



THESIS RAPPORT
THE USE OF ICT TO SUPPORT INFORMAL CAREGIVING
IN ELDERCARE : A SYSTEMIC APPROACH

DECEMBER 2017

BY H.J. (JOANNE) SCHUITEMAN

FIRST SUPERVISOR : dr. R. LIE

SECOND SUPERVISOR : dr. ir. A. HAVEMAN – NIES

MSc Applied Communication Sciences

Chair Group: Knowledge, Technology and Innovation (CPT-80833)

ABSTRACT

Background: The overall aim of this study is to understand from a systemic perspective how the use of an e-health device, such as the Compaan, by elders and their environment provides opportunities for supporting informal caregivers and the way informal care can be given. Current policies in the Netherlands are more focused on developing a system of care in which elder people live longer ‘independently’ at home. To enable elder people to live longer independently at home two different strategies are used: stimulating informal caregiving and the use of technologies and e-health, such as the Compaan. Both informal caregiving as well as Compaan usage take place in a system including a network of actors around the elder. Therefore system innovation theory in combination with the adoption of a network perspective and processes explaining system change formed the theoretical framework. **Method:** 16 semi-structured interviews with informal caregivers have been conducted. Additional data was collected by conducting informal interviews, participatory observation, and document scanning. **Results:** The study showed that (1) there is a great diversity in network composition, roles and tasks of actors, needs within systems and in experienced burden related to informal caregiving; (3) the Compaan was used in diverse ways (as communication tool, control mechanism and care organization tool, entertainment tool, family storage tool, status object, portal to the world) ;(4) Usage was achieved by processes of (social) learning and communication and to a lesser extent self-organization. (5) Using the Compaan resulted in a mix of feelings of rest and control, improvement of communication, easier organization of care and feelings of happiness and satisfaction for informal caregivers; (6) The results also showed explanations for non-use of the Compaan (no need or relevance (anymore) to use it, no time, motivation or skills, an undesired effect on the system, costs, it did not work well and/or because of a lack of knowledge). Finally Compaan usage potentially could led to even more support. **Conclusion:** Although a great diversity in network composition and system conditions was present, actors within systems were able to use the Compaan due to its flexibility and adaptability. Usage of the Compaan provided possibilities for the system to change (patterns, roles, and tasks). These changes resulted in possibilities to create a system in which informal care could be given more easily.

CONTENT

1. INTRODUCTION	5
2. INFORMAL CAREGIVING IN ELDERCARE	10
2.1 IMPORTANCE OF INFORMAL CAREGIVING	10
2.2 INFOMAL CAREGIVING IN PRACTICE	11
2.2.1 Who provides informal care and to whom?	11
2.2.2 Support forms and tasks	12
2.2.3 Informal caregiver burden	12
3. THEORETICAL FRAMEWORK	16
3.1 SYSTEM INNOVATION	16
3.2 NETWORK PERSPECTIVE	18
3.2.1 Relevance of networks	18
3.2.2 Kinds of networks	19
3.2.3 Understanding change in networks	22
3.3 TOWARDS SUPPORTING INFORMAL CAREGIVING	23
4. METHOD	26
4.1 DATA COLLECTION	26
4.1.1 Semi structured interviews	26
4.1.2 Additional data collection	28
4.2 DATA ANALYSIS	30
4.2.1 Semi-structured interviews	30
4.2.2 Additional data	30
5. THE NETWORK AND SYSTEM NEEDS	31
5.1 NETWORK COMPOSITION	31
5.2 INFORMAL CARE BURDEN	32
5.3 SYSTEM NEEDS	32

6.COMPAAN USE AND CONSEQUENCES	37
6.1 COMPAAN USAGE	37
6.2 PROCESSES OF CHANGE	42
6.3 USAGE CONSEQUENCES	44
7. NON-USE AND UNREALISED POTENTIAL	48
7.1 NON-USAGE	48
7.2 POTENTIAL USE	52
8.CONCLUSION AND DISCUSSION	57
REFERENCES	65
APPENDIX	70

1. INTRODUCTION

"It is no art to become old, it is an art to live with it" – Johan Wolfgang von Goethe

In the healthcare sector a division could be made between two types of healthcare: curative care (cure) and long-term care (care), related to the long-term care for elderly, disabled people and chronic ill people (Van Rooijen, Goedvolk & Houwert, 2013). This study will focus on the 'care' side of the healthcare system, and more specific on the Dutch system of long-term elder care. For years the Dutch system of long-term care was based on the idea that the state bears the responsibility for people who are in need of long-term care (Mot, 2010). In the Netherlands institutional care played an important role, compared to other countries. There was no obligation to provide informal care and this kind of care played a less important role in the past years. However, nowadays more people are getting older resulting in an ageing population (Giebers, Verweij, & de Beer, 2013). Expected is that in the Netherlands the number of people aged over 65 increase rapidly from 15.4% in 2010 to 27% of the population in 2040 and the number of people aged over 80 will increase strongly from 4% in 2010 to 9% in 2040 (Verbeek-Ouddijk et al., 2014). While ageing most elderly need some assistance in their daily lives. For those aged 60 or older, the older someone is, the more costs are spend on homecare (Wong et al., 2008). Often this is related to long-term care, used more intensively when getting older (Wong et al., 2008). Consequently, the ageing population results in increasing healthcare expenditure (Wong, Kommer, & Polder, 2008). In the Netherlands the total healthcare costs increased already from 46,9 billion euros in 2000 (RIVM infographic, n.d) to 95 billion in 2014 (CBS, 2015). Costs related to eldercare are approximately 17.9% of the total costs spend on healthcare in the Netherlands and explain 15% of the total increase in healthcare costs between 1999-and 2010. The expected (further) increase in healthcare expenditure, together with an ageing population and a relative smaller active population, created high pressure on the healthcare system. In January 2015 new laws were introduced by the national government which largely transferred responsibilities for long-term care (under which eldercare) to the local governments. The basic principle behind this so called 'transition' is that municipalities are able to organize care more tailored and in cooperation with citizens creating opportunities for a more efficient organization of care (Loket gezond leven, 2015a). One of the objectives is that care is organized within the living environment of citizens, aiming at increasing autonomy, self-reliance and participation of the recipients of care themselves and their social networks (Loket gezond leven, 2015b; Vreugdenhil, 2012). Summarized, the system is now more focused on citizens own responsibility for being and staying healthy. This means that citizens need to participate actively, need to organize more care privately and need to make use of all the possibilities they could receive from their environment first.

The focus also switched to looking at the abilities of (elder) people, instead of the disabilities of people. Only in cases of severe disability or sickness, institutional care is available (Rijksoverheid (b), n.d.). Disability is now even defined based on the conditions of the (social) environment. Barrett et al. (p.18, 2014) states that disability *“does not inevitable arise from specific impairment and people with identical conditions may have different outcomes, depending on the supports available to them.”* In short the environment and the level of support that is provided by this environment have become very important. Translating this to eldercare, current policies in the Netherlands are focused more on developing a system of care in which elder people live longer ‘independently’ at home. This is considered to be both more efficient as more in line with the preferences of the users of care (Mot, 2010, Rijksoverheid, n.d.). However to enable elder people to live longer independently at home requires new approaches and ways of working. To achieve this, two different strategies are used: stimulating informal caregiving and the use of technologies and e-health. Regarding the first in the Netherlands, as well as in other countries of the world, attention for the role of the informal caregiver has risen and is now also extra stimulated in policies (Pickard et al., 2000; Oudijk, Woittiez, & de Boer, 2011; Barrett, Hale & Butler, 2014).

An informal caregiver could be described as someone who is *“giving help to someone voluntary because of a social relationship that exists between the caregiver and the care receiver, rather than of out of profession”* (Rijksoverheid.nl). However, informal care sometimes is given because of feelings of moral obligation or expectancies, instead of entirely ‘voluntary’ (Ministry of Public Health and Sports, Toekomstagenda, 2014). Therefore in this study the definition of Walker, Pratt and Eddy (1995) will be used: *“informal care is generally provided by untrained social network members (family or friends), usually in the absence of any monetary compensation.”* In 2013 already more than one and a half million people were giving intensive or long-term informal care, including caregivers of elderly (RIVM, Gezondheidsmonitor). However, problems with informal caregiving rise. Informal caregivers often experience several adverse outcomes such as reduced leisure time, job costs, conflict between work and family roles, stress, burden and negative impacts on physical and mental health (Rosenthal, Martin-Matthews & Keefe, 2007; Sing Nam, 2004). Besides this mentally and physically impact, informal caregivers are not always ‘available’ because of living distance or pressures of work (Klerk et al., 2015). In the Netherlands with the transition of January 2015, local governments have become legally responsible for supporting informal caregivers. Therefore local governments need to find methods to enhance possibilities for family members (or others) to provide informal care and to support them. Besides this role for informal caregivers, there are high societal and political expectations of new technologies and innovations enabling elderly to live longer independently at home. ‘Telehealth’ and ‘telecare’ technologies are seen as key to enabling

independent living for older people' (Griffiths, 2013). Already, many different assistive technologies are available for elderly and their environments to enhance independence and/or assist elderly in daily tasks, varying from simple warning alarms to (care) robots (Ludwig et al., 2012; Consolvo et al., 2004). Technologies can also be used to support informal caregivers by increasing the independence of the elder on the one hand and decreasing feelings of burden related to informal caregiving at the other hand (Vilans, n.d.). An example of a technology used to assist informal caregivers is the use of mobile (ICT) devices, such as smartphones or tablets. In this research the focus will be on such a specific designed tablet device named the Compaan. The Compaan is a tablet with special software developed to meet the needs of elderly people and their environment – see *Appendix 1*. For example the elder user is able to surf on the internet, send emails, skype and receive pictures. In terms of providing (informal) care, the Compaan provides the possibility to communicate in diverse ways with the elder user and use special care related functions such as the medication alarm, instruction movies, check-ins (to see if the elder person has awaked), and organising functions such as the agenda and contact via the family portal. This family portal is a unique element of the Compaan, including an online environment where (family) members that are connected to the Compaan of the elder can send messages, movies or pictures and are able to contact each other mutually. Important is that family members are able to manage problems with the tablet at distance (e.g. restarting, or check connection to Wi-Fi, keep sight on usage by elder). Therefore, at least one family member should be connected to the Compaan to be able to use it properly.

