration of such innovations could be provided.

Methods of human intervention like reading, eating together, chatting with the caregiver and going for walks to distract the person with dementia have been used to manage wandering. [26] Whereas all formal care providers claim to have client workers for people with mental problems, only one care institution states they actively involve people with dementia syndrome in different activities. In the author’s opinion, to enhance the use of human interventions, priority should be given to person-centred care. Additionally, care institutions should ensure the sufficient number of qualified client workers that could focus on people with dementia syndrome. Moreover, some of the caregivers’ tasks could be reallocated to other care home workers (e.g. bathing, cleaning), so they could also concentrate more on engaging the person in different activities.

2.2.4 Locating the person with dementia syndrome

Formal caregivers indicated that they always start looking for the person from inside, because often he/she is found sleeping in someone else's bed, under the blankets or behind someone else. If the person cannot be located inside, care home workers proceed to looking outside. Finally, if necessary, the police is contacted. Informal caregivers usually started looking by themselves, often involving family members and relatives and then, finally the police. The process of looking for missing persons with dementia, for both informal and formal care providers, is very similar to methods described by Müller *et al.* According to her data caregivers started to look from inside the building, then called the patient's relatives, looked outside and finally contacted the police. [22]

The interviews demonstrated that informal caregivers mostly described wandering episodes that involved the person with dementia syndrome leaving home and going outside. Formal care providers saw wandering also as getting lost inside the building. Situations where the person with dementia syndrome was found in someone else's room were more frequent than those where the person gets lost outside.

Formal and informal care providers located in smaller communities, benefit from the possibility of having people living nearby acknowledge the episodes of wandering, making it easier to react and find the person with dementia syndrome. In lager cities, it is more difficult to involve the community to recognize people who are wandering. Noticing wandering persons can be easier for formal care providers as people living near the care home might be more attentive. In author's opinion it is necessary to improve the overall awareness of people of dementia syndrome and the behavioural changes that occur, so cases of wandering would not go unnoticed.

Other methods of locating the person, suggested by care providers, did not prove to be successful. People with dementia syndrome were either reluctant to use the proposed solution, forgot to take it with them or took it off entirely.

2.2.5 Application of GPS trackers to manage wandering

The majority of interview participants state that they are aware of the possibility of GPS trackers to manage wandering. Nevertheless, none of the respondents had used them before. This corresponds to the information revealed by previous research, which confirms that the uptake of GPS devices among care providers is rather low. [15]

Family caregivers of people with Alzheimer’s disease have reported that the technology they most likely would use is a tracking device (53.3%). [31] Based on the interviews, overall, four out of five informal caregivers agreed to using GPS devices to manage wandering but were somewhat hesitant because they were not sure what it would entail and how the device would work in reality. The author suggests that in order to find out whether the GPS tracker is suitable for the person with dementia syndrome, local governments could offer informal caregivers a possibility to try out the devices. For that local governments could own a set of GPS trackers that they can give out and eventually sell if the tracker proves to be useful to the caregiver. To increase the application of tracking devices real pilots involving caregivers, care institutions and people with dementia syndrome could be carried out. The findings could serve as an input to those planning to use GPS devices.

Formal care providers’ opinions regarding the use of GPS trackers were somewhat opposing. Four out of seven care homes said they would be willing to use GPS trackers to manage wandering. All care providers that agreed to using GPS trackers, specified that the application depends on the specific regulations, rules and financing of the devices.

2.2.6 Benefits of GPS trackers

Based on previous research, the most common benefit of using GPS trackers to manage wandering was the possibility to enhance the safety of the person living with dementia. Additionally, freedom of movement, possibility to continue with outdoor activities and increase the autonomy of the person were mentioned. [22], [27], [29], [43] Informal caregivers that participated in the interview saw that the main benefit could be the possibility to track the person in real-time (Figure 3). Additionally, the possibility to determine a specific location of the person was mentioned. Similarly, according to Bartlett *et al.*, informal caregivers mentioned that GPS trackers could also reduce stress and increase the sense of safety of the caregiver as they are better aware of the person´s whereabouts and have a greater feeling of freedom by using GPS technologies. [27] As none of the caregivers had used GPS trackers before, their answers were mostly based on their assumptions. Interestingly, all informal caregivers only listed benefits that were directly connected to themselves as caregivers, but not to the person with dementia syndrome. For example, instead of referring to the safety of the person with dementia syndrome, they mentioned the sense of safety that the tracker would give to them.

