An analysis of Self-Reliance within (Early Stage) Dementia: A review of the Northern Netherlands

Minor More Healthy Years
University of Groningen
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Group 1 – Living with Dementia

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Foreword

This project has been established under the supervision of the *minor More Healthy Years* (2019-2020) of the University of Groningen, the Netherlands.

The IP generated by this project from the *minor More Healthy Years* belongs to the following students: Anna-Lena Hasselder, Dilay Günal, Julius Govers, Maria Sativa Baumann and Marije van Boven. If any company would like to make arrangements for the use of the IP, they can contact the clients for whom this was designed. The clients, Marijke Teeuw and Klaus Boonstra, can be contacted through the GGD Fryslân, the Netherlands.

There are two parts identified in order to give a broad perspective of the problem:

1. An analysis of Self-Reliance within (Early Stage) Dementia: A review of the Northern Netherlands.
2. The research report: Towards a We-Reliant Health Care System.

We would like to thank the people and organisations that have participated and helped us during this project, as well as the teachers and mentors from the minor. Lastly, we would like to thank our clients for the opportunity to work on this project and for their guidance.

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Abbreviation List

ESD	Early stage dementia
Dyad	Person with dementia and informal caretaker (*Mantelzorger)*
GGD	Gemeentelijke Gezondheidsdienst
GP	General Practitioner (*Huisarts*)
ICT	Informal caretaker (*Mantelzorger*)
PwD	Person/people with (early stage) dementia

1. Introduction

While every era has dealt with their own challenges, this era is undoubtedly faced with the prospect of an ever-ageing population. For instance, the World Health Organization (2018) estimated that between 2015 and 2050, the proportion of the population being older than 60 years, will double from 12% to 22%. Similarly, by 2020, the number of people above 60 will outnumber children younger than 5 years, indicating the immense strain this will have on our current health system and health spending. That being said, one can identify two main drivers of population ageing: increasing life expectancy and falling fertility rates (WHO, 2015, p. 47-48). As an individual is ageing, numerous changes within the body occur, increasing the risk for chronic diseases (WHO, 2015). Although people's health can partially be explained by genetics, much is due to people's physical and social environments, including their homes, neighborhoods and communities as well as gender, ethnicity and socioeconomic status. Also called the determinants of health (WHO, 2010). Accordingly, external factors can influence the ageing process early in our lives. Therefore, it is important to take preventive measures, so people can spend spend later years in good health.

When looking at ageing populations, one can identify several risk factors associated with negative health such as: obesity, sedentary lifestyles, but also lack of social interactions and cognitive engagements. At higher age, there is also the risk of comorbidity, the experiencing of several chronic diseases at the same time. Especially with regard to lack of cognitive engagements, one can see the rise of brain related diseases. In fact, low mental activity, insufficient exercise, and depression are risk factors for one of the most widespread diseases in the world: dementia. In 2015, an estimated 47 million of the world's elderly population was affected by dementia, with predictions of 82 million people by 2030 (WHO, 2015). In fact, dementia can generally be classified as a loss of independence, encompassing several progressive diseases which affect memory, cognitive functions, and behavior. The most common types of dementia are Alzheimer's Dementia, Vascular Dementia, Frontotemporal Dementia and brain injury related Dementia e.g. from Stroke (Alzheimer Nederland, n.d.-c). Since dementia is a cluster of symptoms and encompasses a variety of diseases, it is diverse in its progression and how it affects people's lives. Nevertheless, dementia can constitute a significant constraint to people's day-to-day lives, but also impacting human costs to countries, societies, communities and families. With regard to this, the personal, social and economic consequences of dementia are severe, as the disease will lead to increased long-term care costs for governments, communities, families and individuals (WHO, 2015). As a consequence of this, dementia has been recognized as one of the most considerable challenges for our societies in the next decades.

Taking the case of the Netherlands, one can see the impact of ageing on the population. Of the total population of 17 Million, about 25% were older than 60 years (WHO, 2017). Moreover, the study Public Health Foresight (National Institute for Public Health and the Environment Ministry of Health, Welfare and Sport, 2018) indicated that the life expectancy of the Dutch will increase from 81 years to almost 86 years in 2040, leading age-related diseases to increase. While dementia currently constitutes 12.5% of all deaths within the Netherlands, it is expected to become the leading cause of disease burden and the main cause of death in 2040. Furthermore, the cost associated with the disease amounts to 9.3 Billion Euro, occupying almost 10% of all the healthcare cost. Moreover, costs related to dementia are estimated to increase by 2.7% per year (Alzheimer Nederland, 2019a). Since PwD are frequently institutionalized in care facilities or hospitals, there is an ever-growing interest in increasing the span in which PwD can remain within their homes (Ministerie van Volksgezondheid, Welzijn en Sport, 2018). Conversely, being able to live at home is associated with positive health outcomes such as increased quality of life. With regard to this, the extent to which care at home can be perceived as positive, largely also depends on the situational care context, the caretaker and the surrounding structures. To make the care outcome as pleasant as possible, it is crucial to investigate the current situation at stake and to make recommendations for possible interventions that could enhance the quality of life for all people involved.

With regard to this, it is crucial to state that there has been a restructuring of the Long Care System, which entered into force on the first of January 2015. Under the Long-Term Care Act, which replaces the General Exceptional Medical Expenses Act, people who require permanent or 24-hour home care, find support (Ministry of Health, Welfare and Sports; 2016, p. 13). Under the 2015 reform, many long-term care responsibilities were transferred from AWBZ to the WMO and the Health Insurance Act (Dutch: Zorgverzekeringswet). This means that different responsibilities and competences which were previously organized at the national level, are now decentralized and transferred to the municipalities and health insurance companies (Jongen, 2017, p. 9). In this context, the municipalities are especially responsible for ensuring and facilitating social inclusion and independence for older citizens. But also for providing support for informal caregivers, and to arrange household care. In turn,the provision of nursing services, medical treatments and palliative care of older people receiving care at home, is the responsibility of health insurances (Jongen, 2017, p. 87).

Because of this restructuring of responsibilities, and since ageing and dementia have been identified as important challenges within the Netherlands, the GGD (Gemeentelijke of Gemeenschappelijke Gezondheidsdienst) together with the municipality Friesland and Vitale Regio aim to increase self-reliance within PwD in their early stages. As many factors and stakeholders are involved in the care at home, the following research question will be answered within this report: *How might we create an environment in which people within early stages of dementia are enhanced/strengthened in their self-reliance?* When looking at this research question, three spheres of interest were identified as crucial to answer this question: early stage dementia, the concept of self-reliance, and the concept of living environment. Therefore, both desk and field research will be divided according to these themes. Moreover, the field research consists of a questionnaire and interviews of relevant stakeholders within the Northern Netherlands (Groningen, Friesland, Drenthe). By including many different perspectives, stakeholders, and angles to the situation, we aim to bridge the gap between existing research and practice.

2. Literature Review

2.1. Chapter One: General Information / Early Stage Dementia

When it comes to dementia, most typical symptoms are memory loss, and changes in mood or behaviour. While memory loss is normal within the elderly brain, there is a substantial difference between age-related changes in the brain and dementia induced ones. For instance, healthy elderly people might get confused with completing familiar tasks, but they will eventually figure it out. Conversely, PwD have trouble driving to a familiar location, organising a grocery list or remembering the rules of a favourite game. Another good example are the tasks of speaking or writing. While a person with dementia has trouble participating and continuing in a conversation and is likely to use made-up words for certain objects or activities, a typical healthy elderly will just have troubles with finding the right word (Alzheimer Nederland, n.d.-b). Moreover, PwD may also experience difficulties with language, thinking, and problem solving in general.

In any case, the symptoms described above are caused by changes within the brain structure. In fact, it is normal for the brain to shrink to some degree as one ages. The most common cause of dementia is Alzheimer’s disease (AD), which in the Netherlands is responsible for nearly 70% of all dementia cases. In the early stages, it causes very small changes in the person’s abilities and/or behaviour. It may also affect their memory of recent events. The typical early signs of Alzheimer’s are for instance: poor judgment and decision-making, losing track of the date, place or season, difficulty having a conversation or misplacing objects and being unable to retrace them (Alzheimer Nederland, n.d.-c). However, within the case of AD, neurons are dying as a result of certain proteins aggregations in the brain, causing a loss of functions (Neergaard, 2015). The two main drivers of change within AD are plaques and tangles. These are activated differently than in a healthy brain, thus resulting in problems. While plaques are large accumulations next to neurons, tangles induce problems in the neurons itself, causing difficulties with the transportation within a cell. There are also suggestions concerning a disfunctioning of microglia cells, which no longer properly clean the excess waste and aggregations accumulated in the brain. Furthermore, the vascular system has an important role in the progression of the disease. For instance the blood-brain barrier, which normally protects the brain, could encounter problems (National Institute on Ageing, 2017).

As dementia progresses, it will start destroying neurons in memory-related parts of the brain and will go on to areas responsible for language, reasoning, and social behaviour. In later stages, the whole brain will be affected and the brain volume will be significantly reduced. Nevertheless, looking into the brain for the molecular and cellular changes is only possible post mortem in AD. Therefore, the behavior of people becomes a significant predictor. To classify the degree of progression based on behavior, one can resort to the Braak stages, mapping out the stage of the progression of the disease. However, this is mostly used for Alzheimer's Disease and Parkinson's Disease (National Institute on Ageing, 2017).