It is of great interest to understand if and how these kind of technologies could support informal caregivers and facilitate informal caregiving. However, using a technology such as the Compaan takes place in a broader context namely the eldercare setting in which different actors play a role (e.g. informal caregivers, formal caregivers and the elder). This could be seen as a 'system' in which different actors have their own roles, tasks, modes of thinking and ways of communicating. Therefore adopting a systemic perspective is necessary to be able to understand the real potential of the use of a tool such as the Compaan. Whereas earlier models used to think about innovations as solely a technology or device, from a systemic perspective innovations could be seen as a successful combination of new 'hardware' (new technical devices and practices), 'software' (new knowledge and modes of thinking) and 'orgware' (new social institutions and forms of organization) at multiple levels (Smits, 2000, in: Leeuwis & Aarts, 2011). The implementation and success of such an innovation is not only depending on the characteristics of the device itself, but also on the way the environment responds and adapt to the innovation (Elzen et al., 2012) and the way the device can be adapted to the environment (Leeuwis & Aarts, 2011). The systemic perspective also shed new light on the adoption and implementation process of innovations. Rather than focussing on the individual

response towards a new device (individual level), Leeuwis and Aarts (2011) state that *“innovation processes are conceptualised as conflictive and dependent on dynamics in networks”* (p.24). To achieve fundamental system change (i.e. efficient eldercare at home), actors within the network should adapt to new roles and modes of thinking (Young, Borland & Coghill, 2010). Therefore to understand how a technology such as the Compaan provides opportunities for facilitating informal caregiving to elderly, first there should be focussed on the changes in relationships between the actors in the system. This gives good reason to look from the perspective of networks to the innovation process. Literature on informal caregiving support this idea that looking at networks provides valuable insights. For example Barrett et al. (p. 17, 2014) states that *“many caregivers studies have tended to limit the focus of the dyadic relationships between the family caregiver and the care-recipient, neglecting the broader context that may involve other informal and formal carers”* and Timonen (2009, In Barrett et al. 2014, p.17) states that *“informal care needs to be seen in its social context and in the way the social networks involved in care are integrated.”* Therefore, to understand how informal caregiving to elderly could be supported by such an innovation as the Compaan, it requires a systemic approach in which the network within the system is taken into account.

Summarizing, to enable elderly to live longer independently in their homes, new approaches and ways of working are needed. Informal caregiving by family members, friends or other relatives is seen as important. However many informal caregivers experience a burden in giving this informal care and face other problems that makes informal caregiving difficult. Therefore it seems useful to understand how technical devices, such as the Compaan, could facilitate informal carers to provide care to elders more easy. Taking into account that informal caregiving takes places in a broader context leads to the main question of this research:

RQ: In what way could the Compaan support informal caregiving in eldercare seen from a systemic perspective?

The overall aim of this study is to understand from a systemic perspective how the use of an e-health tool (the Compaan) by elders and their environment, provides opportunities to supporting informal caregivers and the system. This study is scientifically relevant because it looks at how a technology could support informal caregiving in the eldercare from a systemic perspective. Thereby it takes into account the role of the surrounding network to understand how the implementation and use of such a technology is negotiated and achieved. According to Keating et al. (2003) there is little systemic analysis of ways in which groups or networks that are (supportively) related to older adults organize

themselves to provide care. The societal relevance lies in understanding how a ICT tool, such as the Compaan, could enable informal carers to deliver care (more easy) and how the different actors in the network and the aspects of the innovation process interferes and shape the way in which informal care is given. It can help the local governments to find ways to support informal caregivers. Furthermore, it could provide valuable information for companies that are involved in developing technologies in the eldercare sector. In chapter 2 the importance, role and burden of informal caregiving will be addressed. In chapter 3 the theoretical framework of systemic innovation and network theory will be discussed. Chapter 4 explains the method used in this study. Chapter 5, 6 and 7 discuss the results of the study related to the network composition, the use of the Compaan in the system and potential usage. Finally chapter 8 includes the summary of the main findings, conclusion and discussion.

2. INFORMAL CAREGIVING IN ELDERCARE

In this chapter there will be discussed why informal caregivers are of great importance in high quality eldercare after the transition (2.1) and how informal care is given in practice (2.2). Also difficulties that informal caregivers experience will be addressed (2.3).

2.1 IMPORTANCE OF INFORMAL CAREGIVING

As mentioned in the introduction, a transition has taken place in the social domain based on a new perspective on long-term care for elderly in the Netherlands. As a result new laws, regulations and adaptations in the organization of eldercare need to be made. The role of the informal carer has become more important and receives a more central role (Klerk et al., 2015). In the 'old' system formal care, institutional care and informal care were all present, however they mostly functioned independent from each other, with clear roles and division of tasks. Nowadays, institutional care is only available to elders for whom care at home is no realistic option, and not for elders with only mild health problems (Maarse & Jeurissen, 2016). As a result of the new laws the division of tasks have become blurred. This means that all the involved actors need to adapt to new roles, tasks and should ideally cooperate to achieve the most efficient, high quality care for the elder. According to the Ministry of Public Health and Sports (Toekomstagenda, 2014) the enlarged role of informal caregivers asks for an approach in which cooperation and alignment becomes more important. Therefore it is important that formal caregivers, informal caregivers and other members of the social network cooperate. Hiemstra and Woudstra (2015) claim that the transition results both in opportunities as well as risks. Opportunities could be more autonomy for citizens, more social coherence, better cooperation between formal and informal care and a decrease of costs. On the opposite, there is a risk that there will be too much pressure on the 'care network'. This could result in feelings of overload amongst informal caregivers and probably a problematic quality of care for people in need. Making sure the current informal caregivers will be able to provide care, without collapsing, and stimulating people to become informal carer will be necessary to keep the future system working. Or as stated by Barrett et al. (p.23, 2014) *"informal care is a fundamental resource in maintaining disabled and chronically sick people at home and in the community."* Therefore, focussing on the perspective of informal care givers on the use of an innovation, such as the Compaan, in the caregiving system and the consequences of usage seems to be useful.

2.2 INFORMAL CAREGIVING IN PRACTICE

In this paragraph there will be discussed how informal care is given in practice currently.

Furthermore different types of support and tasks will be addressed and the burden that comes with carrying out these tasks.

2.2.1 Who provides informal care and to whom?

The number of informal caregivers depends heavily on the exact definition (Mot, 2010; Klerk et al., 2015). According to a more specific measure in 2012, 1.5 million informal caregivers provided intensive or long-term care in the Netherlands (CBS, 2013). Using a broader definition of informal caregiving, in 2014 the estimated number of 4 million people reported by a large survey that they provided some kind of informal care (e.g. from giving emotional support to very intensive forms of caregiving) (Klerk et al., 2015). This is 33% of the Dutch adult population. Looking at age, people aged 45 to 64 provide support relatively often. Related to gender, for a long time women were seen as the greatest source of informal caregivers, with women traditionally carrying out many of the caring tasks in a family (Barrett et al., 2014). Reasons for this could be found in women having more time available and their recognition of someone who needs help. However, while women are still more likely to provide informal care (58% of the informal carers in the Netherlands), nowadays also men play an important role (Klerk et al., 2015). According to Kruijswijk et al. (2016) informal caregiving takes place in networks and certain mechanisms and patterns in this network ensure that men are doing less compared to their sisters. Of all informal caregivers (in the Netherlands) four out of five provides care to a family member (i.e. parents (in-law) 45% or partner 14%) (Klerk et al., 2015). Others provide care to friends or neighbours.

Another division made is based on differences in roles amongst informal caregivers. For example, Rosenthal et al. (p.758, 2007) described the concept of 'primary caregiver'. Almost the same Kruijswijk, Hermans and Van Rooijen (2016) use the Dutch term 'centrale mantelzorger' (English: central informal caregiver) to describe a specific role within informal caregiving. This indicates that within the informal caregiving 'network' there is differentiation in roles. The primary caregiver could be described as the one that performs most of the care (Brodsky, Resnick & Citron, 2006). In other words in every family it is likely that one person has the most responsibility and therefore is the 'primary' caregiver. Besides fulfilling a central role, the primary caregivers often also function as contact person for the formal healthcare professionals (Thesaurus, 2016). Therefore, in this study the primary giver is seen as the person(s) that carry the most responsibility and plays a central role in organizing and providing the care. In most cases the primary caregiver is either the spouse or an

adult child of the elderly person (Brodsky et al., 2006). In this study there will be focussed on the adult child as primary caregiver, because these buy the Compaan for the elder more often.

2.2.2 Support forms and tasks

Informal caregiving exists of many tasks that could be divided in different support forms. James (1992) distinguished three main support forms of informal caregiving: (1) psychical labour (i.e. ADLs or IADLs), (2) emotional labour (providing emotional support) and (3) organizational or managerial labour (ensuring that care is provided in time and in an acceptable manner). The first, physical labour is both concerned with providing help with bathing and clothing (ADLs) as well as material or tangible aid, including household tasks such as meal preparation, house cleaning shopping providing transport; bill paying and banking (IADLs) (Keating et al., 2003). Emotional labour includes *“the provision of social interaction, reassurance, validation, cheering up and monitoring”* (Harlton, 1998). This means all the activities related to social support, visits to prevent the care recipient from feelings of loneliness, and is focused mainly on the emotional (and social) well-being of the care recipient. Managerial care includes all other tasks that do not involve direct, hands-on care or emotional support (Rosenthal et al., 2007). These managerial tasks are multi-dimensional and can be divided in two main kinds of activities: orchestrating care (e.g. care-related discussions with other family members, relevant paperwork, seeking information and coordination of the informal care network) and financial and bureaucratic management. Financial management is seen here as ‘managerial tasks’ whereas the conceptualization by James (1992) place this under the ‘physical labour’ as part of assisting with the daily living activities of the care recipient. However, in this study it is not important which concept includes which specific tasks, but rather to recognize that these tasks are related to informal caregiving in general. Research showed that the sorts of informal care that were most given included emotional support, assistance with visits, domestic help and assistance with administrative matters (Mot, 2010). In the next paragraph the consequences of providing informal care will be addressed.