Formal caregivers saw the possibility to quickly locate the person with dementia syndrome as the main benefit of using GPS trackers (Figure 4). Similarly, to informal caregivers, real-time tracking and provision of exact location was brought up. Additionally, decreased caregiver burden and workload were mentioned. Previous research also indicates that GPS trackers gave formal caregivers more time to concentrate and complete their tasks, consequently reducing staff burden. [29] Similarly, to informal caregivers, formal care providers mentioned increased sense of safety of the caregiver rather than focusing on the safety of the person with dementia syndrome.

Only one formal care provider said that GPS devices could increase the autonomy of the person with dementia syndrome. Nevertheless, she specified that autonomy can be increased only when inside the building, but not be expanded outside as it might be too dangerous.

After receiving a diagnosis, caregivers and people with dementia syndrome could be directed to dementia support groups that could help to provide insight regarding the use of GPS trackers. When the person gets diagnosed in an early stage of dementia, the support group could help pointing out the benefits of using GPS trackers for the person living with dementia syndrome. Consequently, the person can decide early on and indicate whether he/she would consent to the use of GPS devices.

2.2.7 Barriers of using GPS trackers

Interviews revealed that most informal caregivers do not know, whether there are any limitations to GPS trackers. The main restraint mentioned was that the person with dementia syndrome might not be willing to wear the device and therefore it is useless (Figure 5). Other barriers mentioned during the interviews included the fact that the trackers can be easily removed and therefore the person might forget to take the device with him/her. Also, it was indicated that people with dementia syndrome mostly do not know how to use technological devices. One of the caregivers was not sure whether using GPS trackers will raise any conflicts regarding violation of privacy. This indicates that informal caregivers have very little knowledge on the real use of GPS trackers. Therefore, when using such devices in care institutions, awareness among informal caregivers has to be raised. This means that the care institution has to make sure that the legal representative of the person with dementia really understands and is conscious of all the aspects, rules and regulations that have to be taken into account when using GPS trackers to manage wandering.

Compared to informal caregivers, formal care providers were more aware of the possible limitations associated with the use of GPS trackers. Bartlett *et al.* showed that using GPS trackers has raised a concern about harm to human rights. [27] Care institutions are hesitant to use GPS trackers, because they are afraid of litigation problems due to privacy issues. [23] Similar issues came up in the interviews with formal care providers (Figure 6).

Currently, it is not clear to most care managers whether using GPS trackers is a violation of human rights and can they be seen as a freedom depriving measure or not. Some care providers explained that using a GPS device is like tagging a prisoner with a tracking device and saw it as rather degrading. Majority of care institutions were unsure what are the exact data protection regulations that have to be followed, therefore leaving them hesitant to use GPS trackers. The author's suggestion is that clear instructions and regulations have to be formulated in the national level. Additionally, specific forms could be provided to ensure that data protection regulations are followed unanimously.

The device should be affordable, otherwise the tracker will probably be inaccessible for those, who need it the most. [27] The exact issue was also mentioned by formal care providers, who were worried that because of the high price of the device, it will not be available to care homes who really need the device. Also, it was not sure, who would pay for the acquisition of the GPS trackers, whether it should be the service provider, local government, the state or the care receiver. For example, the price of one of the GPS trackers available in the Estonian market starts from 430€. [42] As all general care services are mostly financed by service fees paid by the service users, it is difficult for care homes to find financing for this kind of expenditure. One of the care institution managers proposed that in case such devices are used, this should be a decision made by the legal representative or family of the person living with dementia syndrome. As just a service provider, it should not be up to them to decide whether such a device should be implemented. Additionally, the expenses concerning the acquisition of the device should be covered by the family of the person living with dementia, not the care service provider. In case the family is not able to pay for the GPS tracker, it should be the local government or the state, because the care home will not agree to take on a financial obligation like that.