Another type of dementia frequently diagnosed is vascular dementia. Different from Alzheimer's, Vascular dementia is provoked by a lack of oxygen, set off by a stroke or by damage to blood vessels in the brain. There are different types of vascular dementia that progress at different rates. The most common early symptoms are: problems with thinking, problems with organising, and problems with planning. A third type of dementia that is seen less frequently is Frontotemporal Dementia (FTD), which is caused by damage to the frontal and temporal lobe. Symptoms related to this type within early stages are for example: loss of boundaries in behaviour, making impulsive decisions, showing no initiative and having no interest in others. The fourth type of dementia seen less frequently is Lewy Body Dementia, which is closely related to Alzheimer’s and Parkinson’s Disease. In the early stages, there is often no signs of memory loss or difficulty performing tasks, but patients often develop attention disorders. Symptoms that are often seen are for example: loss of boundaries in behaviour, making impulsive decisions and showing no initiative, and having no interest in others. Other symptoms common in the early stages are: attention that varies from day to day, difficulty planning, very disturbed sleep, visual hallucinations and difficulty moving (Parkinson’s). It is important to keep in mind that everybody with dementia will be affected differently and will develop different symptoms, making it difficult to define a general scheme of the most common symptoms (Alzheimer Nederland, n.d.-b)

Since there has not yet been a cure found for dementia, prevention becomes a focal point. As mentioned earlier, sedentary lifestyles, lack of exercise, and cognitive engagement are risk factors for dementia or early onset. When looking at the capability of the brain, the concept of cognitive reserve proposes that both enhanced cognitive ability and increased brain volume may contribute to healthy brain ageing (Allen et al., 2005). In this sense, increasing cognitive reserve through learning of languages, musical instruments and so on, might reduce the chance of developing dementia. In general, a regular routine of exercise as well as social engagements are positively associated with cognitive abilities. To foreground, dementia prevention should be a more crucial point within politics and medical research to reduce the burden of the situation.

2.2. Chapter Two: Self-Reliance

In order to investigate how the self-reliance of PwD, and especially ESD can be increased, it is first necessary to define what it constitutes. Self-reliance means being able to rely on oneself and to remain independent. Whereas self-management interventions are increasingly used for people suffering from chronic illnesses, a care gap can be observed when it comes to practices of self-management for people within early stages of dementia. This is contradictory, as PwD on average live 11-12 years after their diagnosis. Moreover, although more services become available at later stages of the disease, people at early stages are often neglected from the picture (Martin et al., 2013) for which reason it is necessary to develop a full picture on how self-reliance can be enhanced.

2.2.1. Self-Efficacy/Self-Management

An important part of being able to perform tasks independently is self-efficacy. Self-efficacy is one's belief in one's ability to influence events that affect their life or to perform tasks. According to Bandura (1997), this constitutes the foundation of human motivation, performance accomplishment, and emotional well-being.

Self-management is an important concept related to self-efficacy and self-reliance. In general, self-management refers to a person's ability to manage symptoms and treatment; physical, psychological and social lifestyle changes, and consequences resulting from the disease. In this sense, the overall aim of self-management is to find strategies to live as normal as possible with one's chronic disease (Martin et al., 2013). In line with this, self-management is a set of skills such as problem solving, decision making, locating and using resources, the creation of a partnership between the person and the health professional and making an action plan and executing it. While there are disease-specific approaches for self-management, there are some specific problems that appear in the case of dementia. For instance, since dementia is diverse and progresses over time, symptoms in early stages differ significantly from patient to patient.

Similarly, Mountain (2006) states that concepts of self-management for early stage PwD need to focus on the person with dementia as well as their carer. Accordingly, he argues for an approach called personal disease management. In this context, personal means the personal interpretation of problems, and need for care and advice. Disease constitutes a direct reference to the condition and need in order to provide intervention response, and management suggests a whole system approach. For Martin et al. (2013) self-management for PwD should target five areas: the relationship with the family, maintaining an active lifestyle, psychological well-being, techniques to cope with memory changes, and information about dementia. When it comes to the relationship with the family, it needs to be stressed that appropriate social support can facilitate and enable goal achievement which simultaneously has a positive impact on the well being of everyone involved. Therefore, an intervention should target joint problem solving of the PwD together with the caretaker.

Furthermore, maintaining an active lifestyle allows the PwD to improve quality of life and to stay engaged within his/her community. According to the authors, outdoor activities can provide a sense of meaning and enjoyment which can counteract perceived experiences of the PwD that his/her world might be shrinking (due to decreased networks), (Martin et al, 2013) Another relevant aspect is increasing psychological well-being by counteracting beliefs of insecurity, low self-efficacy, low-esteem and acceptance. In fact self-acceptance has been identified in the study of the authors as a relevant coping strategy especially at the early stages of dementia. Opportunities, such as group sessions or memory support groups were rated as helpful by people as there is a perceived unity in dealing with problems.

Next, the authors stress the need to develop techniques to cope with memory loss, as this is a key problem for PwD, causing distress and frustration. While memory-based interventions have not provided the hoped results, the subjective experience of the PwD while following memory strategies can make losses of memory feel more manageable. Finally, Information about the disease and how to cope with it was also important when it comes to self-management. Having knowledge about the disease is important to adjusting to life with dementia. Concluding, it should be highlighted that self-reliance in dementia should not only focus on ADL, but should take a more holistic approach to health by including as many factors as possible.

2.2.2. Activities of Daily Living

A report by Thoma-Lürken et al. (2018) has identified many different problems a person with dementia may encounter when it comes to Activities of Daily Living (ADL). Daily tasks such as eating, drinking, washing, housekeeping, taking medication, mobility and transfers are no longer self-evident. The article provides an overview of the different problems a person with dementia may encounter in their (i)ADL. These are categorised according to domains, such as self-reliance. Not only are the problems related to the activities, but also problems such as a lack of structure, lack of meaningful activities and disrupted day/night rhythm (Thoma-Lürken et al., 2018).

However, problems with ADL are not the only obstacles PwD may encounter. There are also several safety-related issues, such as an inability to judge risk and make independent decisions, improper use of electronic devices, risk of being mistreated or robbed, falling accidents, getting lost outside, or not wearing proper clothes for different types of weather.

The PwD or their ICT may also encounter social network-related problem with can partially be attributed to care burden. These include excessive responsibility for the informal caregiver, inability of the informal caregiver to handle the person with dementia, loss of social contacts, misinterpretation of the behaviour of the person with dementia, or no social network, which leads to earlier institutionalisation (Thoma-Lürken et al., 2018). Accordingly, it is important to maintain self-management processes as long as possible and to find ways to engage the PwD to increase sense of responsibility and purpose. Similarly, this will also help the caretaker to remain balanced in early stages.

2.2.3. Informal Caretakers

As mentioned above, dementia is classified as a loss of independence. Since it is progressive, the level of independence of a person will decrease over time so that external support becomes essential. In many cases, once a person is diagnosed with Mild Cognitive Impairment (MCI), or dementia, a relative will often take over the task of caregiving due to their emotional proximity. The relative in this context will be referred to as the ICT, in most cases consisting of either the spouses or adult children, but also siblings and cousins are included. If the PwD has no family, friends, or someone else that supports and helps them, they will encounter more difficulties, and in theory remain less long at home (Gräßel & Adabbo, 2011); and Mahoney LaRose & Mahoney, 2015) It is then often suggested to have a mentor. Moreover, in definition, the ICT is a private person who looks after a person with impairment on a regular basis without having worked or trained in the field of caregiving before (Gräßel & Adabbo, 2011, p.143). The relationship between the carer and the person suffering from memory loss is based upon trust and growing dependency. As the PwD will become less independent as the disease progresses, ICTs have to give more support and thus have a crucial role within their care. Moreover, a care relationship in the case of dementia is difficult as it demands a considerable amount of physical and emotional attention. To be able to create a favourable environment for persons living with ESD, it is demanded for an environment of assistance for caregivers, so that their responsibility and burden may be reduced.

2.2.4. Care Burden

Caregiver burden is understood as the stress perceived by caregivers within home care environments. Beinart, Weinman, Wade & Brady (2012) define it as a multiplex construct, including financial, psychological or emotional, and social consequences that can be experienced by family members when caring for people with illness. This subjective burden of the carer is crucial when estimating the likelihood of institutionalisation of the person requiring care, but especially with regard to the health of the caregiver. In fact, caring is associated with poor quality of life and deteriorating health outcomes for many carers, especially in extremely demanding cases and long-term care (Beinart et al, 2012). Due to an increased demand on physical and emotional support, dementia carers have exceptional morbidity and mortality rates, whereas 60% report high stress levels and 33% indicate depressive symptoms (Mahoney et al., 2015).. Especially, in the first days or weeks after the diagnosis, the impact of care burden is tangible, family caretakers show heightened rates of depressive symptoms (Terayama et al., 2012).

Demographic and psychosocial attributes are contributing factors to caregiver burden. For instance, higher care burden can be predicted if the carer is of older age and comes from a lower Socio-Economic background. Differences between male and female caretakers can be found in susceptibility to physical illnesses and higher risks for psychological symptoms, such as depression (Beinart et al., 2012). Thus, it is pivotal to understand the relationship between the PwD and their ICT (dyad). Depending on who is taking care of the person with dementia, different problems may occur. D.F. Mahoney, La Rose & E.L. Mahoney (2015) have identified a major difference between partner and adult children caregivers, such as being comfortable with nudity and its connoted intimacy. While for a partner it is normal to wash and dress their significant other, it may be a very difficult and unpleasant task for adult children. As mentioned above, differing risks of caretaking burden have been presented along the lines of gender differences, showing an unproportionate division of caring labour, keeping in mind that providing care still is mostly seen as a female stereotype (Terayama et al., 2012).

Mahoney, La Rose and Mahoney (2015) investigated the role of the carer at different stages of the disease. They looked at accompanying themes and issues, indicating the stage where the deteriorating health of the carer becomes more important as it can negatively impact the dementia progression and care conditions, called the precipice. Since our research focuses on ESD, not all levels have to be discussed in detail, however, attention has to be placed to the reasons why caregivers are overburdened. If this is ignored, the care situation will be affected negatively.. While the authors have focused on the circumstances of the different stages, we mostly looked at the roles they have subscribed to the caregivers.