2.2.3 Informal caregiver burden

As mentioned in the introduction, problems with informal caregiving rise. Informal caregivers often experience several adverse outcomes such as stress, job costs (Peetoom et al., 2016; Klerk et al., 2015; Rosenthal et al., 2007; Sing Nam, 2004), problems with the collaboration between informal care and formal care (Klerk et al., 2015; Struijs, 2006) and difficulties with managing care by informal caregivers (Noelker & Browdie, 2014; Rosenthal et al., 2007; Arno & Memmott, 1999). This is often referred to as the ‘informal caregiver burden’. Klerk et al. (2015) found in their analysis that in the

Netherlands of all informal caregivers one out of seven experiences a heavy burden (approximately 400.000 persons). This means that they, because of the care they provide, are too tired (or ill) to undertake other activities. Besides this level of heavy burden, three other levels of experienced burden could be distinguished (Timmermans, De Boer & Iedema, 2005). The lightest form of burden is related to the obligatory character of providing informal care, because the care-receiver is depending on the care. In this situation informal carers report that the situation is never out of their mind, so that they feel responsibility for the situation at all times. Slightly heavier is the burden when providing care at the expense of other obligations. In this case, informal carers report that they do not have enough time for other tasks (e.g. controlling their own household or job related tasks). The next level, is the level of burden that includes informal caregivers that experience feelings of pressure or feel that they have too many tasks. Especially women and primary caregivers often report that providing informal care is experienced as heavy burden (Klerk et al., 2015).

The cause for this experienced burden could be explained by different primary stressors (related to the caregiving itself) and some secondary stressors (related to how the caregiver experiences the caregiving) (Wallance Williams, 2008). Primary stressors are related to the length of care, the complexity of the care, time spend on care, the way in which care is provided, the intensity of the care, the relationship between caregiver and care-recipient, the communication between different actors, and feelings of mastering (Struijs, 2006; Yates, Tennstedt, & Chang, 1999). It involves the negative effects which are related to caregiving itself. Secondary stressors are for example reduced leisure time, job costs, conflict between work and family roles, stress, burden and negative impacts on physical and mental health (Rosenthal et al., 2007; Sing Nam, 2004). More specific Struijs (2006) reports several issues that could lead to an excessive level of stress amongst informal carers. These are: (1) time problems; (2) financial burdens; (3) social isolation; (4) the sandwich generation and (5) little support. More than four out of every five carers (83%) experiences one or more time problems during the period with the highest need for support (Struijs, 2006; Visser-Jansen & Knipscheer, 2004). Often this results in difficulties with maintaining their own household, less time for leisure activities, little possibilities for leaving the care-recipient for some time and shortcomings in their work (Rosenthal et al., 2007; Sing Nam, 2004; Struijs, 2006). Especially this last issue, combining caregiving with a job, seems to result in time problems. Because women more often participate in the labour market nowadays, a dual burden situation have become more common and will probably become an even bigger problem in the future (Klerk et al., 2015; Struijs, 2006;).

Regarding the financial burden, informal caregiving often involves extra expenditure (e.g. travelling expenses, phoning etc.) (Struijs, 2006). Of all carers 72% experiences 'financial burden', but the costs related to it varies widely between care situations. Another problem related to informal caregiving is

the risk of social isolation. This means that when a caregiver puts a lot of time into caring, there is little time to meet other people. The next issue related to feelings of stress is the so-called problem of the sandwich generation (Struijs, 2006). This group on the one hand provides care for their elder parent(s) and on the other hand for their children. Finally, the last aspect related to feelings of stress is the level of support received by an informal caregiver. De Boer (2005) found that around 40% of all informal caregivers provide care alone and the other 60% receive support from one or more (secondary) carers from the family network or network of friends. De Klerk et al. (2015) found that one out of three informal caregivers does not dare, is not able to or does not want to ask for help. Explanations for this are being shy, relying on a small support network, and/or the care-recipient not willing to receive support from someone else (Klerk et al., 2015).

Another aspect that could increase feelings of burden is related to the collaboration with the formal care (when a combination of informal and formal care is used to deliver care to the elder). Litwin and Attias-Donfut (2009) found that in situations of greater need, a mixed provision occurs more frequently and that the relationship between both should be seen as complementary rather than competitive. According to Struijs (p.45, 2006) *“carers have a considerable need for professional support, especially advice, emotional support and respite care”* and *“professional caregivers are still too often falling short in this regard.”* In addition Klerk et al. (2015) found that nearly half of the informal caregivers are not very satisfied about the way formal caregivers involve them in decision making processes and in sharing the care tasks. In their view formal caregivers also pay too little attention to examining the well-being of the informal caregiver(s). According to Klerk et al. (2015) appreciation for informal caregivers is very important, both expressed by the care-recipient as well as other caregivers (e.g. formal care). Therefore it is important that the informal caregivers and the formal caregivers collaborate from the needs assessment stage onwards. Also regular communication, task allocation and having a shared vision on care could prevent informal caregivers from stress (Struijs, 2006). So, better cooperation between both formal and informal caregivers could be an effective strategy to reduce levels of stress amongst informal caregivers. This collaboration ‘issue’ also seems to be related to the problem of managing care.

For a long time, families or mostly primary caregivers struggle with management of the care for the care-recipient (Rosenthal et al., 2007). Especially being able to find information on service- and caring options and organizing care is time-consuming and difficult. Because of changes related to the transition (e.g. tasks division, importance of informal caregiving) it is likely that the management of care has become even more complex. Co-ordination of the informal care network is another facet of managerial care (Rosenthal et al., 2007). The term network implies that two or more people are

involved in providing informal support. An adult child experienced lower care-giver burden when the informal care-giving network size was larger, when more types of tasks were shared across the network, when care was shared for a longer period, and when the adult child had no disagreements with the other members of the network (Tokacheva, Broese van Groenou, de Boer & van Tilburg, 2011). Considering the need for care of older parents is growing, being in an informal care-giving network will be beneficial for adult children involved in long-term care. However, being with more caregivers also results in the importance of organising care among informal helpers and coping with disagreements among the members of the network (Tolkacheva et al., 2011).

Summarized, informal caregivers can have many tasks and they often experience a burden related to providing care. Caring tasks carried out mostly are related to providing emotional support, assistance with visits, domestic help and managing the care situation. Feelings of burden result from having less time, social isolation and being responsible for the well-being of the elder. Also a lack of cooperation with formal caregivers or a small informal caregiving network could contribute to feelings of burden. Going back to the Compaan, its usage could provide possibilities to enable communication, organize care and manage care related issues at distance. Therefore, it could probably be a supportive tool for informal caregivers. However using the Compaan could only work if it is accepted in the environment in which it is used and if other members are able and willing to use it. To find out in what way the Compaan could support informal caregivers, the bigger system should be taken into account. In the next chapter there will be discussed why it is useful to take a systemic perspective to understand the potential of a technology such as the Compaan and the most important related concepts to system innovation.

3. THEORETICAL FRAMEWORK

In this chapter the theoretical framework will be discussed. First the importance of taking a systemic approach and the theory of system innovation will be addressed (3.1). Furthermore as part of a systemic approach, network theory will be addressed (3.2) as well as the conceptual framework (3.3).

3.1 SYSTEM INNOVATION

The first innovation models originated around 1950/1960 and were focused on explaining what drives innovations, rather than explaining how innovations occur (Trott, 2012). One of the first developed models was the technology push model assuming that scientists do unexpected discoveries, technologies apply them to develop product manufacturing and engineers and designers turn them into prototypes for testing (Trott, 2012). Advanced models, in addition to this linear basic models, started to recognise the context as relevant to understand the innovation adoption process and the effect of innovations. However, the context was still seen as apart from the innovation. Whereas the linear models nowadays have been criticised by many (Leeuwis & Aarts, 2011), the advanced models have grown further into the current models that try to understand and predict innovation processes and outcomes. The focus on an innovation as independently fixed product and the focus on the results of the use of certain technologies or innovations have shown to be ineffective and incomplete. For example Leeuwis and Aarts (p.22, 2011) state that *“numerous studies showed that ‘innovations’ developed by research were often not adopted, and that successful innovations were usually based on an integration of (technological and other) ideas and insights from not only scientists, but also of users, intermediaries and other societal agents.”*

Nowadays innovations are seen from a more coherent and integrative perspective called a ‘systemic perspective’. From this perspective innovations are no longer seen as just new technical devices, but also including social and organizational elements, such as new rules, relationships or agreements (Leeuwis & Aarts, 2011). This means that the context is no longer separated from the innovation (as solely technical device) but is seen as part of the innovation and therefore of the innovation success. For example Elzen et al. (2012) state that *“the technology does not simply diffuse but changes in the process.”* The same development could be found in the health intervention literature. Oldenburg and Glanz (p.321, 2008) state in their chapter about the use of innovation diffusion models in the development of health intervention programs: *“it has become increasingly clear that factors influencing diffusion are not just static features of the innovation or of the adopters. Rather, there is usually a dynamic interaction among features of the innovation, intended adopters, and the context or setting where the process is occurring.* This incorporation of contextual factors into the innovation

process and innovation could be called system innovation. Innovations operate within certain systems and the innovation and the system are shaping each other. This is referred to as a co-evolutionary process pointing to the *“continuous interaction of technical, social and institutional elements”* (p.66, Kilelu, Klerkx & Leeuwis, 2013). Co-evolution, together with interactive design and learning are seen as key processes in system innovation (Leeuwis & Aarts, 2011). This means that during the development of a technological device the views and experiences of users and other stakeholders are incorporated (e.g. policymakers, other companies, families, users etc.). This process does not stop after the introduction to the market, but continues after the implementation of the device by continuously asking for feedback. Co-evolution then involves on the one hand the formation of new ideas by the company that lead to new applications (or services) and at the other hand the incorporation of (future) user’s feedback to further adapt the device to the needs of the environments in which it is used. This is also referred to as co-designing and includes incremental improvement, even after the introduction and implementation of the original device. These processes perfectly fit within the idea of system innovation because they provide the opportunity to respond and adapt to the needs originating in the system. Both at the level of private users and their environment as well as at the level of organisations these process can take place to adapt to specific needs. System innovations thus includes multiple levels (micro-, meso- and macro-level), involving multiple actors and multiple factors (an interplay of multiple factors that influence each other) (Elzen & Wieczorek, 2005). According to Elzen and Wieczorek (p.655-656, 2005) *“the key feature is that system innovations occur through the interplay between the dynamics at the multiple levels.”* In this regard focussing only on the relation between the device and the user, the individual level, is not very useful (Leeuwis & Aarts, 2011).