Care home managers also emphasized that not all people with dementia syndrome are able to give their consent. Care institutions mostly deal with people in a severe stage of dementia, which means that consent has to be provided by the legal representative. However, there are cases, where the person does not have a legal representative and it is unclear, who should give the consent, whether it should be the state or the local government. When the person is not able to give their consent for being monitored, it can be seen as a violation of their privacy. [23] Formal care providers believe that both, the legal representative and the person with dementia syndrome should agree to use the device. At a later stage of dementia, the person might not be able to understand the necessity of the device, therefore he/she might not agree to wearing the tracker. One of the solutions could be asking the consent from the person with dementia syndrome at an early stage of the condition. Nevertheless, it will not solve the issue with those arriving to the care home at a later stage of dementia.

2.2.8 Attitudes of formal and informal care providers

Previous studies regarding the attitudes of formal and informal care providers, mainly raised the issue of ethics and the predicament of autonomy and safety. Wan *et al.* revealed that care providers feel that at the earlier stages of dementia GPS trackers can enhance the autonomy and freedom of the person with dementia syndrome by letting him/her to go outside independently [26]. Interviews with the Estonian care providers showed that the provision of independence and autonomy is not seen as a priority. Increase in autonomy though the usage of GPS trackers was mentioned only by one formal care provider. According to Wan *et al.* caregivers are also concerned that GPS trackers invade the person’s privacy [26]. Estonian care providers mostly brought up the issue of data privacy, rather than the general privacy of the person with dementia syndrome.

Overall the majority of formal caregivers were reluctant to use GPS trackers as there were a lot of confusion regarding specific regulations and requirements. On the other hand, most of the informal caregivers showed higher support to the use of tracking devices, as depicted by Landau *et al* [37].

Similarly, to the participants in a survey by Xiong *et al.* [48], informal caregivers in Estonia had an overall positive attitude towards the use of GPS trackers to manage wandering. Nevertheless, none of the care providers had previously used GPS trackers. Xiong *et al.* [48] also indicated that from the 12 technologies proposed in the research, GPS trackers were the least used. Furthermore, the research explains that it might be due to the stigma associated with being monitored or tagged [48]. Estonian caregivers are most probably influenced by the lack of awareness and information about the usage of GPS trackers.

2.2.9 Limitations

One of the main limitations of the study is that it is based on the opinions of informal and formal care providers, excluding the attitudes of people with dementia syndrome. Nevertheless, to some extent the care receiver's view is presented through the care providers. Due to the nature of dementia syndrome, it is quite difficult to involve people with dementia syndrome into the study, especially those in later stages of the condition.

Additionally, the sampling method used in the research does not allow to make inferences that can be allocated from the sample to the whole population. In general, it was quite difficult to find respondents from informal caregivers as they were rather hesitant to participate in the research. Moreover, they were quite reluctant to provide further contacts, as they were not sure whether their acquaintances would be willing to participate.

Furthermore, during the development process of the interview questions, an in-depth pilot was not conducted. Nonetheless, the interview questionnaire was validated with the representatives from the target group. For background information, insight from specialist on this topic was gathered.

Interviews were carried out on the phone, meaning that some participants might have been more open while participating in a face-to-face interview. Therefore, some important insights might have been excluded. A few participants also experienced connection problems, which were solved after the person changed her location and the connection was restored.

2.2.10 Suggestions and further studies

As demonstrated by the results of the study, there is a lot of uncertainty regarding the specific rules and regulations that should be applied, when using GPS trackers to manage wandering. Therefore, further studies could focus on the legal perspective of using tracking devices in wandering management. The research could serve as an input to a specific set of rules, regulations and framework that focus on using tracking technologies in general care. This would help to make sure there is a clear and common understanding of the actions to be taken, when using GPS trackers. It might also support the overall adaption of new technologies in general care. Additionally, informal caregivers should be better informed about the rules and regulations regarding the use of GPS trackers. Clarity on what rules and regulations apply in home care, when using GPS trackers, should be achieved.

Furthermore, to use GPS trackers, the process of providing consent should be very clear. Currently, care providers are uncertain who should provide the consent, when the person with dementia syndrome is not able to or he/she does not have a legal representative. Possible scenarios could be mapped and specific guidelines on how to proceed could be provided. One of the possibilities is to ask for the consent of the person at the early stages of dementia, nevertheless it is difficult to determine whether the person fully understands the purpose of the device. Also, it should be clear, on what terms the legal representative is granted the right to provide the consent for the person with dementia syndrome.