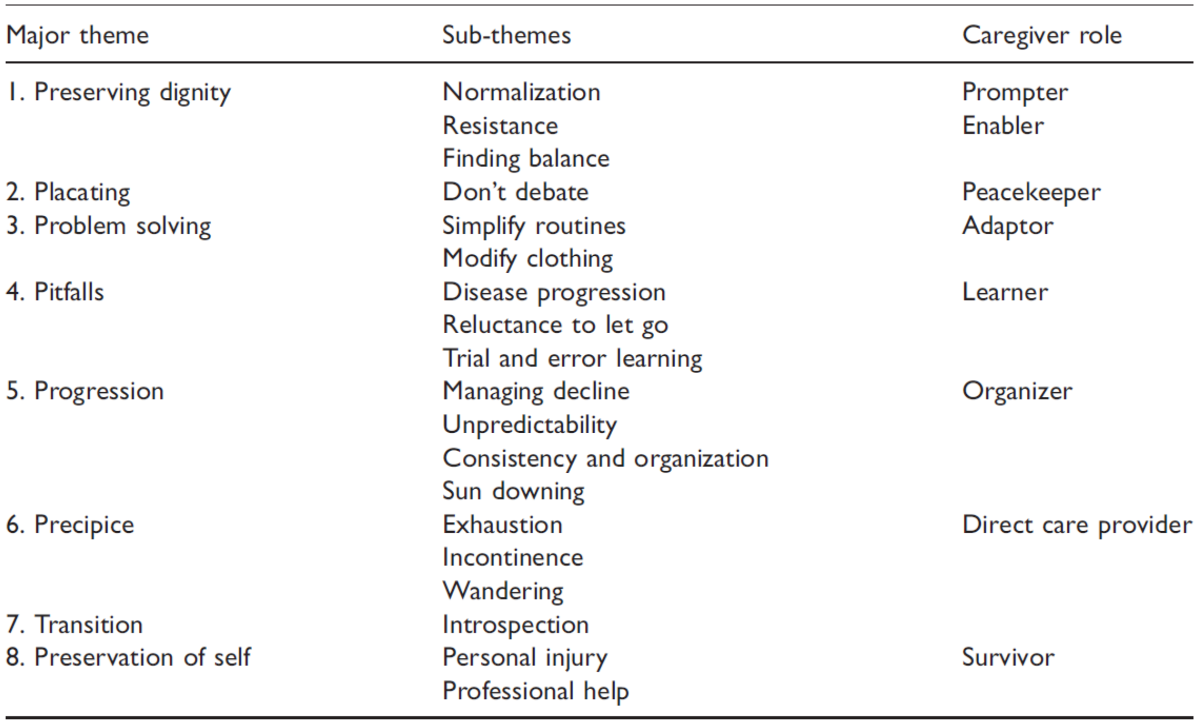
In the first stage, the caretaker is regarded as the *promoter* and *enabler* of care, meaning that they engage in strategies aiming to establish a balance between the normalisation and resistance of the new status of the sick person. The aim is to preserve the PwDs dignity by attempting to maintain usual patterns of life. Accordingly, carer and PwD have to structure daily activities conscious of memory-related problems. Nevertheless, as the disease progresses, the PwD will become less able to do activities of daily living which can result in frustration and agony between the Pwd and the caretaker. At this stage, named *Placating,* the carer should take the role of a peacekeeper to ease the struggles and irritability of the person suffering from dementia by being understanding and not debating the ESD circumstances perceived by the PwD.

After conciliation, a stage of problem solving follows. Here, the caretaker turns into the *facilitator* of new conditions and circumstances by simplifying routines and modifying clothing, redesigning the interior, and further. The carer turns into a learner in a trial and error learning process, as strategies that worked once at an early stage may not be suitable and effective anymore at later stages. For the caregiver and PwD alike, this may have enormous emotional implications and may cause reluctance, or difficulties in communication

Having accepted that a person suffering memory loss has changed, progression is possible and the carer takes the role of the *organizer.* After passing the pitfall stage, it is imperative to manage the cognitive decline and establish a consistent and optimised structure to be aware and alerted of indicators signal the next level of disease. Nevertheless, flexibility or working with what works for the sick person, as well as acceptance of unexpected behaviour is necessary.

The next stage is the most crucial one and shall be delayed as long as possible, the *precipice*, the moment when a family caregiver's health deteriorates to the extent that caring turns into self-harm. At this stage, a caretaker has to devote most of his/her time to the PwD and is considered the direct care provider. This marks the need for caretakers to consider and preserve their own health, and possibly seek support in order to still be able to care for the PwD. In the last two stages, the carer becomes a survivor and works towards the preservation of their health and dignity. The *transition* stage marks the self-reflection of the caregiver in the situation, which seamlessly merges with the final stage, the *preservation of the self.*

While the model of preservation of self by D.F. Mahoney, La Rose and E.L. Mahoney represents a rather linear development of the caretaking up to the moment of institutionalisation, reality looks less categorised and especially the stages, problem solving, pitfalls and progression may be repeated before the carer arrives at the precipice.



Major theme	Sub-themes	Caregiver role
1. Preserving dignity	Normalization Resistance Finding balance	Prompter Enabler
2. Placating	Don't debate	Peacekeeper
3. Problem solving	Simplify routines Modify clothing	Adaptor
4. Pitfalls	Disease progression Reluctance to let go Trial and error learning	Learner
5. Progression	Managing decline Unpredictability Consistency and organization Sun downing	Organizer
6. Precipice	Exhaustion Incontinence Wandering	Direct care provider
7. Transition	Introspection	
8. Preservation of self	Personal injury Professional help	Survivor

Figure 1 summary of themes and link to caregiver's role (D.F. Mahoney, La Rose and E.L. Mahoney, 2015)

Accordingly, one can see how the role and situation of the caregiver should not be neglected and is crucial for a positive care outcomes. If the caregiver is too overburdened at early stages, the likelihood of institutionalisation of the PwD becomes higher. This is also associated with reduced quality of life. Therefore, it is necessary to create sufficient support structures for the caretaker and to acquire external support.

2.3. Chapter Three: Living Environment

The living environment of any person is important for their development, social networking, access to services, and mobility in general. Within the case of PwD, their living environment should be observed and analysed to detect constraints and opportunities to self-reliance. The living environment can be divided into the micro and macro level. The micro level is concerned with the home environment, while the macro level is concerned with the neighbourhood and/or town. While the structuring of the home environment is rather subjective and individualised, the neighbourhood has to be considered from an objective perspective to find ways to enhance self-reliance.

2.3.1. Micro level Living Environment

The home environment of persons with dementia is a determining factor for their self-reliance. A 'perfect' home environment is difficult to develop, because every PwD has its own unique needs and preferences. However, it was possible to detect some recurring needs for the home environment, and distinguish a set of aspects that can improve the home environment.

Based on research, it became clear that assistive technology (AT) is rapidly developing and can have a great contribution to the living environment of PwD (Sriram, Jenkinson, &

Peters, 2019, p.1). Assistive technology can be defined as ‘any advanced electronic equipment, which can be used to enhance support and care, act as a prompt for intervention by carers, monitor welfare and assist in communication and leisure activities for a person with dementia’ (Sriram, Jenkinson, & Peters, 2019, p.3). Not only does assistive technology increase self-reliance, it also alleviates the burden on caretakers. Moreover, keeping in mind the increasing number of PwD, assistive technology will in the future have an even greater role, because there will not be enough financial resources and caretakers for every PwD. Therefore, AT can take over some roles that are now mainly done by caretakers. This will save both time and money, making it an essential aspect of the home environment.

There are many different types of assistive technology, used for different ends. Based on the literature, it is possible to distinguish a set of different types and uses of AT. Different types of AT can be standalone (e.g. tablet computers) or be part of an integrated system (e.g. sensor trackers or GPS), and can be stationary or mobile (Sriram, Jenkinson, & Peters, 2019, p.3). Most of the AT is used for support in the field of memory aids, safety and security, prevention of social isolation, basic activities and daily life.

Generally, assistive technology is perceived as improving self-reliance, benefiting both the PWD and the caretaker. However, as mentioned before, most PwD have unique needs, which makes it difficult to create a “one-size-fits-all” device. Another problem regarding AT is that most devices are not easily integrated into the daily routine, and that they cannot be disguised as everyday objects. Concluding, AT might be a sustainable solution for the growing number of PwD, but first the devices have to be accepted by the PwDs themselves to be effective in real life.

2.3.2. Macro Level Living Environment

Whereas the micro level is concerned with the home environment, the macro level is concerned with the outside living environment, and is also a crucial aspect of self-reliance. The possibility to access and use the outside environment is necessary to perform ADL. There is a set of design principles for the outdoor environment that are relevant for PwD. These principles require the design of the outdoor environment to be familiar, legible, distinctive, accessible, comfortable, and safe (Mitchell & Butron, 2010).

A familiar environment can alleviate and prevent spatial disorientation, confusion, and impaired memory problems. Thus, PwD are better able to understand and feel comfortable in public spaces that have a recognizable appearance with familiar street furniture styles, facades, paving and street art (Mitchell, 2003).

Legibility of the environment ensures that PwD can understand where they are, and which direction they have to go. This, again, can prevent and alleviate spatial disorientation, confusion and anxiety. For most PwD it is difficult to seek help or follow directions. Therefore, it helps when the outside environment consists of small and heterogeneous streets with connected routes that have clear visual access (Judd et al., 1998).

A neighborhood that has various distinctive parts increases the attention and concentration of PwD, which aids their orientation and wayfinding skills. So, outside areas that provide wayfinding signs, such as visually distinctive landmarks, increase the functional ability and reduce confusion, disorientation and agitation (Mitchell & Butron, 2010).

Moreover, it is important that the outside environment is accessible. Accessibility ensures that PwD, regardless of their cognitive and physical impairment, are able to reach and move around the places they desire to go to. It is most preferably, if possible, that PwD live on a walking distance away from services and facilities, which is most feasible in urban areas (Mitchell & Butron, 2010). When dementia facilities are nearby, it encourages PwD to continue their activities within the local community. Further, level changes should be avoided, because PwD often have a reduced sense of balance (Brawley, 2001).

The principle of comfort ensures that PwD feel at ease and have the ability to go and enjoy places without feeling physically or psychologically uncomfortable. In the outdoor environment, heavy traffic and noisy areas are likely to result in discomfort for PwD because it negatively affects their feeling of safety and wayfinding. Ideally, spaces, such as parks or public squares should be provided. These enable people to retreat or avoid areas with heavy traffic and big crowds. Regular seating areas are also effective, because it allows PwD to shelter from extreme weather (Mitchell, 2003).

Lastly, the environment should be safe. This enables PwD to freely move around their neighborhood without having to fear coming to harm. PwD often suffer from decreased hearing and vision. Regarding the diminished visual acuity, it is important in the outdoor environment that unsheltered areas in direct sunlight and dark shadowy places should be avoided. For example, a transition between a bright street and a dark entrance can be very difficult for PwD. Furthermore, the decreased ability to hear can be very dangerous for PwD because they might have trouble hearing audible warnings such as ambulance sirens. Consequently, it also takes longer for PwD to register and react to such signals. Noise-attenuation measures, as well as the pitch and timing of audible cues, such as at pedestrian crossings, could therefore contribute to a more dementia-friendly environment (Mitchell, 2003).