Therefore the perspective on the adoption process of innovations also changed. Whereas earlier linear models saw the adoption process as an individual process, system innovation views the adoption process as a collective process within nested networks of interdependent stakeholders (Leeuwis & Aarts, 2011). This means that the network is a part of the innovation, which implies the involvement of a number of stakeholders. Going from the idea that an innovation involves many actors this also influenced the perspective on the innovation process. Whereas in more linear modes of thinking, the process of innovation was seen as plannable and predictable, nowadays the process is seen more as an evolutionary process. From this perspective innovation processes are conflictive and dependent on dynamics in networks (Leeuwis & Aarts, 2011). Or as Krohn (p.31, 1995) stated *“to see in networks the organizational conditions for the dynamics of innovation”* (In: Ahrweiler & Keane, 2013). It puts the network as the driving force behind innovations and sees it as the factor which determines the trajectory of an innovation. According to Leeuwis and Aarts (p.30, 2011) *“innovation*

inherently implies are-configuration of relationships within and between networks, and possibly the formation of new networks and/or the demise of the existing one.” Summarized, innovation processes are depending on dynamics in networks. Innovation processes and innovation itself require a re-definition of relationships, norms, values and approaches between network members. In the end actors within these networks *“may or may not succeed to coordinate their actions and achieve an effective and contextually adapted balance between ‘hardware’, ‘software’ and ‘orgware’”* (p.24, Leeuwis & Aarts, 2011).

Thus, to understand how the Compaan could support system change, one should understand how the network within the system functions. Namely, the relationships between different actors (informal caregivers, formal caregivers and the elder) shape the way an intervention (such as introducing the Compaan into the existing system) affects the system (the way care is given and received). Therefore to understand how the Compaan could support system change so that it enable facilitate informal caregiving in an efficient way, it is important to understand the way the network(s) functions first. Or as stated by Leeuwis & Aarts (2011) it is *“due to the web of relationships involved in a complex system, such an intervention may simultaneously have ‘positive’ and ‘negative’ influences on achieving certain ends”* (p.29). Therefore it is necessary to take a network perspective in order to understand how change within a system takes place.

3.2 NETWORK PERSPECTIVE

The next section describes the relevance of networks, the different kinds of networks that could be distinguished related to eldercare and which process are playing a role in network change.

3.2.1 Relevance of networks

Network theories examine why ties form between two or more actors and the consequences of particular network positions (Powell, White, Koput & Owen-Smith, 2005). Other terms used are network approach or network perspective. The basic premise of every network approach is that knowledge of the relations between and within units enriches explanations based on knowledge of the attributes of these units themselves (Knoke & Kublinski, 1982). A network could be defined as a *‘concrete pattern of relationships among entities in a social space’* (Owen-Smith, n.d.). A network consist of nodes (also called members or actors that can be individuals, groups or organisations), resources and activities (Andersson, 1998; Knoke & Kublinski, 1982). In order to understand a network it is important to understand the relationships between the different actors (Andersson, 1998). Consequently, taking a network perspective involves identifying the actors in the network and understand the relationships between the different actors and the consequences of these

relationships. The perspective on the structure of the network determines how relationships between actors in the network could be described. The structure of a network can be described in terms of dyadic characteristics (focussing on specific relationships between an individual and the other people in the network) and in terms of characteristics of a network as a whole (Heaney & Israel, 2008). Thinking about the network of the elder (including the informal caregivers) the dyadic characteristics such as the reciprocity, intensity, formality and complexity of relationships are of relevance. When adopting a network perspective one should first determine which network becomes the unit of analysis. In the next section different kinds of networks relevant to the elder care sector will be introduced and described.

3.2.2 Kinds of networks

Extensive research has been done on the influences of networks on a variety of topics related to the psychical and social sciences (Borgatti, Mehra, Brass & Giuseppe, 2009). One of the most influential ideas in the social sciences is that *“individuals are embedded in thick webs of social relations and interactions”* (p.892). In the social sciences most of the network research is based on the social network theory, which uses ‘social networks’ as unit of analysis. Social networks could be defined as: *“the number, frequency and linkages of contacts with other individuals or groups”* (p.140, Worcester, 1990) or *“the web of social relationships that surround individuals”* (p.190, Heaney & Israel, 2008). These networks include all the contacts that are available to someone. In some research social networks of ‘frail elders’ were seen as equalling the informal sector which could provide long-term care (Havens, Donovan & Hollander, 2001). However, although there is a lot of knowledge about social ties providing resources for support giving, this knowledge is not used to understand how families and friends from networks of carers. Keating et al. (p.115) concluded therefore that *“it is useful to make conceptual distinctions between ‘social’, ‘support’ and ‘care-giving’ networks.”* Social networks in this sense are all the people that somebody knows and potentially could perform support or care related tasks. Someone’s entire social network includes all persons someone is connected to. However, many of these links could be impersonal or wasted away, so it is the personal social network including members such as friends, family members, neighbours or others who can be called close personal ties. Whereas someone’s entire social network could exist of hundreds of people, the personal social network is on average likely to equal twenty members (Keating et al., 2003). When looking at the support network this seems to be even smaller. It is often based on the ties that are related to someone’s personal social network referred to as the actualised potential or the functional subsets of social networks. This includes the members providing emotional and tangible aid (Keating et al., 2003). Wenger (p.149, 1991) defined the support network

as *“all those closely involved with the elderly respondent providing companionship, advice, help, or care. [...] the support network is not the whole social network but formed the core of it.”* What separates social support from other functions of social relationships, is that the provider of the support intends to be helpful (Heaney & Israel, 2008). So, within someone’s entire social network, there is a personal social network which seems to equal the potential social ties that could give support and therefore become part of the support network.

But Keating et al. (2003) also made a distinction between the support network and the care network of the elder. Only a few studies have made a distinction between support networks on the one hand and care networks on the other hand. This is probably due to the overlap and shared common features of both concepts (i.e. they both involve people that perform supporting or caring tasks). However, according to Keating et al. (2003) the difference between the two lies in the circumstances under which these tasks are provided, rather than in the differences of tasks. They state that *“when support is provided because of a senior’s long-term health problems or functional limitations, it should be designated as care”* (p.120, Keating et al., 2003). Because the distinction between support and care networks is not made often, little research on care networks is available. Care networks help in coping with day-to-day life in terms of performance of care tasks within the house or in the community setting. Care network members appear to provide different types of tasks, depending upon their relationship to the recipient and to each other (Keating et al., 2003, p.120). This distinction in networks described by Keating et al. (2003) provides an interesting perspective that can be used to understand how the (informal) caregiving is emerging out of networks of elders – see *Appendix 2 Figure 1*.

Another distinction in networks related to eldercare is informal versus formal caregiving networks. Informal caregiving networks include all the members that provide support based on their relationship with the care receiver, whereas the formal caregiver networks exists of members that provide care out of profession and receive payment (Timonen, 2009). Healey and Israel (p.197, 2008) state that *“social support can be provided by many types of people, both in one’s informal network and in more formal helping networks, and that different members are likely to provide different amounts and types of support.”* In the conceptualisation of Keating et al. (2003) the role of the formal network (members) in the care-, support- and social network is neglected. Other models tried to incorporate both formal and informal members in the same conceptualisation. According to Barrett and Lynch (p.695, 1999) *“informal carers along with caregivers from formal organizations compose the caregiving networks that assist elderly people with functional limitations.”* From this perspective both informal and formal caregivers could be part of the care network. This statement is based on the substitution hypothesis stating that when close relatives are not available to care, other actors

more at distance such as friend or formal caregivers are substitutes. In the same line Lensink (in: Steyaert, 2012) has developed a model that can be used to map the social network of an elder which includes four circles: (1) the most close relatives; (2) close friends or other relatives; (3) acquaintances; and (4) professional services – see *Appendix 2 Figure 2*. Compared to the model of Keating et al. (2003) the model of Lensink and the substitution hypothesis add the role of the formal care in the network(s) around the elder. Both also define the role of formal care based on the closeness with the elder. This assumes that formal caregivers could not belong to the network of intimici or friends. However, Timonen (2009) states that *“both types of caregiving are inter-personal and often highly emotive in nature”* (p.9).

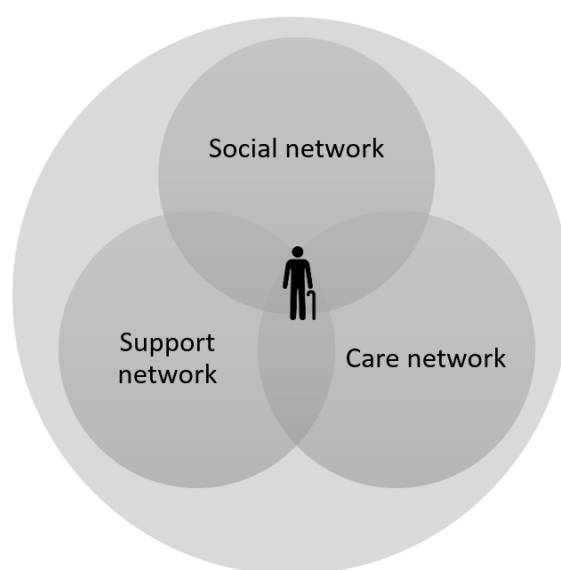


Figure 1 - Graphic conceptualization of the overlapping networks around the central elder within the eldercare system.