Furthermore, real pilots with care homes, informal caregivers and people with dementia syndrome could be done. Different steps of the process can be researched and recorded (e.g. selecting a suitable device, documentation asking for consent, installing the technology, training the caregivers to use the device, using the device). The lessons learned could serve as an input to all the other care providers that would like to implement such devices.

Besides looking into the processes, different GPS trackers can be tested, to see whether some are more suitable and user friendly than others. People in different stages of dementia might need different solutions. Additionally, the research showed that people with dementia syndrome might not be willing to wear the devices. Therefore, the design and the function of GPS device should be carefully thought through. The tracker should not be too bulky or disturbing. It should be something familiar, small and unnoticeable, so the person would agree to wear it and would not take it off. Also, GPS trackers that are suitable for care institutions might not be appropriate for home care. Therefore, studies focusing on the user experience, user acceptance, design and necessary features of the tracker could be done.

2.3 Conclusions

Based on the findings of the research the following conclusions can be made:

1. Main challenges for informal caregivers in managing wandering are extra stress and performing care activities in parallel with their job responsibilities. Main challenges for formal care providers are increased levels of stress and fear.

2. Strategies used by informal caregivers to prevent wandering are locking the door and taking the keys away. Formal care institutions mostly rely on caregivers' heightened levels of attentiveness.

3. Strategies used to locate the missing person are the same for informal and formal care providers. First, they look for the person from inside the building, then proceed outside and finally contact the police.

4. Care providers are willing to use GPS trackers to manage wandering behaviour but need assurance that the devices are useful and provide support to their care activities.

5. Main benefits of GPS trackers are the possibility to track the person in real-time and quickly determine his/her exact location.

6. Formal care providers are hesitant to use GPS devices, as it is unclear what are the exact rules and regulations to be followed. Clear guidelines regarding data privacy, basic human rights and provision of consent are needed.

7. Both, formal and informal care providers indicate that for the successful implementation of GPS trackers, people with dementia syndrome should not be able to take the device off

8. People with dementia syndrome might not be willing to wear the device. Therefore, the device should be discreet in design and rather small in size.
9. The GPS device should be attached to the person with dementia syndrome at all times, so it would not be left behind or forgotten.

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Appendix 1 – Formal care interview guide in Estonian

SISSEJUHATUS

- Uurija ja uurimuse tutvustamine
- Asutuse taustainfo küsimine:
    - Asukoht
    - Hooldatavate inimeste arv
    - Hooldatavate keskmine vanus
    - Hooldajate arv

INTERVJUU

Teema 1: Valmisolek dementsussündroomiga inimestega tegelemiseks

Taustinfo: Sotsiaalministeeriumi andmete põhjal on Eestis 164 institutsionaalseid hooldusteenuseid pakkuvat asutust. Nendest 102 on valmis vastu võtma ka dementsuse diagnoosiga patsiente ning vaid kaks omavad selleks spetsiaalset osakonda.

- Kas asutuses on eraldi osakond dementsetele?
    - Mitu kohta on osakonnas dementsete jaoks?

- Kui asutuses ei ole eraldi osakonda, millistel alustel olete valmis dementsussündroomiga inimesi vastu võtma?
    - Ainult kergema dementsusega kliente
    - Lisatasu eest, kokkuleppel
    - Kui diagnoos on saadud hooldekodus
    - Kui ei vaja liikumisel järelevalvet
    - Kui ei ole agressiivne, vägivaldne, ei põgene
    - Ainult lamavad haiged

- Kas asutuse hooldajatele võimaldatakse osa võtta koolitustest, mis suurendavad valmisolekut dementsussündroomiga inimestega töötamiseks?

Teema 2: Toimetulek uitamisega

Taustinfo: Varasemad uuringud näitavad, et dementsusega seotud uitamist esineb rohkem kui 60%-l diagnoosiga inimestest. Sellega toimetulek mõjutab oluliselt hooldaja koormuse- ning stressitaset.

- Kas teie asutuses on dementsete patsientide hulgas esinenud uitamise episoode majast väljas? Kui tihti?