So, there are many options which can make the outside environment more dementia-friendly. It is important that PwD have the ability to identify and understand where they are, and at the same time, feel safe and comfortable to access their neighbourhood.

3. Field Research

3.1. Methodology

Having familiarized ourselves with already existing literature on dementia, we also conducted our own field research. This was necessary in order to gain a better view on the situation at stake and particularly with regard to the Northern Netherlands. Moreover, our field research was based on the spheres of the research question stated above. It was executed via a questionnaire and multiple interviews. The set up, outcomes and conclusions will be discussed in the sections below.

3.2. Stakeholders

When it comes to field research, it was necessary to attach a specific focus on the lived experience of PwD, and those surrounding them. This is necessary as existing research often neglects their perspective, leading to diminished care outcomes. In order to gather a well-rounded perspective on the problem of self-reliance in PwD, we employed a mixed-method consisting of both quantitative and qualitative data to acquire a more patient-centered view on the situation. To achieve this, we identified several stakeholders as crucial to understanding and improving the care situation.

1. The first stakeholder is the *person with dementia (PwD) who lives at home,* and more favorably is being diagnosed with Early Stage Dementia (ESD). It is crucial to include this category and to investigate their perspective on the situation to ensure their needs are fulfilled and their capabilities strengthened.
2. The second stakeholder, the Informal caretaker, dyad, care partner or *mantelzorger* (in Dutch); is a crucial figure to include. As dementia progresses, people become more reliant on support from family members, and/ or care home agencies. With regard to this category, it is important to foreground that caretaker refers to *ICT*, a person with no prior experience or connection to the care system. As this group is working closely with the PwD, it is necessary to investigate their roles and needs to ensure a positive care situation.
3. The third stakeholder group are the *health and care professionals.* In contrast to the latter, this group is currently employed by a public or private health organisation providing care or support. Since this group of stakeholders is rather broad, it can include General Practitioners, Nurses, Psychologists, Physiotherapists and other people working within Dementia.
4. Another group crucial for gaining better insights are people with current or recent experiences of undertaking dementia related research or involving aspects related to dementia.
5. The last group consists of policymakers and other people with a role in shaping national, regional, or local dementia policies, including those who plan services.

3.3. Materials and Instruments

By using quantitative methods, via self-assessment questionnaires and rating scales, it is possible to learn which factors are most important for PwDs, and which are seen to be more problematic. Questionnaires are also useful in evaluating the standpoints and opinions of other stakeholders playing an important role in the care for PwD, to achieve a multidimensional perspective on the situation. Furthermore, qualitative research, via interviews and observations, was employed to acquire in-depth insights into the lives of people living with ESD, also from their caretakers, and other stakeholders. With respect to this, the research especially aimed to conceptualise what self-reliance in the context of dementia constitutes, and how it can be strengthened. It also aimed to enquire about the living environment of PwD and their caretakers, as well as the neighbourhood surrounding it. Moreover, interviews with health professionals and experts in the field were also necessary to make generalisable claims and to learn about new developments in the field.

3.4. Participants Questionnaire

The recruitment of participants for the questionnaire was done through Facebook Groups of Caretakers and people working with dementia, the “let’s Gro” event by the organisation Mensen met Dementie Groningen, and through other stakeholders. The questionnaire was completed by 37 people who belonged to a diverse group of stakeholders, with the majority being family members (10 people) and family caretakers (6), health professionals such as formal caretakers (Dutch: verzorgende, 5), nurses (3), physiotherapists (3), assistance providers (Dutch: helpende, 2), and volunteers (3). A brief overview of the different relationships with PwD can be found in graph 1.1. Lastly, 4 participants identified as ‘Other’. Most of the respondents come into contact with either early stage PwD or middle stage PwD, as can be seen in graph 1.2. The questionnaire itself consisted of 12 closed/rating questions, 7 optional open questions where participants could elaborate on their choice and one open question asking about the most important factors necessary to improve self-reliance in someone with ESD.

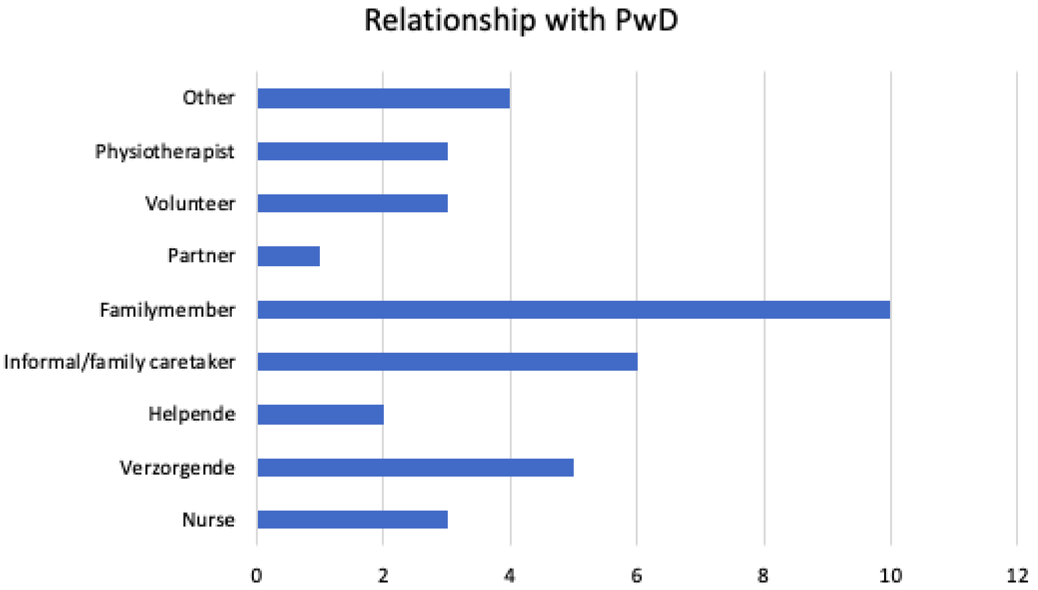


Figure 2.1 *Relationship of respondents with PwD*

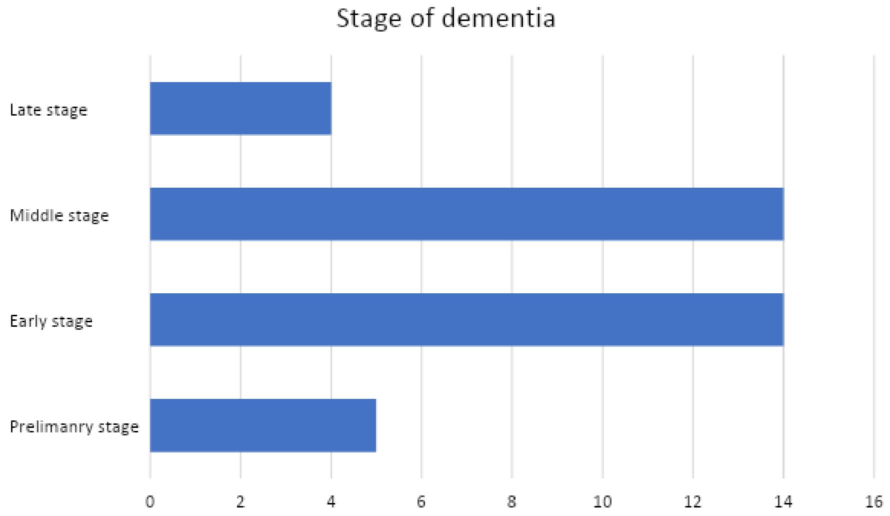


Figure 2.2 *Stage of dementia respondents come into contact with most often*

3.5. Participants Interviews

For the Interviews, 13 people were recruited. These 13 people were divided into two groups, depending on the perspective they would take on the problem: worm's eye view (bottom up) vis-à-vis a bird's-eye perspective (top-down). Accordingly, the first category (Group 1) consists of one elderly healthy person, to differentiate between basic needs associated with ageing and those with memory problems. The PwD were represented by two people with ESD. As a PwD is very much dependent on their caretaker and the caretaker's life is highly affected by the condition as well, the ICT was also included within this category. The second category (Group 2) represents a diverse field of experts, consisting of healthcare professionals as well as experts working within a dementia-related field. While the health care professionals were primarily recruited through care organisations, the experts within the field have a background in diverse fields such as biomedical sciences, spatial sciences, psychology and dementia organisations. Nevertheless, one limitation is considered to be that no policymaker could be recruited, leading to a diminished perspective within this field.

3.6. Procedure

The aim of the interviews, and open questions within the questionnaire, was to identify a list of factors crucial for enhancing the self-reliance of a PwD. With this aim in mind, the interview questions were designed to expand on the data identified in the desk research. Although the interview guide was specific for every group, there were general themes discussed throughout the interviews. These themes were used as a guide within the interview so that results could be generalized afterwards. Recurring questions evolved around general questions associated with dementia and care, the living environment, divided into micro (home environment) and macro (the neighborhood/town), mobility, social aspects, awareness and support, and finally self-reliance. At the end of each interview, participants were asked to rank (on a scale from one to ten) the importance of the home environment, the neighborhood, mobility, and awareness of support on the aspect of self-reliance. This was necessary in order to have a common frame of reference in all interviews.

3.7. Data analysis

A thematic analysis was applied to the interview questions, and the open questions situated in the questionnaire. This analysis was divided into several stages, similar to the methodology applied by Harding et al. (2019). Since both research designs aim to include a variety of stakeholders and aim to identify the most important aspects for people living with dementia, the methodology was deemed applicable to this research, although it was changed slightly. Accordingly, the phases were divided as follows:

1. *Familiarisation with data:* the data and Interviews were read several times
2. *Creation of a set of initial codes*: Interviews were screened for themes which a priori have been defined as important for people living with dementia. These codes included: Social Aspects, Care Services, Home Environment, Living Environment, Mobility, Medical-related needs, and random information.
3. *Themes:* Within the next phase, the information contained within the identified codes were screened for recurring themes.
4. *Review:* The prior themes identified in stage two, were reviewed, adapted and merged into groups.
5. *Finalizing:* Themes and groups were completed, groups renamed, defined and finalized.
6. *Framework:* A framework of items identified as important for people living with dementia resulting from the interviews, and the open part of the questionnaire was developed .