A method including both formal and informal care and making a division for both categories in closeness to the care recipient is the ‘Wijkecogram’ (English: district ecogram) of Scheffers (2010). She makes a distinction between three categories: (1) family; (2) friends, acquaintances and colleagues and (3) societal services – see *Appendix 2 Figure 3*. This method acknowledges that formal caregivers could also differ in their level of closeness to the care-recipient. Therefore the inner circle could now include both informal and formal caregivers and consequently see them as members of one network. Furthermore, according to Timonen (2009) *“formal and informal care increasingly co-exist and interact especially in the home and community care context”* (p.2). From this perspective informal and formal caregivers could not be separated strictly. In the same way other studies pointed to the absence of attention to the total support network (Barer & Johnson, 1990). The total support network could be seen as the total system in which care is given to an elder. It includes all the actors

that are related to the elder and provide care in a way. To come to a useful conceptualization all these actors should be incorporated in the networks. As Timonen (2009) argued all caregivers continually must adapt to change within the contexts of their respective roles. From this perspective it is possible that both formal and informal caregivers are members of the social, support or care network, based on their roles and within a specific context. Some people will only be part of the social network, others will in specific contexts function as social network member, but in another as a support network member – see Figure 1. In this study therefore the social-, support- and care-network will be taken as network of analysis as part of an individual system of which the elder is part and in which care is given.

3.2.3 Understanding change in networks

In this section some processes will be described that could provide valuable insights in how networks change. Three important processes which could explain changes in systems are: (1) self-organization (2) communication and (3) social learning. These three processes will be addressed in the next part.

Self-organisation

It is often hard to achieve change (i.e. meaningful innovation) due to complex interdependencies and regularised interaction patterns, especially because the actors within a network are likely to have an interest in maintaining the already existing situation (Leeuwis & Aarts, 2011). Despite such structural constraints and despite experiences of difficulties in reaching designed change, the world changes continuously. However, instead of being controlled and directed, self-organisation (i.e. the emergence of order without external control) plays an important role in bringing about patterns of change (Leeuwis & Aarts, 2011). Self-organisation involves the action of human beings, but is not directed at a certain direction on purpose, but rather spontaneous. Rotmans (2005) drawing on social theory (i.e. social structure is both the result and means of acting) states that “*structure emerges from the (intended and unintended) effects of acting*” (p.40). From this insight he concludes that transitions involve a process of co-evolution between structures, actors (including oneself) and practices. When thinking about the importance of the re-ordering of social relationships to achieve meaningful innovation, self-organisation seems to be a critical process. The process of self-organisation also implies that existing structural conditions can be both constraining as well as enabling, and therefore opportunities for change always exist (Leeuwis & Aarts, 2011).

Communication

As mentioned before from a systemic perspective innovation involves the contextual re-ordering of relations in (multiple social) networks. According to Leeuwis and Aarts (p.26, 2011) “*communication*

obviously plays an important role in such re-ordering.” Taking into account that innovation is eventually performed by interdependent actors who interact with each other in numerous settings and networks, communication will be inevitably used to perform this interaction. So it can be expected that in the everyday conversations and communication between actors in a certain network, space for change (or manoeuvre) occurs and is negotiated. In literature on networks the concept of ‘communication networks’ is used to describe how communication plays a role in networks. Links between actors (i.e. relationships) are from this perspective seen as communication flows (Rogers, 1986). Therefore communication seems to be an important aspect of relationships between actors in networks to understand changes in networks.

Social learning

Rotmans (p.20, 2005) stated that social learning is crucial to transition processes, because neither the definition of a problem nor the direction of the solution is unequivocally known *à priori*.” Social learning is not the same as learning in the sense of the transfer of knowledge, but involves learning in terms of developing another viewpoint of reality in interaction with others. Interactions between people take place, as showed before, in networks. The process of social learning contains cognitive elements (i.e. recognizing the complexity of reality) as well as perceptions of one’s own abilities and the influence of social surroundings (Leeuwis, 2003; In: Rotmans, 2005). Social learning thus helps to develop some sense of coherence in the (possible) direction and organization of the actors.

According to Leeuwis & Aarts (2011) learning must be seen as a critical process for developing a favourable fit between innovations and their environment. So (social) learning seems to help achieve change that is functional, suitable and desired to the environment. It contains a process of finding out by doing what are directions for sustainable solutions. Or as state by Rotmans (p.38, 2005): *“By negotiation, adaptation, co-production and debate, actors change their own vision and redefine their own position.”* Changes within networks could therefore be seen as a process of learning by doing and a searching process with several outcomes.

Summarizing, when looking at networks in order to understand change processes a focus on the way actors within the network organises themselves, communicate with each other and develop by learning seems to be relevant.

3.3 TOWARDS SUPPORTING INFORMAL CAREGIVING

It has become clear that to understand the potential of an innovation such as the Compaan it is necessary to look at the system in which it functions. Furthermore to understand how systems

develop looking at networks is important. The actors within these networks are able to transform the system through processes of self-organization, communication and social learning. This paragraph explains how the theoretical framework could be applied to the issue of informal caregiving in eldercare. In this study the unit of analysis will be the system on the micro-level: the elder, informal caregivers, formal caregivers and other members that are part of the network of the elder. This means that each individual situation in which care is given to an elder is seen as a system. Each system is unique and built on the actions of actors that are part the network. So informal caregiver(s) are not seen as individual group, but as part of a system in which all kinds of actors and factors are present. Within this network actors could be part of the specified social, support and care network. Actors could move between this networks from one another by a change in role and/or tasks.

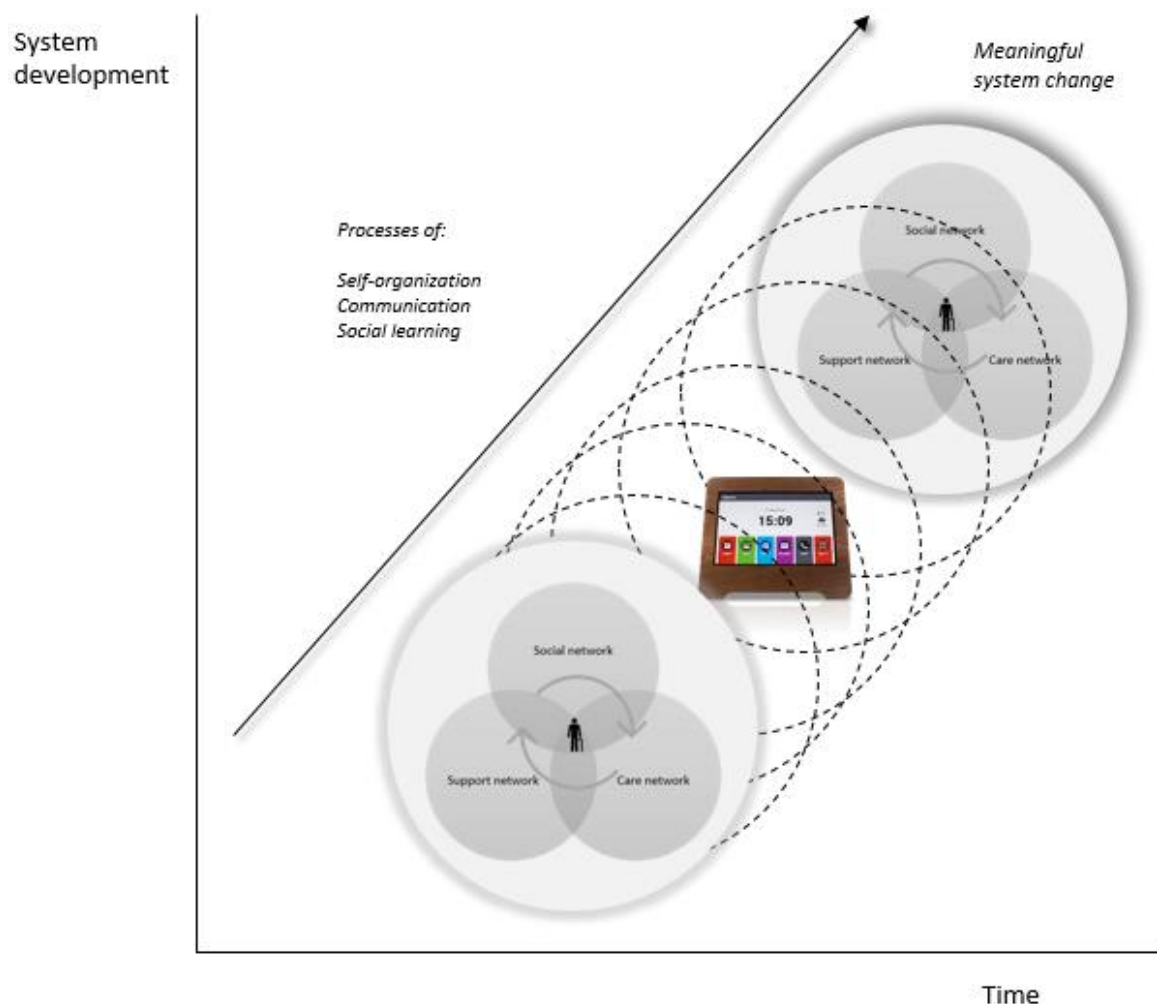


Figure 2 - Visual presentation of the conceptual model

This system develops over time and is constantly trying to balance modes of thinking, roles, tasks and ways of doing in order to succeed. In this study the Compaan is seen as technology added to a system

(as intervention). The question is how the Compaan is implemented in the system, how it enables the system to meaningfully change and how this could provide support to informal caregivers. The processes that could enable this change process are that of self-organization, communication and social learning. Therefore it is important to first examine who are important actors in the system (thus part of the network of the elder). This could be friends, neighbours, family members (including informal caregivers) and formal caregivers, both medically (e.g. home caregiver) as assisting (e.g. cleaner). Furthermore it is necessary to understand how the system is functioning before the entrance of the Compaan and to see how the system has developed after the introduction of the Compaan from the perspective of informal caregivers. This process of change should then be explained by looking at the processes that enable networks within a system to change – see *Figure 2* for the visual presentation of the conceptual model.