- Kas kasutate uitamisega toimetulekuks mingisuguseid ennetavaid meetodeid? Kui jah, siis milliseid?
    - Füüsilise ruumi kohandamine
    - Pikad koridorid – liikumisring/kõndimisrajad
    - Pidev patsiendi turvalisuse jälgimine hooldaja poolt
    - Alarm-matt
    - Liikumisandur
    - Toast lahkumise andur
    - Kaamera
    - Liikumisvõrud (kiibiga käepael)
    - Sensoorne aed
    - GPS
    - Liikumistegevused (füüsiline koormus)
    - Erinevad teraapiad
    - Ravimid
    - Kinni sidumine
    - Toa lukustamine

- Kuidas toimite, kui inimene on läinud uitama? Palun kirjeldage protsessi.

- Kuidas teie arvates mõjutavad uitamise episoodid ja sellega toimetulek hooldajaid?
    - Stress
    - Ärevus
    - Ajapuudus
    - Rahulolematus tööga

Teema 3: GPS lahenduste kasutamine uitamisega toimetulekuks

Taustinfo: Üks meetodeid uitamisega toimetulekuks on GPS seadmete kasutamine. GPS seadmed võimaldavad dementsuse diagnoosiga inimest distantsilt jälgida ning vajadusel tema asukohta määrata.

Näide: GPS kell, mis pannakse dementsussündroomiga inimese käele ning kella äpp laaditakse telefoni/arvutisse. GPS näitab inimese asukohta 8 m raadiuses. Süsteemi saab lisada raadiuse, millest väljudes edastatakse hooldaja telefonile/arvutisse alarm. Raadiuseid võib seada mitu nt öö ja päeva raadius. Kella saab kanda tavalise rihmaga, rihmaga mida ei saa ära võtta või vööklipiga.

- Kas olete teadlikud GPS seadmete kasutamise võimalusest uitamisega toimetulekuks?

- Kas kasutate või olete uitamisega toimetulekuks GPS seadmeid kasutanud?
    - Kui jah, siis milliseid?
    - Kui ei, siis mille tõttu te ei ole varasemalt GPS seadmeid kasutanud?

- Kas oleksite valmis uitamisega toimetulekuks kasutama GPS seadmeid?

- Milles seisneb teie arvates GPS seadmete kasutamise kasulikkus?
    - Suurendab dementse vabadust
    - Annab võimaluse vabalt liikuda
    - Annab võimaluse jätkata välitegevustega
    - Parandab dementse elukvaliteeti
    - Suurendab turvatunnet
    - Suurendab privaatsustunnet, sest dementne ei vaja pidevat järelevalvet
    - Tagab hooldajale kergendustunde, kuna hooldaja saab lähedase asukohta GPSi abil jälgida
    - Vähendab hooldaja stressi
    - Võimaldab uitama läinud hoolealuse kiiresti leida

- Mis võiksid olla GPS seadmete kasutamisel negatiivsed küljed?
    - Petliku turvatunde tekkimine (turvatunde tekkimisel hooldaja tähelepanu ja fookus hooldatava suhtes väheneb)
    - Ainult tehnoloogiast sõltumine ning fookus hooldatavale kaob
    - Valealarmid
    - Alarmiväsimus
    - GPSi ebaefektiivsus siseruumides
    - Liiga suur seade
    - Ebavajalikud funktsioonid
    - Kulukas
    - Aku vastupidavus
    - Kasutaja ei kanna seadet
    - Rikub privaatsust, võtab inimeselt vabaduse
    - Dementne ei saa anda nõusolekut seadme kasutamiseks

Appendix 2 – Informal care interview guide in Estonian

SISSEJUHATUS

Uurija ja uurimuse tutvustamine
Demograafilise informatsiooni küsimine

- Sugu
- Vanus
- Elukoht

INTERVJUU KÜSIMUSTIK

Teema 1: Dementsussündroomiga inimese hooldamine

Taustinfo: Enamasti on dementsussündroomiga inimese hooldajaks nende lähedane või sõber, kes teeb hooldustööd oma igapäevase töö kõrvalt ning ei saa selle eest tasu.

- Hooldatava vanus
    - Alla 60
    - 60-64
    - 65-69
    - 70-74
    - 75-79
    - 80-84
    - 85-89
    - 90-94
    - 95-99
    - 100+

- Milline on teie suhe hooldatavasse?
    - Abikaasa
    - Laps
    - Lapselaps
    - Sugulane
    - Sõber
    - Muu

- Kas olete hooldatava peamine hooldaja või jagate hoolduskoormust kellegi teisega?