4. Results Questionnaire

4.1 Questionnaire

We were able to identify 7 themes from the analysis of the questionnaire. These themes were grouped into: ESD, Self-Reliance and Living Environment. This division corresponds to the research question and the literature review above.

4.1.1. Early Stage Dementia

With regard to ESD, two themes were identified: ‘Awareness’ and ‘Coping with dementia’. Awareness is seen as beneficial for the self-reliance of people with ESD. According to respondents, people need to be aware of dementia, what it entails, how to recognize it and how to approach PwD. This is important not only for the close relations, but also for the broader community.

‘Coping with dementia’ is another theme that came forward from the questionnaire. People with dementia are often in denial or unaware of the fact that something is wrong with them. They show behaviours like confusion, sadness, insecurity, anxiety, restlessness, forgetfulness, disorganization, frustration, and loneliness. These behaviours can hold people back in accepting their disease. It is important to be open and to communicate with the PwD. Moreover, the person with dementia should be involved in the decision making process, instead of further reducing his responsibilities.

4.1.2. Self-Reliance

In relation to the theme of self-reliance, two important themes came forward from the analysis. The first being 'Social network' and the second being 'Activities of Daily Living (ADL)'. The type of Social Network is dependent upon the person themselves and the environment they come from. Even so, close family and friends are considered very important for the self-reliance of PwD, though dependency might vary. Community around the person with dementia could play an important role in enhancing self-reliance, however in most cases there is a lack of support from the community which can be related to stigma. Additionally, daycare can provide more social connections for someone with a smaller social network.

The second theme relating to self-reliance is 'Activities of Daily Living (ADL)'. Being able to perform ADL is important for retaining one's self-reliance. People with dementia have problems performing ADL, such as cooking, cleaning and doing groceries. Another part of ADL that is difficult for PwD to do is maintaining their personal hygiene. Some respondents state there is enough support in doing ADL, others say there should be more support. This is also very dependent on the personal needs and preferences of the person with dementia.

4.1.3. Living Environment

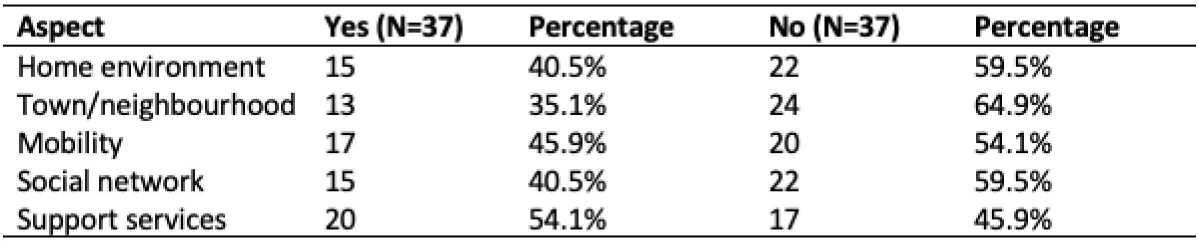
Two themes came forward from the responses on the questionnaire with regards to Living Environment: 'Mobility' and 'Services'. Within mobility, mode of transportation was mentioned most often and respondents mentioned taxi services as most adequate as public transportation was perceived as too difficult and complex for PwD. Nevertheless, a possible solution mentioned by many was having a travel buddy to accompany the person. Another aspect relating to mobility mentioned by respondents was concerned with physical (body) mobility, and particularly with staying active in and around the house to remain mobile and to prevent falling.

The second theme relating to the living environment is 'Services', which divides into 'Available services' and 'Acquiring services'. In general, respondents indicated that services related to activities of daily living such as home care, meal services and cleaning services, are widely available and generally well provided for PwD. Nevertheless, having a case manager, or someone who knows how to find care services, is perceived as positive since it can reduce the burden of finding care for the PwD and the caretaker according to one informal caretaker. Similarly, daycare is also perceived as a service that provides a positive influence on the person with dementia.

With regards to 'Acquiring services', respondents noted that many services are available for PwD and their caretakers. However, it is difficult to find information on specific services and their suitability. Once it is clear which services are useful for the PwD, it remains difficult and timely to apply for these services. Moreover, administrative duties which require assistance and time, and a lengthy bureaucratic process further complicate the situation.

4.1.4. Ratings of Self-Reliance Domains

In order to gain a better understanding of what is important for PwD and their caretakers, both the respondents of the questionnaire and the interviewees, answered rating scale questions. These questions relate to five different aspects of self-reliance we identified à priori based on the literature review: home environment, town/neighbourhood, mobility, social network and support services. The respondents rated these aspects on how important they are for the self-reliance of someone with ESD, on a scale of one to ten, one being 'not important' and ten being 'very important'. The respondents to the questionnaire also answered a question whether or not PwD receive enough support on the five aspects related to self-reliance.



Aspect	Yes (N=37)	Percentage	No (N=37)	Percentage
Home environment	15	40.5%	22	59.5%
Town/neighbourhood	13	35.1%	24	64.9%
Mobility	17	45.9%	20	54.1%
Social network	15	40.5%	22	59.5%
Support services	20	54.1%	17	45.9%

Table 1 *Ratings of self-reliance domains*

For the first four aspects (home environment, neighborhood, mobility, social network) the majority of respondents reported not enough support was given to PwD, the main outlier being 'town/neighbourhood' for which 64,9% of respondents report there is not enough support. Conversely, in the dimension of support services, a majority of respondents reported there is enough support for PwD available according to their perception.

The mean ratings of the different aspects are the combined ratings of both the questionnaires and the interviews, since the exact same questions were asked in both settings. In Figure 3 can be found a clear overview of what is most and least important for the self-reliance of PwD, according to professionals, volunteers and family members or caretakers.

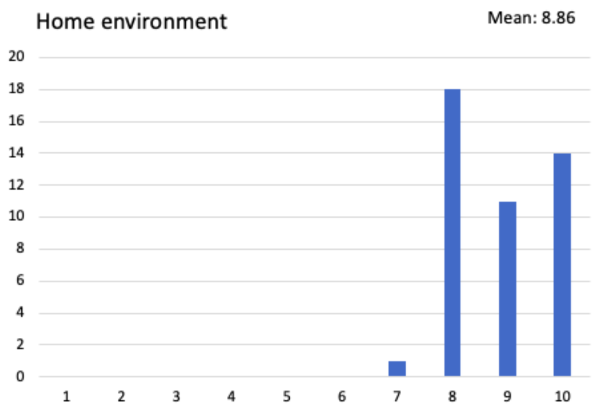


Figure 3.1 *Frequencies importance rating 'Home environment'*

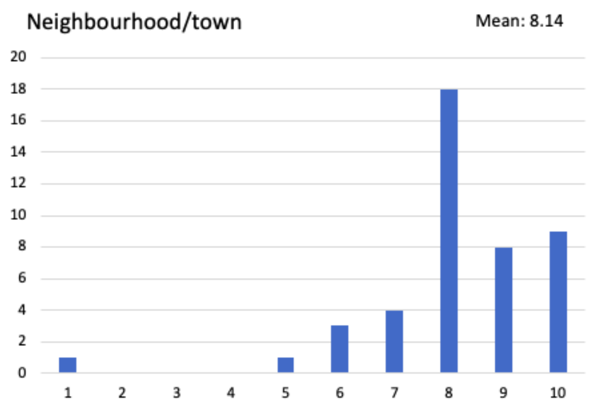


Figure 3.2 *Frequencies importance rating 'Neighbourhood/town'*

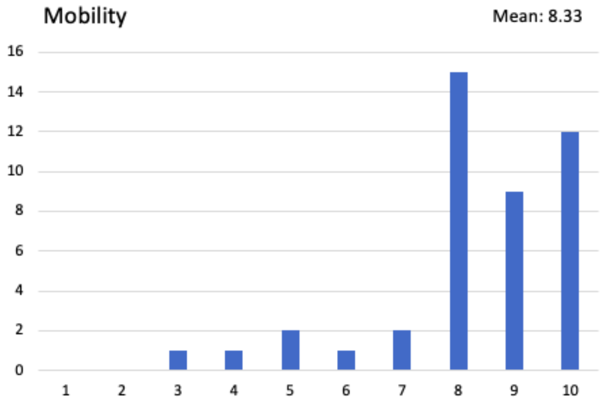


Figure 3.3 *Frequencies importance rating 'Mobility'*

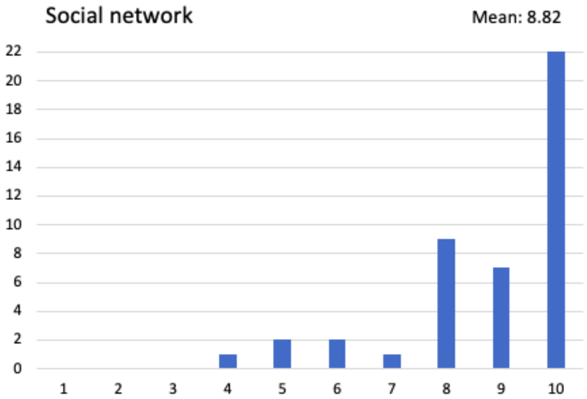


Figure 3.4 *Frequencies importance rating 'Social network'*

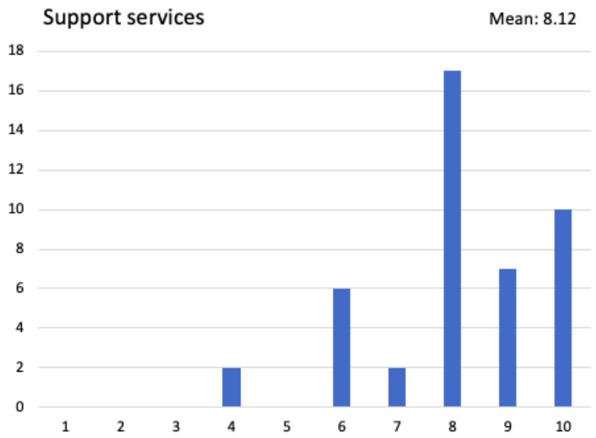


Figure 3.5 *Frequencies importance rating 'Support services'*

Looking at the spread of the rating, two aspects immediately stand out. The only domain of self-reliance that consistently ranked high is 'Home environment', with only one rating of 7 and the rest being 8 or higher. The domain 'Social Network' receives a few more lower ratings, however half of the respondents rated the social network with a 10. The domain 'Home environment' received a mean rating of 8.86 out of 10, with not many striking differences in the distribution of the ratings.