Summarizing, the Compaan as intervention is placed within a web of relationships involved in the complex system of caregiving to elderly. To understand how the Compaan could support informal caregiving, the system in which the care is given and the network within this system should be taken into account. Therefore the two sub questions addressed in this study are:

- 1. How are the relations between the informal care, formal care and care receiver seen from the perspective of the primary informal carer and what are system needs?**
- 2. How does the way the different actors are related influence the way in which the Compaan supports system change towards facilitating informal caregiving?**

4. METHOD

4.1 DATA COLLECTION

To collect the data different methods were used. The largest collection of data was originating from semi structured interviews. A second part of data was collected by using participatory observation, complementary interviews and scanning documents. These will be further discussed in the next part.

4.1.1 Semi structured Interviews

To gain deeper understanding of how introducing the Compaan into the eldercare giving system influence the way care is given and informal caregiving could be facilitated, semi structured interviews with informal caregivers were conducted. Although using a systemic perspective, including perspectives of other stakeholders (e.g. formal caregivers or the elder) was seen as less important, because the goal was to find the conditions of a system in which informal caregiving could be optimal. Because of the explorative character of this study, semi structured interviews were conducted because they could provide rich data to get insight in the processes in the system in which informal care is given.

Inclusion of cases

The cases were selected in collaboration with the company of the Compaan. First a selection was made of all the administrators of the families in which the Compaan was used private, recently (last 2 weeks), and during a period of at least two months. Expected was that the main administrator registered at the Compaan was likely to be the primary caregiver (based on experiences of the company) and therefore would have the overview on the whole care situation. From this list a random selection was made of 30 administrators registered at Compaan. Following the order of the list, phone calls were made to make a more specified selection. The criteria for inclusion were (1) presence of formal care (e.g. cleaner, home care) to understand the network composition and collaboration, (2) presence of one of more family members (not a spouse) providing informal care, as main Compaan buyers and experiences most burden, and (3) the interviewee being a primary informal caregiver and willing to participate. Three suitable cases were selected that met the criteria for testing. Based on the three interviews the inclusion criteria were slightly adapted so that cases in which no formal care was present, but another form of disability was present (e.g. elder being deaf), were included. After the first three interviews, thirteen other cases were randomly selected from the list. In total sixteen cases were included in the study. These sixteen interviews led to a point of saturation, meaning that the amount of new information found when conducting a next interview became low. The interviews were conducted in a semi structured way meaning that the same

questions were asked during each interview, but because every system got its own context and issues, specific adaptations in questioning were made – *see Appendix 3* for the interview checklist. All interviews were recorded, after having consent from the respondent. *Table 1* presents the fictive names of included cases, a case description and information about the interviewee. All cases included an informal caregiver who was registered as contact person at the Compaan.

Table 1 - Characteristics of the included cases.

CASE *	CASE DISCRIPTION	INTERVIEWEE
DE JONG [1]	Father, 93, Alzheimer disease	Son and his wife
	Living independently, Amsterdam	Engineer (technical)
	Extensive home care	Retired
	Daughter, son both caring, both distance	Married, children
MEIJER [2]	Mother, 84, Healthy	Partner daughter
	Living independently, Haarlem	Care related job
	No care, father in institution	Flexible job
	4 daughters, all caring, 2 distance, 2 nearby,	Married, children
BROUWER [3]	Brother, 68, Brain injury, forgetful	Sister (mentor)
	Living in care institution, Alkmaar	Care related job
	Extensive care (24/7)	Irregular
	1 brother, 2 sisters, 1 sister caring, all distance	Married, no child
VAN WIJK [4]	Mother, 80, Psychological // pain	Daughter
	Living independently, Haarlem	Care related job
	Homecare, 1x week; father in institution (Alzheimer)	Flexible job
	2 daughters, both caring, both nearby,	Married, children
MORREN [5]	Mother, 82, Diabetic // Alzheimer	Daughter
	Living independently, Sittard	Managing job
	Homecare, 4x day	Flexible job
	2 daughters, both caring, both distance	Married, children
HUISMAN [6]	Brother, 71, MS (mental // physical)	Sister and partner
	MS clinic, Zandvoort (from Rhoden)	Painting job
	Extensive care (24/7)	Flexible job
	1 brother, 2 sisters, all caring, all nearby	Married, children
KRAMER [7]	Father, 89, Diabetic	Daughter
	Elder apartment, Almere	-
	Home care, 4x day	Flexible job
	1 son, 2 daughters, 2 daughters caring and nearby	Married, children
JONKER [8]	Mother, 89, Healthy (but ageing)	Daughter
	Elder apartment, Tilburg	Ambulant mentor
	No formal care	Flexible
	1 son, 4 daughters, all caring, 2 nearby	Married, children
TAX [9]	Mother, 85, COPD	Daughter, elder
	Elder apartment, Berkel Rodenrijs	Care related job
	Only meal service	-
	Daughter, son, both caring, both nearby	Married, children
WOLTERS [10]	Mother, 78, deaf	Daughter, partner
	Living independently, Maastricht	Home care job
	No care	Flexible job
	son and daughter, both caring, son nearby	Married, children

P O S T M A [11]	Mother, 81, Healthy (but lonely)	Daughter
	Living independently, Putte (Belgian border)	Speech therapist
	No care	Fulltime job
	son and daughter, both caring, both distance	Married, children
K L O K [12]	Mother, 82, Healthy (but lonely)	Daughter
	Living independently, Kuddelstaart	Managing job
	Cleaner; father in institution	Busy job
	2 daughters both caring, both distance,	Married, children
B O S C H [13]	Mother, 93, medicines	Daughter
	Elder apartment, Lemelerveld	Care related job
	Home care 3/4 x week	Flexible
	1 son, 4 daughters, all caring -	Married, children
J O C H E M S [14]	Mother, 86, Healthy (but lonely)	Daughter
	Living independently, Amsterdam	Communication
	No care	Interim based
	1 daughter, caring, nearby, mother ill partner	Married, no child
J A N S E N [15]	Father, 80, Amnesia	Son
	Care institution, Eindhoven	Music teacher
	Extensive care, wife at home	-
	son and daughter, both caring, both distance,	-
B O U W [16]	Mother, 86, Alzheimer (1 st phase)	Daughter
	Living with spouse, Veenendaal	Care related job
	homecare	Irregular
	4 daughters, all caring, 2 nearby, 2 distance	Married, children

* The case names are fictitious names.

** This category is related to the decision to start using the Compaan. If the initiative came from the elder there is mentioned 'elder pull' and if the initiative came from the family there is mentioned 'family push'. Between brackets is further specified who was responsible and with what main reason.

Most interviews were held with the informal caregivers alone. In some situations (n=4) the elder or the partner of the informal caregiver joined the interview which sometimes enriched or limited the conversation.

4.1.2 Additional data collection

Additional data collections methods used were (1) informal interviewing, (2) participatory observations and (3) document scanning. Informal interviewing consisted of interviews with four formal caregivers and a number of conversations with employees or the owners of the Compaan. As agreed in advance once in two weeks I visited the office (varying from a few hours to one working day). During this visits informal interviews with the owners or other employees took place. When relevant issues were discussed, notes were made. Informal interviews with formal caregivers (n=4) were conducted to get more background information on (potential) Compaan usage by formal caregivers – see Table 2 source 1. The participatory observations and conversations were part of the collaboration with the company of the Compaan (e.g. attending meetings with local governments,

healthcare institutions and other companies). These meetings were directed at presenting the Compaan to relevant actors or building strategic alliances of which notes were made – *see Table 2 source 2*. Finally, the document scanning included a few documents related to the company (e.g. a manual) and one rapport on e-health usage. Document scanning was used to gain contextual information – *see Table 2 source 3*. Especially documents related to the Compaan were used to understand functions, options and possibilities of the Compaan. Data was extracted, by underlining relevant information. Overall, the additional data provided information on the functioning of the Compaan, the disconnection of formal caregivers to the Compaan and the potential developments of the Compaan.

Table 2 - Sources of data collection

SOURCE	ORGANIZATION	DATA	LOCATION
1. Informal interviews			
Case manager dementia	Home care organization	Phone interview**	Amstelveen
District nurse // intern	Home care organization	Physical interview*	Haarlem
Team manager	Nursing home	Email interview**	Haarlem
Home care employee	Home care organization	Email interview **	Sittard
Owners and employees	Compaan	Information	Bloemendaal
2. (Business) meetings			
Policy advisor // manager member services	Zorgbalans	Observation Meetings (2)	Haarlem
Manager member services // policy advisor	Carinova	Observation Meeting	Deventer
Councillor // policy advisors social domain	Municipality of Dordrecht	Participate in Workshop (1) Observation Meeting (1)	Dordrecht
Councillor // policy advisors social domain	Municipality of Lingerwaard	Observation Meeting	Lingerwaard
Councillor // policy advisor WMO	Municipality of Buren	Observation Meeting	Buren
Sales manager	Apetito	Observation Meeting	Bloemendaal
Sales manager	Beter Horen	Observation Meeting	n.s.
Director // Think-tank	Vegro	Observation Meetings (3)	n.s.
Owner	TicTac	Observation Meeting	Bloemendaal
3. Documents			
Manual Compaan// folder // website //articles in magazines	Compaan	Information	-
Ministry letter on e-health*** (2-07-2014)	Ministry of Public Health, Well-being and Sports (received by Compaan)	Information	-
4. Installation			
Installation Compaan by elder	Compaan	Observations // informational interviewing	Amersfoort

* *This interview has been recorded and transcribed.*

** *These interviewees were included based on snow-ball sampling. Informal caregivers that expressed that formal care members were not connected were asked to provide contact information of these members. The members were contacted by email or phone.*

4.2 DATA ANALYSIS

4.2.1 Semi-structured interviews

The recorded interviews were transcribed in medium detail (all sentences included, quotes include all words). The transcriptions are encrypted in order to analyse the data. This was done by organizing the raw data into conceptual categories and by creating themes or concepts (labels). First a method called 'open labelling' was used which includes identifying themes and assigning preliminary codes to gain better understanding of the mass of data (Van de Bunt & Nencel, 2012). This was done by marking interesting parts of the transcribed interviews and naming them. Second, axial coding was used to review and examine the preliminary codes to further specify the key concepts in the analysis. All corresponding concepts were put together and further specified. After that, the parts that were labelled the same were analysed and compared to understand the meaning, similarities and differences between them. When necessary defined labels were adjusted to come to a relevant division. Lastly, by selective coding the major themes guided the search process and quotes were selected to illustrate themes found. Sometimes quotes have been composed of two parts of the data that are related to the same issue indicated by using the symbol [...] (e.g. a question or irrelevant side information was left out).