- Kaua olete hooldatavat hooldanud?

- Kas hooldatav elab teiega koos või üksi?

- Kas lisaks hooldamiskohustustele käite ka tööl?
    - Täiskohaga töö
    - Poole koormusega töö
    - Ei tööta üldse

- Kas olete mõelnud oma lähedase suunamisest hooldekoduse?
  - Kui jah, mis on olnud selle põhjuseks?

Teema 2: Toimetulek uitamisega

Taustinfo: Tüüpilisemaks dementsusega seonduvaks käitumuslikuks muutuseks peetakse uitamist – järelevalveta, sihitut ja juhuslikku ringi liikumist või kõndimist, mis võib viia inimese kadumiseni ja vigastuste tekkimiseni. Varasemad uuringud näitavad, et dementsusega seotud uitamist esineb rohkem kui 60%-l diagnoosiga inimestest. Sellega toimetulek mõjutab oluliselt hooldaja koormuse- ning stressitaset.

- Kas teie hooldataval on esinenud uitamise episoode? Kui tihti on neid esinenud?

- Kas kasutate uitamisega toimetulekuks mingisuguseid ennetavaid meetodeid? Palun täpsustage, milliseid?
  - Füüsilise ruumi kohandamine
  - Pidev hooldatava turvalisuse jälgimine
  - Alarm-matt
  - Liikumisandur
  - Toast lahkumise andur
  - Kaamera
  - Liikumisvõrud (kiibiga käepael)
  - GPS
  - Liikumistegevused (füüsiline koormus)
  - Erinevad teraapiad
  - Ravimid
  - Kinni sidumine
  - Toa lukustamine
  - Naabrid aitavad silma peal hoida („naabrivalve“)

- Kuidas toimite, kui inimene on läinud uitama? Palun kirjeldage protsessi.

- Kuidas uitamine teid mõjutab ja kuidas te sellega toime tulete?
  - Stress
  - Ärevus
  - Unetus
  - Ajapuudus

Teema 3: GPS lahenduste kasutamine uitamisega toimetulekuks

Taustinfo: Üks meetodeid uitamisega toimetulekuks on GPS seadmete kasutamine. GPS seadmed võimaldavad dementsuse diagnoosiga inimest distantsilt jälgida ning vajadusel tema asukohta määrata.

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- Kas olete teadlikud GPS seadmete kasutamise võimalusest uitamisega toimetulekuks?

- Kas kasutate või olete uitamisega toimetulekuks GPS seadmeid kasutanud?
    - Kui jah, siis milliseid?
    - Kui ei, siis mistõttu te ei ole varasemalt GPS seadmeid kasutanud?

- Kas oleksite valmis uitamisega toimetulekuks kasutama GPS seadmeid?

- Milles seisneb teie arvates GPS seadmete kasutamise kasulikkus?
    - Suurendab dementse vabadust
    - Annab võimaluse vabalt liikuda
    - Annab võimaluse jätkata välitegevustega
    - Parandab dementse elukvaliteeti
    - Suurendab turvatunnet
    - Suurendab privaatsustunnet, sest dementne ei vaja pidevat järelevalvet
    - Tagab hooldajale kergendustunde, kuna hooldaja saab lähedase asukohta GPSi abil jälgida
    - Vähendab hooldaja stressi
    - Võimaldab uitama läinud hoolealuse kiiresti leida

- Mis võiksid olla GPS seadmete kasutamisel negatiivsed küljed?
    - Petliku turvatunde tekkimine (turvatunde tekkimisel hooldaja tähelepanu ja fookus hooldatava suhtes väheneb)
    - Ainult tehnoloogiast sõltumine ning fookus hooldatavale kaob
    - Valealarmid
    - Alarmiväsimus
    - GPSi ebaefektiivsus siseruumides
    - Liiga suur seade
    - Ebavajalikud funktsioonid
    - Kulukas
    - Aku vastupidavus
    - Kasutaja ei kanna seadet
    - Rikub privaatsust, võtab inimeselt vabaduse
    - Dementne ei saa anda nõusolekut seadme kasutamiseks

- Kas GPS seadme kasutamine võiks aidata hoida teie lähedast kauem kodus ning vältida tema hooldekodusse suunamist?