The domain ‘Neighbourhood/town’ received a mean rating of 8.14 out of 10. There are two outliers when looking at the distribution of these ratings. There is one respondent who rated ‘Neighbourhood/town’ with a 1, however this person did not provide an explanation as to why they gave this rating. There is also one respondent who rated ‘Neighbourhood/town’ with a 5, but they also did not provide a reason as to why.

Next, the domain ‘Mobility’ which received a mean rating of 8.33 out of 10. There are a few more outliers in the rating of this domain. There is one respondent who rated ‘Mobility’ with a 3. This person stated there is enough support when it comes to mobility, since there is a taxi service that is (partially) paid for by the government. There is one respondent who rated ‘Mobility’ with a 4. This person did not provide us with a reason as to why. There are two respondents who rated ‘Mobility’ with a 5. One person stated there should be more knowledge about this subject, but they did not go into more detail. The other person stated that it is difficult to determine whether a person with dementia is still able to participate in traffic. This is a valid point and a good reason why mobility may not be as important as other domains when it comes to self-reliance for the person with dementia. There is one respondent who rated ‘Mobility’ with a 6. This person stated that the partner will take over any problems with transportation, however it is important to keep in mind that not everybody with ESD has a partner to assist them in these matters.

Furthermore, the domain ‘Social network’ received a mean rating of 8.82 out of 10. One respondent rated ‘Social network’ with a 4. This person stated that PwD turn more inward and want/ask for less social connection the way they used to. There are two respondents who rated ‘Social network’ with a 5. One person did not provide us with a reason as to why. The other person stated that they are in a special situation in which the client chooses to not engage in contacts with others.

Finally, the domain ‘Support services’ received a mean rating of 8.12 out of 10, making it the lowest rating domain in the interviews and questionnaire. Two respondents rated ‘Support services’ with a 4. One person explained that support services are not necessary in Early Stages, unless the person with dementia is living alone. Another respondent remarked that services should not follow a one-size-fits-all approach as people are being treated as commodities.

4.2. Conclusion

From the questions, we were able to identify seven themes: Awareness, Coping with Dementia, Social Network, Activities of Daily Living (ADL), Mobility, and finally Services, which divides into Available Services and Acquiring Services. In general, we received valuable insights from the diverse group of participants (37). It was generally remarked that stigma and acceptance play a great part within the care for dementia. Moreover, to retain self-reliance ADL and Mobility were deemed as crucial. Moreover, while services are generally available, it is difficult for the PwD and their caretaker to navigate through the system. Finally it should be foregrounded that there is no one-size-fits-all solution when it comes to dementia care and that a more personalized approach is necessary.

5. Results Interviews

5.1 Early Stage Dementia

Similar to the questionnaire, two themes relating to the category of general information and ESD were identified: Cognition and Illness Perception. Whereas all medical aspects and cognitive tasks were clustered within the category of Cognition, aspects relating to how an illness is being perceived by the PwD, their surrounding network, and within society, were clustered within Illness Perception.

5.1.1. Cognition

Cognition was an overarching theme discussed within the interviews. From the perspective of the health professionals, the decline of the brain functioning is something normal in terms of ageing. However, one expert in the field of biomedical sciences explained that cognitive decline within dementia is not just associated with memory loss, but also includes language issues, behavioural changes and difficulties with decision-making. The memory problems could be ranging from forgetting names and losing objects to other important aspects of daily living. The aspects related to cognitive decline are associated with memory retrieval problems, but also cognitive aspects relating to social health such as mood disorders and social withdrawal. Moreover, because the circadian system (biological clock) is affected, PwD often face disrupted day-night rhythms, leading to disturbance during the day time and restlessness at night.

Another aspect mentioned frequently was the necessity to include PwD into decision-making processes to keep them involved and aware of future life choices. For instance, needing more care or not being able to drive anymore were mentioned as relevant subjects. One PwD remarked that he was first unable to accept that he was not allowed to drive the car anymore as it was a substantial part of his life, but his family agreed to help him. A further aspect mentioned by both experts and the ICT was the importance of an active lifestyle for cognitive functioning, but also as a meaningful activity. For instance, the ICT explained how his father had been exercising his whole life and concluded it was good for his father. Similarly, the expert on biomedical sciences mentioned the importance of exercise for a healthy lifestyle multiple times, due to the link between cognition and motor functioning. While there are many exercise related interventions, the relevant question when it comes to PwD is how to keep them motivated to participate. This indicates a disconnection between the behavior-intention link, meaning a person is not always motivated to do activities or recognizes their utility in improving mood, cognitive abilities and social networks. To counteract, the biomedical scientist is working on a solution to bypass the motivational problem by using the utility of whole body vibration to stimulate the brain, through a passive way of doing exercise.

5.1.2. Illness Perception

As stated above, the theme illness perception was also identified. From the perspective of health professionals and experts, Illness Perception was estimated to be hindering. A relevant topic falling within this theme was stigma. One expert noted how the difference between illnesses of the mind and illnesses of the body still leads to complications when it comes to services and understanding of people within society. The stigma attached to dementia is limiting as it contributes to the way a disease is being perceived. For instance, it was noted by one professional from an organisation for a more dementia friendly society that "You have an illness, but the illness is not who you are". Being characterized as demented often demarcates the PwD as someone essentially different from the rest of society, leading to decreased social connections. Some remarked they were unsure how to behave around someone with a condition such as dementia. This can have negative effects on the overall well-being of the person and can lead to the risk of isolation and depression. Stigma and illness perception have also been identified as risk factors when investigating preventive measures or aiming to defer the onset of the disease. Because PwD do not want to be treated differently, they might conceal their illness or are in denial about their symptoms. An expert in the biomedical field has noted that this is problematic from a prevention perspective as dementia within people with mild cognitive impairment can still be deferred and targeted efficiently. However, these people are difficult to locate and thus intervention strategies can often not be applied.

Furthermore, stigma was also a relevant theme within Group 1. For example, a PwD indicated that he did not have dementia. His reasoning was that he encountered memory and learning problems all his life and that this is normal for him. The caretaker however stated that he was just in denial about his condition. In fact, being in denial about an illness makes it difficult for the PwD to communicate his/her needs and thus also complicates the situation for the caretaker. In contrast, the healthy elderly person noted that she accepted ageing and that she was unable to do everything by herself. This acceptance helps her to efficiently communicate her needs and to have a more "realistic" perspective on life.

Finally, one caregiver mentioned a great difference within the mood of the PwD at home, vis-à-vis at day-care activities. This is due to the fact that PwD often pretend to be better than they actually are. If we were to reduce the stigma around mental health diseases and especially dementia, it would positively impact prevention and symptom management as PwD can communicate their needs more effectively.

5.2. Self-Reliance

In contrast to the questionnaire, only one theme was identified in relation to self-reliance within the interviews. Nevertheless, it should be emphasized that many other aspects relating to self-reliance were also mentioned. However, these were instead grouped within chapter 3: Living Environment. Accordingly, one can suggest the close connection of both domains. The theme which came forward in the interviews was social aspects. In relation to this, any aspect relating to the social health of the PwD and or other professionals working within dementia care were clustered within this category.

5.2.1. Social Aspects

When looking at the interviews from the health professionals and experts, it was recognized that PwD, and elderly people in general, have a smaller social network due to the fact that friends often move away or are deceased. This is problematic as it decreases the daily interactions the PwD have in their daily life. In line with this, several experts noted that social engagement is crucial for the overall health of a person. This is specifically important in the case of dementia, as a lack of social engagement leads to earlier memory decline in isolated PwD.

When examining the responses from Group 1, social health was a recurring theme and deemed as very important. For example, one of the PwDs noted that he was wishing his family would be visiting him more often and that he was grateful for having a caretaker from a care organisation. Both PwDs recruited through a carefarm noted that they enjoyed being there, since they would meet other people and felt like the activity would give them a purpose. In fact, the same was noted from the healthy elderly person interviewed, indicating a general relevance for social health within the elderly. Another aspect mentioned by participants in this group was social dependency. Whether PwD had to be driven in order to do their activities (e.g. going to church or to a birthday), or needed assistance from others, it was crucial to have someone that was able to support them. Accordingly, it can be suggested that the size of the social networks has an impact on how active a PwD would be. Another point mentioned by the family caretaker was the problem of care burden. Due to reduced social networks of the PwD, the ICT has less space and time to meet other people and realize his/her own needs. This is heightened by the fact that not enough care or supportive staff is available, limiting the personal space of the ICT.

Similarly, in the second group, an expert within the biomedical field remarked that cognition within a PwD is often understood as memory functioning. However, having conversations with others is an ideal way to engage the brain and strengthen cognition as social interactions activate many areas within the brain. This has been supported by another researcher who maintains that the use of language and bilingualism can have a very positive impact on dementia symptoms. On another note, three experts explained how isolation is a big risk factor in dementia and can worsen the progression. Therefore, the inclusion of PwD in social settings is crucial.

Moreover, it was also mentioned that dementia does not only affect cognitive abilities, but can also lead to personality changes. With regard to this, people who might have initially been social could be more kept for themselves at certain stages, whereas other people might feel more social. Accordingly, there is not a “one-size-fits-all” approach when it comes to the social health of a PwD. Moreover, similar to Group 1, it has also been noted that a bigger social network was crucial for the dyad of the PwD to offer the caretaker some respite.

5.3. Living Environment

Within the domain of living environment, three overarching themes were identified. First, the theme of ‘Needs and Services’ composed of all statements that relate to the needs of a PwD or his/her caretaker and services which can assist with these needs. Therefore, this theme was subdivided into the aspects of Home Environment and Mobility to differentiate between the nature of the need. Another theme identified was Assistive Technology, relating to all technological services which can assist the PwD and his/her caretakers within the living environment. The last theme identified was Health Landscape which relates to the surrounding legal and political structure.

5.3.1. Needs and Services - Home Environment

Within the interviews conducted with experts of Group 2, it was mentioned that PwD experience different problems within the home and living environment. Moreover, it showed that PwD have a diverse set of needs. Moreover, many of these needs are fully or partially covered by the services available.