4.2.2 Additional data

The additional data gained through participative observation, taking notes of meetings and scanning documents was used to improve the interpretation of the data gained by the semi-structured interviews. Besides that it was used to complement the analysis of the data gained by the semi structured interviews. This was done by using the notes, observations and information as complementary information to the findings related to the interviews. This is called triangulation of measure (i.e. using different methods to answer the same question) and is based on the idea that more can be learned by observing from multiple perspectives than by looking only from a single perspective (Van de Bunt, & Nencel, 2012). When additional data has been used to complement the analysis, this is mentioned in chapters 5, 6 and 7.

5 THE NETWORK AND SYSTEM NEEDS

As mentioned in the theoretical framework, to understand the functioning and processes of change in a system, it is important to look at the network within the system and the consequences of this network. In this chapter first the diversity of the network composition will be discussed (5.1), secondly informal caregivers feelings of burden will be addressed (5.2) and finally the needs within the systems before using the Compaan (5.3) will be discussed.

5.1 NETWORK COMPOSITION

The interviews showed that members, tasks, roles and size of the network within each unique system were diverse. The networks around the elders consisted of a varied number of family members (children, grandchildren and sometimes a sister or brother of the elder), a few close friends or neighbours and -depending on the health status- none, one or more formal caregivers (including cleaner or meal service provider). The size of a network differed strongly from elders having only one child and a friend to elders having more children, a number of friends and other relatives. In two cases the elder had no children and the partner passed away, resulting in a smaller number of family members as part of the network of the elder. The number of friends was in all cases low, mostly because many of them already passed away. Elders seem to have the most close relationship with (some of) their children and to a lesser extent with their grandchildren. In most cases one or more children were providing informal care to their parent(s) (or brother). Grandchildren, friends and other relatives were also important members for the elder, in providing social support by visiting and face-to-face contact. In some cases relatives of the elder also had an important caring function in the system. For example in the case of family De Jong the brother of the elder checked if he stood up every morning by letting the phone ring three times. Neighbours of the elder had a more shallow relationship by greeting each other and having a small talk. In some cases neighbours were also keeping an eye on the elder (thus more caring) or undertook activities with the elder. Contact between informal caregivers and friends or neighbours of the elder was not commonly found in the networks included in this research. An exception was the relationship between informal- and medical formal caregivers (e.g. GP or home care nurse). Based on the interviews it seemed that in cases in which the elder was very dependent, the family members and medical formal care members were more connected. Summarized, the network compositions within the included systems were very diverse and functioned all in a specific way.

5.2 INFORMAL CAREGIVER BURDEN

Besides the great diversity in network composition, also feelings of burden experienced by informal caregivers varied. Almost all interviewees expressed some feeling of burden related to providing care to their parent(s), but the heaviness of this burden was experienced differently. Most of the informal caregivers expressed that they found taking care of their parent(s) heavy. Reasons given were the responsibility that came with the care, the time it costs, the organization of care, the character of the elder, and the difficulty to obtain information on care related issues (e.g. budgets, opportunities and subsidies etc.). Especially in situations where the elder received a lot of care (e.g. more than a cleaner only) feelings of burden related to the informal care given were present. In the case of family Brouwer the sister explained that she was the only one responsible for the care of her brother which cost a lot of time and effort, also because she was having a job and lived at distance. In the case of family Huisman the sister explained that having the full responsibility for the well-being of her brother was very heavy. In the case of family Van Wijk the daughter explained that it was heavy to take care of her mother mainly because of her mother's psychical problems and instability. She described the situation as being 'never out her mind'. Another example is the daughter of family Morren who explained that her mother does not express any form of thankfulness, making it heavy. She also explained the time consuming process of collecting all the information regarding the care for her mother. It seemed that having a flexible job or being retired created more space for the family members who provided informal care. For example in the case of family Kramer the daughter explained that the burden was not too heavy or bothering her, due to the fact that she did not have a fulltime job and worked a lot from home. Besides that her father lived in a sheltered housing apartment, which made that she felt less pressure because formal care was always nearby. It thus depended on the conditions of the system in which the informal care was given if the informal care given was experienced as a heavy burden.

5.3 SYSTEM NEEDS

This part discusses which needs were present in systems and the aspects creating these needs. Overall it seemed that the reason to start looking for and deciding to buy a Compaan was because the communication within the system was not optimal or as desired in the eyes of some or all of the actors within the system. A broader perspective on this deep desire of family members and the elder to keep connected to each other is to look at the function of contact and communication in relationships. Contact could be seen as a prerequisite for maintaining a relationship, taking care of someone and involvement in someone else's life. If keeping contact becomes difficult this probably results in negative feelings amongst especially the family members. The interviews showed that a

number of aspects contributed to the need for more (adequate) communication: (1) changed communication habits (2) level of independence of the elder (3) feelings of shared responsibility (4) consequences of major life events and (5) distance between actors. Each of these aspects played a role within the system and contributed to the need for more communication.

(1) Changed communication habits

The first aspect that contributed to the need for more (adequate) communication was a change of communication habits. From the interviews it became clear that some of the actors within the network preferred to use other ways of communication to maintain the relationship with the other. According to informal caregivers, elders expressed feelings of 'not being part of' or 'missing something', whereas family members expressed the wish for being able to have contact in other (less time consuming) manners. This seemed to be related to a change of communication patterns in the system (e.g. from printed and face-to-face contact, to digital and online). Therefore the need arose for something that could support the system in facilitation of communication fitting the 'changed' system. Often children and grandchildren, sometimes the elder or sometimes both, expressed their desire to be able to use digital communication to stay involved in each other lives.

"So I thought like that's fun for him, and for us, well for us, because well, we are using WhatsApp of course, and we app, send messages to each other and I want to involve him as well in a certain way, to be able to, to send it to him. [...] Just to be able to say sometimes 'he dad, how are you? I am now here and here for something or whatever and to be able to share photos'" – Fam. Jansen

"Well it started with my mother saying that she thought she didn't get any photos of the grandchildren you know. Because everything nowadays is going by smartphone you know.., so real photos weren't present anymore." – Fam. Jonker

"... she just felt like 'everyone is communicating in an easy way with each other and .. I can't fit in'" – Fam. Bosch

In the relationship the elder got with friends and neighbours the desired ways of communicating seemed to be physical visits. This physical aspect of their relationship seemed to be so important that having contact in other ways (i.e. digital communication) was less suitable and desirable. So the different actors within the network of the elder had different communication habits in order to maintain their relationship and stay involved. In the case of family members it seemed that these habits were so different, that it resulted in a need for facilitation of new ways of communicating.

(2) Level of independence of the elder

Another important reason contributing to the need for more (adequate) communication was the level of independence of the elder. If the elder needed a lot of care and/or was very depending on care from others, informal caregivers expressed the need for more frequent and adequate communication (and information) for organizing and controlling the situation. In cases where the elder received care, but still was relatively independent (e.g. diabetic) there was less need for such an 'intensive' relationship. In such situation this even led to feelings of control and rest for family members. For example the daughter of family Kramer explained that her father was checked four times a day and because of that she did not feel the need to have contact with his formal caregivers. There was no need to communicate with assisting formal care members (e.g. meal delivers, cleaners, haircutters, pedicure etc.) from the informal carer's point of view, because elders managed that by themselves. Thus if the elder could maintain the relationship with formal caregivers independently, the family was not necessarily involved and thus the need for communication or information was low. On the opposite when the elder needed a lot of care and could not manage this by him/her self, the family was in need for more (adequate) communication.

".. you know, they are visiting him four times a day so, then they already have contact [...] it is, what we have is a family conversation once a year and in other cases if there is an emergency I directly go to him or they call me" – Fam. Kramer

(3) Feelings of shared responsibility

Another aspect contributing to the need for more (adequate) communication was a feeling of shared responsibility. These feelings were related to the desire to collaborate and to be involved. When a number of members in the network felt a shared responsibility towards the elder, there was a greater need of communication (in order to discuss with each other) and organizing (making appointments). For example in some systems the children of the elder were very well connected and provided care together with a clear division of tasks. This asked for some kind of discussion about the organization of care that implies the need for communication. In situations where only one or two persons were responsible, there was less need for this.

"I am going with her to all the appointments, [...] my brother is doing other things, once in the week she has dinner at his place.. and he is taking care in case of emergencies, when I can't go, he is doing groceries with her.. He is living very close by, so he can easily walk in with her, so he is doing other things. And I have another sister who is responsible for the plants.. and my other sister is doing the administration, finance and economy and that kind of stuff, she is working on the contract etc." – Fam. Jonker

(4) Life events

The next aspect contributing to the need for more (adequate) communication was the occurrence of a life event (e.g. a partner dies or a disease is diagnosed). This often resulted in the change of needs (e.g. different organization of care) and/or of limitations and abilities (e.g. tasks and roles), increasing the importance of communication. For example in the case of family Brouwer the sister explained that after her brother got sick the need for having more contact arose. She explained that her brother was not a kind of person that wanted to have a lot of contact with his other brothers and sisters, but his changed health status asked for someone to take care of him. A life event in some cases also led to the need for other ways of communicating. For example because the partner of the elder who was able to use a computer died. Losing a partner, friends or other family members obviously also reduced the number of actors with whom the elder could communicate. At the same time the importance of communication with the members left increased. Sometimes life events thus seem to have such an impact on the functioning of the total system that there is a need for other ways to stay connected and therefore for more adequate communication.