The home environment can also be referred to as the micro level or material living environment. The problems experienced in the home environment were mainly with cooking, cleaning the house and personal hygiene. This is due to the complexity of the task as these involve many different steps. Moreover, a PwD might also sometimes forget whether they have eaten or not, which may result in weight loss. Besides, cooking may also result in safety concerns, as PwD may forget to turn off the oven or stove. Furthermore, PwD experience the same kind of problems with cleaning the house and personal hygiene, as both of these activities also require various steps which are hard to remember. Generally, it was indicated that the services for these problems within the home environment were most accessible. Especially meal services are widely available and not difficult to apply for.

The neighbourhood can also be referred to as the macro-level of the material living environment. PwD often forget the routes they have to walk which results in the problem of wandering. Also, most of the activities that are done in the neighbourhood such as grocery shopping or getting money from the bank are highly complex for PwD. They might, for example, forget what to buy or accidently steal products in the supermarket. Especially in city environments, the problems are more frequent, because cities are bigger and more often restructured which is troublesome for the orientation of PwD. They orient themselves around their memory, so that changes in cities might result in confusion and anxiety. Moreover, people in rural areas are more familiar with each other which means that PwD in rural areas can rely more on others if problems occur. Nevertheless, planning issues can be overcome by making grocery lists or practicing walking routes. With regard to this, one expert remarked that practicing walking routes with a neighbour also has a social component, which is beneficial for the PwD. In the case of wandering, it was mentioned that assistive technology in the form of GPS tracking systems can be very helpful. However, the use of a GPS can also be considered to be an intrusion of someone’s privacy. Moreover, it was mentioned that for the problem of wandering more practical and pragmatic solutions such as clear walking routes are needed. Lastly, it seems as more safety concerns arise at the macro level as it requires the input from other people. This is especially relevant in cities due to their dynamic nature, but also in rural areas with more isolated individuals.

5.3.2. Needs and Services - Mobility

The last set of problems related to the needs of PwD that were mentioned by health professionals and experts, were related to the aspect of mobility. Mobility is very important, as it relates to social engagement. When the mobility is increased, PwD are able to participate in social events which has positive effects on their social brain and cognitive functions. Moreover, increased mobility tackles the problem of physical inactivity, as some remain at home due to lack of mobility or transportation.

It was mentioned that the use of public transportation is often too complicated for PwD, because they often find it difficult to remember how to get to the bus stop or train station in the first place, and they also have trouble memorizing when to get off. The dementia campaign by the NS which teaches people how to recognize PwD in trains was perceived as positive, and initiatives such as these were greatly supported. Further, it was mentioned that when PwD are not able to use public transportation or drive themselves, they become very dependent on their family members or close friends who can drive them places. This is, however, a great burden on the family and therefore not an ideal solution.Taxi-services were in many of the interviews mentioned as the best way of transportation for PwD. However, there were some problems related to taxi services, for example the high price or when a PwD has to wait outside for too long.

In the interviews with the first group (PwD & ICT), it also became clear that the environment and mobility were both important aspects of self-reliance. With regard to the environment, it was mentioned that people prefer to stay in their own house as long as possible, because it is a familiar and safe place. In the home environment, it was mentioned that PWD experience mainly problems with activities such as cleaning and cooking, which makes them very dependent on services. This is also related to safety concerns such as leaving on the stove. Regarding the macro level of the environment, being outside alone often results in wandering, and therefore they have to be accompanied.

With regard to mobility, it was mentioned that PwD often find it very hard to accept they are not able to drive anymore. Driving is an important aspect of self-reliance, and taking this away from someone is often experienced as very difficult. It means someone becomes way more dependent on others, which is not preferable. It was mentioned that people were mostly dependent on family or close friends to drive them places. However, it is experienced as very important to go to places because it increases social engagement which provides more purpose in life. Furthermore, all of the interviewed clearly preferred the car over public transportation, because it was experienced as too complex and less comfortable.

5.3.3. Assistive Technology

When looking at the use of assistive technology, it can be observed that this was mentioned only by professionals and experts, suggesting a lack of awareness of these services for current generations. Nevertheless, it was broadly recognized that the use of assistive technologies is beneficial for PwD. Technologies can especially be helpful in assisting people in their daily lives. For example, it can be used to remind people to carry out certain tasks, and to give instructions on how to carry out these tasks. Moreover, assistive technology can provide more safety by using sensors that can, for example, detect when a person has fallen. It was also mentioned that technology can help to increase physical activity. As is the case in the Whole Body Vibration Chair explained above. This is an efficient solution for physical inactivity, because it does not require a lot of skills from the PwD and it can be done at home. Further, as the number of PwD is increasing, assistive technology will be more necessary, because there will not be enough caretakers and financial resources per person with dementia.

However, it was also clear that assistive technology has its limits, and rather supplements than replaces care provided by people. One of the main problems is that much of the current technology is not useful for the current elderly population, as they are not accustomed to technology, which will likely take two more generations. Furthermore, a great concern regarding assistive technology is that it takes away the personal aspect of care, and will eventually make society itself less engaged. As many persons with dementia experience loneliness, a caretaker can provide the social interaction that a technological device cannot. Therefore, assistive technology can take over some small roles from the caretaker, but not replace the caretaker as that would take away the personal and social aspects of care.

5.3.4. Health Landscape

First of all, there are several points where the system lacks transparency, structure or quick adaptation opportunities. Within the first group, one family caretaker explained that the system is often too difficult and slow. This is especially the case for people who have not been previously in touch with the public health system and thus are not familiar with where to find help. With regard to this, when a person has less knowledge about the public health system or certain diseases, it is more difficult for instance to know what is required of them, to find the necessary care needed, and which care opportunities are available. The care chain is difficult to make sense of and it is also difficult to be followed. One of the professionals from an organisation for a more dementia friendly society, also indicated that there is less trust in system structures and organisations, preventing people from receiving adequate care. As a consequence, the projects and services in favour of helping the dyad or the PwD are not well coordinated. Therefore, the ICT stressed the need for other forms of assistance such as mentoring or buddy systems which can guide the PwD and dyads through the organisations, projects, and services in order to get the best possible (day-)care.

Moreover, dementia is a progressive disease, indicating that different variations of care are required at different stages of dementia. According to the family caretaker, when a person applies for services according to their needs, the indication procedure (whether the care suits the needs) is taking too long (about 6 weeks). Similarly, future care needs are not anticipated. However, the caretaker mentioned that a progressive disease requires a form of care quickly adaptable to changes within the disease progression. Similarly, the experts from organisations mentioned that since the indication process takes way too long, there is a care lag, meaning that at the time the care is put into place, the needs and symptoms could differ already. One professional mentioned an example of someone receiving care at one organisation, but then when this person was referred to another organisation, he/she had to go through the indication process again, as organisations are obliged to check whether the needs fit the services, causing further care lag. Accordingly, a person with a progressive disease gets stuck in a care chain, as the legislation and guidelines which care institutions have to follow make it difficult to accept new clients and to deliver services in real time.

Additionally, it was mentioned by an expert from spatial planning that services should be more individualised as some people will fall out of the current classification. The care applied to PwD who encounter memory problems is also applicable for people with memory problems due to strokes or brain injuries. Care and social services are sometimes not available for these PwDs since they are specifically designed for PwD. The problem lies within the classification of the symptoms and the disease in connection to the available care. To look at it from the other side, PwD are at one time too ill and restricted in their freedom, but are at the same time too healthy to get on to the next step in the care chain. This is one example of falling out of the system, however there are more, as explained in Needs and Services.

Within the second group, consisting of health professionals and experts, the lack of money for funding professional caretakers and general problems with financing was a recurring theme. Whereas the ICT had no difficulties with having too little budget for buying the care or the nurses, they had more difficulties with finding the right and suited nurses who were also able to care at night. This was a major problem for the ICT since he had no time to have some rest and thus to reduce his care-burden. Likewise, this interferes with the ability to live longer at home.

5.4. Conclusion

Within the interviews, we identified seven themes: Cognition, Illness Perception, Social Aspects, Needs and Services, divided into Home Environment and Mobility, and Health Landscape. In general, we received valuable insights from the 13 interviews we conducted with caretakers, experts from diverse fields, mentors, and other stakeholders. The aspect cognition helped us to acquire a better perspective on the medical aspects related to dementia. In turn, Illness Perception and Social Aspects helped us to understand personal relationships and the role of society, Needs and Services and Health Landscape were of a more structural nature and related to the living environment and health infrastructure. With regard to these themes, it can be said that the situation of the PwD needs to be viewed from all these aspects in order to find better solutions.

6. Conclusion

This report shed light on the question: *How might we create an environment in which people within early stages of dementia are enhanced/strengthened in their self-reliance?* While the desk research, or more specifically the literature review, helped us to gain a general understanding of dementia, the field research offered valuable insights into the practical lives of people involved within dementia care, and personal accounts of people with ESD, family members, caregivers and experts within the field. One could say the literature review helped us to acquire a bird's-eye perspective, whereas we gained a more worm's eye perspective through the interviews we conducted. By combining the knowledge gained through both perspectives, we aimed to paint a more complete and realistic picture of people living with dementia, while also bridging the gap between the existing knowledge and the practical aspects of dementia.

The themes we identified within the field research namely, *Activities of Daily Living, Awareness, Cognition and Illness Perception, Mobility, Social Aspects, Needs and Services,* and *Health Landscape* are important aspects within the life of a person with dementia and his or her caregiver. To visualize, it can help to map the aspects within a circular approach. The PwD and their informal caregiver are depicted within the center, surrounded by health professionals, family, friends, and volunteers within the living environment. Self-Reliance will be enhanced when the person with dementia and the ICT can be properly connected to the system to increase external support. Moreover, early disclosure of diagnosis, support with the consequences of the disclosure, focus upon the specific needs of the person with dementia, a more anticipatory system, and increasing awareness within society, are crucial aspects to increase the self-reliance of a person with dementia, but also to increase their quality of life and well-being. Additionally, it needs to be especially foregrounded that the ICT plays a pivotal role within the life and the care of a husband, wife, father, mother, or friend of a person with dementia. Their well-being should not be neglected in order to achieve a good situation for all people involved in the care. Moreover, since there is not a-one-type-fits-all approach to dementia due to the diversity of disease and lifestyles, it is important to take the determinants of health into consideration and to reduce risk factors early on. Finally, there are especially risks associated with people that feel lonely, live isolated, or are generally little included within society so that further research within this field is encouraged.

Bibliography

Allen, J. S., Bruss, J., & Damasio H. (2005). The aging brain: the cognitive reserve hypothesis and hominid evolution. *American Journal of Human Biology*, 17(6), 673-689.

Alzheimer Nederland. (2019a). *Factsheet cijfers en feiten over dementie*. Retrieved from https://www.alzheimer-nederland.nl/factsheet-cijfers-en-feiten-over-dementie.

Alzheimer Nederland. (n.d.-b). *Herkennen en symptomen*. Retrieved from https://www.alzheimer-nederland.nl/dementie/herkennen-symptomen

Alzheimer Nederland. (n.d.-c). *Soorten dementie*. Retrieved from https://www.alzheimer-nederland.nl/dementie/soorten-vormen

Bandura, A. (1997). Self-efficacy: The exercise of control. *Freeman/Times Books/ Henry Holt & Co.*

Beinart, N., Weinman, J., Wade, D., & Brady, R. (2012). Caregiver Burden and Psychoeducational Interventions in Alzheimer's Disease: A Review. *Dementia and Geriatric Cognitive Disorders Extra*, *2*(1), 638–648. https://doi.org/10.1159/000345777

Bharucha, A. J., Anand, V., Forlizzi, J., Dew, M. A., Reynolds, C. F., Stevens, S., & Wactlar, H. (2009). Intelligent Assistive Technology Applications to Dementia Care: Current Capabilities, Limitations, and Future Challenges. *American Journal of Geriatric Psychiatry*, 17(2), 88–104.

Brawley, E. C. (2001). Environmental design for Alzheimer's disease: a quality of life Issue. *Aging and Mental Health*, 5(1), 79-83.

Chester, H. (2018). People with dementia and carer preferences for home support services in early-stage dementia*. Ageing & Mental Health*, 22(2), 270-279.

Cipriani, G., Lucetti, C., Nuti, A., & Danti, S. (2014). Wandering and dementia. *Psychogeriatrics*, 14(2), 135-142.

Cummings, J., Tong, G., & Ballard, C. (2019). Treatment Combinations for Alzheimer's Disease: Current and Future Pharmacotherapy Options. *Journal of Alzheimer's Disease*, 67(3), 779–794.

Evans, J., Brown, M., Coughlan, T., Lawson, G., & Craven, M. P. (2015). A Systematic Review of Dementia Focused Assistive Technology. International Conference on Human-Computer Interaction. *Technologies Lecture Notes in Computer Science*, 9170, 406–417.

Glisky E. L. (2007). Brain Aging: Models, Methods, and Mechanisms. Chapter 1: Changes in Cognitive Function in Human Aging. Boca Raton (FL): CRC Press/Taylor & Francis.

Gräßel, E., & Adabbo, R. (2011). Perceived burden of informal caregivers of a chronically ill older family member: Burden in the context of the transactional stress model of Lazarus and Folkman. *GeroPsych: The Journal of Gerontopsychology and Geriatric Psychiatry, 24*(3), 143–154. https://doi.org/10.1024/1662-9647/a000042

Harvard Health Publishing, Harvard Medical School (2019). *What is cognitive reserve?*

(2015), 27(6), 927-36. Retrieved from https://www.health.harvard.edu/mind-and-mood/what-is-cognitive-reserve

Harding, A. J. E., Morbey, H., Ahmed, F., Opdebeeck, C., Lasrado, R., Williamson, P. R., Reilly, S. T. (2019). What is important to people living with dementia?: the 'long-list' of outcome items in the development of a core outcome set for use in the evaluation of non-pharmacological community-based health and social care interventions. *BMC Geriatrics*, 19(1). doi: 10.1186/s12877-019-1103-5

Jongen, W. (2017). *The impact of the long-term care reform in the Netherlands: an accompanying analysis of an 'ongoing' reform (dissertation)*. Retrieved from https://inthealth.mumc.maastrichtuniversity.nl/sites/intranet.mumc.maastrichtuniversity.nl/files/inthealth_mumc_maastrichtuniversity_nl/e-book_dissertatie_wesley_jongen.pdf.

Judd, S., Marshall, M., & Phippen, P. (1998). *Design for Dementia.* London, United Kingdom: Hawker Publications.

Kaplan, R., Kaplan, S., & Ryan, R. (1998) *With People in Mind: Design and Management of Everyday Nature.* Washington, United States: Island Press.

Kolata, G. (2019, October 22). That New Alzheimer's Drug? Don't Get Your Hopes Up Yet. *The New York Times*. Retrieved from https://www.nytimes.com/2019/10/22/health/alzheimers-dementia-aducanumab.html

Mahoney, D. F., LaRose, S., & Mahoney, E. L. (2015). Family caregivers' perspectives on dementia-related dressing difficulties at home: The preservation of self model. *Dementia (London)*, *14(4)*(494–512). https://doi.org/10.1177/1471301213501821

Martin, F., Turner, A., Wallace, L. M., Stanley, D., Jesuthasan, J., & Bradbury, N. (2013). Qualitative evaluation of a self-management intervention for people in the early stage of dementia. Dementia, 14(4), 418–435. doi: 10.1177/1471301213498387

McKenzie, B., Bowen, M. E., Keys, K., & Bulat, T. (2013). Safe home program: a suite of technologies to support extended home care of persons with dementia. *American Journal of Alzheimer's Disease & Other Dementias*, 28, 348–54. https://doi.org/10.1177/ 1533317513488917.

Ministerie van Volksgezondheid, Welzijn en Sport. (2016). *Healthcare in the Netherlands*. Retrieved from https://www.government.nl/documents/leaflets/2016/02/09/ healthcare-in-the-netherlands.

Ministerie van Volksgezondheid, Welzijn en Sport. (2018). *Programma Langer Thuis*. Retrieved from https://www.rijksoverheid.nl/documenten/rapporten/2018/06/15/ programma-langer-thuis.

Mitchell, L., Burton, E., Raman, S., Blackman, T., Jenks, M., & Williams, K. (2003). Making the outside World Dementia-Friendly: Design Issues and Considerations. *Environment and Planning B: Planning and Design*, *30*(4), 605–632. doi: 10.1068/b29100

Mitchell, L., & Burton, E. (2010). Designing Dementia-Friendly Neighbourhoods: Helping People with Dementia to Get Out and About. *Journal of Integrated Care*, *18*(6), 11–18. doi: 10.5042/jic.2010.0647

Mokhtari, M., Aloulou, H., Tiberghien, T., Biswas, J., Racoceanu, D., Yap, P.. (2012) New Trends to Support Independence in Persons with Mild Dementia. A Mini-Review. *Gerontology*, 58(6), 554–563.

Mountain, G. A. (2006). Self-management for people with early dementia. *Dementia,* 5(3), 429-446.

National Institute for Public Health and the Environment Ministry of Health, Welfare and Sport. (2018). *Public Health Foresight Study 2018: A healthy prospect.* Retrieved from https://www.vtv2018.nl/sites/default/files/2018-11/LR_116406_010947_VTV_kernboodschappen_ENG_V5.pdf

National Institute on Ageing (2017). *Causes of Alzheimer's Disease: What Happens to the Brain in Alzheimer's Disease?* Retrieved from https://www.nia.nih.gov/health/what-happens-brain-alzheimers-disease (*Unravelling the Mystery of Alzheimer's Disease*. Retrieved from https://www.youtube.com/watch?v=wzkQyWpu10E)

Neergaard, L. (2015, 26 mei). *Researchers use brain scans to hunt for Alzheimer's cause*. Accessed on 24 januari 2020, van https://www.pbs.org/newshour/health/researchers-use-brain-scans-hunt-alzheimers-cause. PBS NewsHour. (2011, September 12).

Robinson, L., Brittain, K., Lindsay, S., Jackson, D., & Olivier, P. (2009). Keeping In Touch Everyday (KITE) Project: Developing Assistive Technologies with People with Dementia and Their Carers to Promote Independence. *International Psychogeriatrics*, 21(03), 494.

Rowe, M. A., Kelly, A., Horne, C., Lane, S., Campbell, J., Lehman, B., & Benito, A. P. (2009). Reducing dangerous nighttime events in persons with dementia by using a nighttime monitoring system. *Alzheimer's & dementia: the journal of the Alzheimer's Association*, *5*(5), 419–426. doi:10.1016

Schoenmakers, B., Buntinx, F., & Delepeleire, J. (2010). Factors determining the impact of care-giving on caregivers of elderly patients with dementia: A systematic literature review. *Maturitas*, 66(2), 191-200. doi:10.1016

Sriram, V., Jenkinson, C., & Peters, M. (2019). Informal carers' experience of assistive technology use in dementia care at home: a systematic review. *BMC Geriatrics*. 19(1). doi: 10.1186/s12877-019-1169-0.

Thoma-Lürken, T., Bleijlevens, M. H. C., Lexis, M. A. S., De Witte, L. P., Hamers, J. P. H. (2018). Facilitating aging in place: A qualitative study of practical problems preventing people with dementia from living at home. *Geriatric Nursing*, 39(1), 29-38.

Vilans. (2017). *Foutloos leren bij dementie.* Retrieved from https://www.databankinterventies.nl/dei/publicatie-beschrijving-foutloos-leren-bij-dementie.pdf

Wolfs, C. A., Verhey, F. R., Kempen, G. I., De Vugt, M. E. (2015). Qualitative study on needs and wishes of early-stage dementia caregivers: the paradox between needing and accepting help. *International Psychogeriatrics,* *27*(6), 927-936. doi:10.1017/S1041610214002804

World Health Organization. (2010). *The determinants of health.* Retrieved from https://www.who.int/hia/evidence/doh/en/

World Health Organization. (2015). *World report on ageing and health 2015*. Retrieved from https://www.who.int/ageing/events/world-report-2015-launch/en/.

World Health Organization. (2017). *Global action plan on the public health response to dementia 2017 - 2025*. Retrieved from https://www.who.int/mental_health/neurology/dementia/action_plan_2017_2025/en/.

World Health Organization. (2018). *Mental health of older adults*. Retrieved from https://www.who.int/news-room/fact-sheets/detail/mental-health-of-older-adults.