"Well you just see that his network around him becomes very small.. I mean all his brothers and sisters died, his wife passed away, and you know friends are dying left and right.. so who visits him that is me, and my sister and once in a while the grandchildren, but that is it"-
Fam. Kramer

"Well my mother start using it at the time that my father lived at home.. and they didn't have a computer.. so eh.. but the communication became very important, because my dad need a lot of care.. and then you just only have the phone, or we should visit him." - Fam. van Wijk

(5) Distance between actors

The last aspect contributing to the need for more (adequate) communication were situations in which network members were living at greater distance from the elder. Distance played a role in case of living at distance, working at distance, during holidays and when people were not mobile enough to overcome distance. The distance made it difficult to have contact when it was only possible to call or visit someone. It was or time consuming or without seeing the other and both required having time for it at the same time (happening real-time). This created the need for video calling and sending online messages to overcome distance (still seeing each other or when having time). The need for more adequate communication seemed to be especially present when the elder needed more care and the family wanted to be more involved. For example the sister of family Huisman explained that taking care of her brother who got very ill created a need to connect easier and in more diverse ways because all family members lived at great distance from their brother.

"We were looking for, because he lived in Rhoden, that is in the north, in Drenthe and we were all living here (Leiden)... we looked for something to communicate" – Fam. Huisman

Related to working distance, it is more about the flexibility of someone to provide care when needed. For example in the case of family Kramer there are two daughters and one son who is living in Canada. The two daughters are living both relatively nearby but one of them is working at quite some distance from home and thus cannot provide care as easily as her sister who is flexible. On the short term, the distance during holidays or the non-presence due to immobility (e.g. birthday parties) created the need for more (diverse) communication.

"When we are going on holiday, she is vulnerable and old.. then I find it pleasant to keep contact with them" – Fam. Jochems

Summary

To shortly summarize, the interviews showed that the members, tasks, roles and size of the network within each unique system were diverse, resulting in different feelings of burden discussed in paragraph 5.1 and 5.2. Despite this in all systems there seemed to be a need for more adequate communication. This need resulted from having different communication habits, more dependent elders, a feeling of shared responsibility, the occurrence of life events and distance between actors.

6 COMPAAN USE AND CONSEQUENCES

After looking at the network composition and existent needs within the system, in this paragraph the use of the Compaan in the system and the process of adopting and starting to use the Compaan within the system will be discussed (6.1). The Compaan was used in diverse ways to fulfil different needs. To achieve this usage within the system process of social learning, communication and self-organization played a role (6.2). Furthermore, the consequences of this use will be addressed (6.3).

6.1 COMPAAN USAGE

In general in systems there was either a high intensity (i.e., daily contact), or a relatively low intensity (i.e., once a week, or every few weeks). Elders used it often at a daily basis. Regarding the placement of the Compaan for most elderly it stood on a table in the living room (often besides a favorite chair/sofa) or in the kitchen. The most important reasons for the decision of placement were easily usage by the elder and being close by a socket. More specific, the interviews showed that the Compaan was no longer just 'a device' but often was seen as a specific tool fulfilling one or more needs. Usage of the Compaan was specifically adapted by a system so that it had a different function in each system. Words used to refer to the Compaan were for example: 'a family thing', 'my mother care-communication dossier', or 'communication tool' (i.e. 'a kind of WhatsApp'). Based on the interviews seven kinds of Compaan usage were distinguished: (1) *communication tool*, (2) *(care) organizing tool* (3) *(family) storage tool* (4) *entertainment tool* (5) *status object* (6) *control mechanism* and (7) *portal to the world*. Hereafter these different approaches to Compaan usage will be discussed.

(1) Communication tool

In most systems the Compaan was used as a communication tool for sending messages, photo's, videos and skyping. Obviously the functionalities mostly used for this were the message-, photo-video- and video calling function (i.e. skype). It was not only used for the facilitation of communication in general, but also to select which communication channel suits the needs within the system the best. Especially in caring situations this seemed to be helpful because the best means to communicate could be selected. For example some interviewees mentioned the importance to have visual communication in addition to the regular phone calls or texts messages. In these cases the health status of the elder led to the desire of the informal caregiver to easily being able to see the elder. But also when children lived at distance it was an important tool to make it possible to see each other without the need for traveling. Another situation in which the Compaan fulfilled an important gap in the communication needs was during holidays. A number of informal caregivers

explained that the elders did not like it when family members were far away. The Compaan was also used to facilitate a form of 'direct' contact similar as using WhatsApp (i.e. instant messaging). Lastly, in one system there was a specific high need for making communication at distance possible at all because this elder was deaf. Therefore, the system had trouble with the transmission of simple but essential messages such as canceling or changing the time of the visit. So the Compaan was used as communication tool facilitating it in such a way that it suited the system.

"Well obviously skypeing is very important, that you are able to see how someone is doing, how he is looking" – Fam. Huisman

"My father would have loved to go there [Canada], but that wasn't possible anymore because of his health, well and now he is able by using skype to see how the house looks, how does the environment looks.. Yeah and that is for him fantastic" – Fam. Kramer

(2) (Care) organizing tool

In a number of systems the Compaan was used as organizing tool in supporting the planning of appointments, remembering appointments, establishing division of tasks, keeping important members up-to-date with important information and to document important information. The functionalities used for this reasons were mostly the agenda function, the logbook function and the medication recall. Support in the planning of (care) appointments was very important for families to plan visits to the elder in such a way that they were not visiting the elder at the same time. In the same way the agenda was used by the informal caregiver(s) to add medical appointments. For example the daughter of family Jonker made an appointment with the dentist and then simply notified it to her mother by using the agenda function. Besides using the Compaan for planning, it was also used for remembrance, especially for those elders that suffered from dementia. For example by putting appointments in the agenda with a recall in advance. In the same way the medication alert function (part of the agenda) was used to assist elders in remembering. For example the daughter of family Tax scheduled the alert at a specific moment during the day when her mother forgot her medicine intake. Another important use of the Compaan was to divide tasks amongst (family) members. For example the agenda was used to divide the tasks related to the transport of the elder in a clear way. The Compaan was also used to inform each other in order to facilitate care. For example the agenda was used in a number of systems to involve the elders in their care by giving them an overview of their medical appointments and/or to inform other family members. The family Jonker used the logbook function to keep the family informed. After a visit with their mother to a medical specialist, an update was send to the rest of the family so that they know directly what happened. Lastly the Compaan was used to document information. The daughter of family Morren

used the logbook function to document all the health care data related to the kind of medication her mother uses, contact information of the GP and other medical contact persons. She used that for example when she was working and needed to order new medications for her mother. In this situation, the logbook was used as a sort of drug specifications register and contact book. So Compaan usage assisted system in organizing care.

"So the fixed appointments she has, she bridges every Wednesday, those are in it.. and I just add an appointment with the dentist this morning, and I put that in it as well. And all the birthday celebrations we go to, and who drives.. and how she will be picked up" – Fam. Jonker

(3) (Family) storage tool

Another interesting manner in which the Compaan was used, was as a (family) storage tool. A platform where all kinds of pictures, family messages and information was shared amongst the whole family. It was thus not only about the communication between the elder and the other members of the network, but also about consulting messages and photos send on the Compaan by the elder and (visiting) family members over time. So, it was used a storage tool in that it also gave the opportunity to collect all kinds of memories on the Compaan. Using digital forms of communication instead of traditional ways of communication also affected the ways in which memories could be kept: from tangible to digital. Using the Compaan for communication supported the elder and the family members in collecting and storing memories. This was both for entertainment reasons (e.g. nice photos) as well as functional (e.g. have appointments black-on-white). Related to using the Compaan for the read-back of information the daughter of family Van Wijk explained that it was very important to use the message function to make appointments in order to enable her mother to document important information. Both for the elderly as well as informal caregiver it was important to have things clearly written down to prevent discussions. Summarized, Compaan usage supported the storing of precious memories of the elder and providing access to these memories. It also supported systems in the 'storage' of important information to keep things clearly and therefore also is important in 'caring'.

"She likes the pictures on it very much, so if she went somewhere and there is a photo available or we have been somewhere and we make a picture, I [...] just scan it with my phone and then put it on the Compaan" – Fam. Morren

"..and also if something happens, that it we have things black on white, that is also nice, with parents, a mother that forgets things sometimes, or 'what about this?' Then she is able to read it back, you know" – Fam. van Wijk

(4) Entertainment tool

The Compaan also functioned in some systems as a kind of entertainment tool for the elderly and sometimes also for family members visiting the elder. Functions which played a role were the games, news, internet, church, and recently the 'quote of the day'. This was both useful for the elder, as well as for the informal caregiver(s). Especially when the elder depended on others for entertainment during the day, informal caregivers found it important that the Compaan provided entertainment for the elder. Related to the usefulness for the elders the son of family De Jong explained that his dad was using the Compaan during each day to play on the internet and the informal caregivers of the families Meijer, Tax and Klok all explained that their mothers liked playing games on the Compaan. Sometimes Compaan usage also facilitated things that were no longer possible or had been never possible but important to the elder. In one system the elder was used to read the newspaper but after she moved to another apartment at the eleventh floor it was difficult to pick up her newspaper on the ground floor. Using the Compaan to read the news provided an easy solution. The daughter of Family Bosch explained that her mother was not able to read the newspaper anymore because of her eye problems, but because of a large letter type she was able to read it on the Compaan. Related to the usefulness for informal caregivers, the sister of family Huisman caring for her brother living in the MS clinic expressed her feelings of happiness knowing that he got something to do during the day. In the same way the sister of family Brouwer told that she liked the distraction provides by the pictures stored on the Compaan to her brother. Also the possibility of using the Compaan as digital photo frame was seen as nice for elders to look at.

"So I am very happy if I see that he is doing patience.. because that is they only thing he does at the moment [...] So I send an email to them [nurses] like 'God it would be very nice if Kees is able to do something when he is laying in his bed.. could you please turn on that thing'" – Fam. Huisman

The daughter of family Bouw explained that it was very important to create some kind of entertainment for her mother to protect her father (from feelings of burden). In some systems the Compaan was even used for entertainment for family members visiting the elders (especially grandchildren playing games on it).

(5) Status object

In some systems the Compaan was also used as a kind of status symbol for the elderly. Some elderly felt that using the Compaan said something about who they are as a person according to their informal caregivers. This resulted in positive feelings for the elders as well as informal caregivers. For example in the case of family Tax the elder was also present during the interviews and told that she

did not like to undertake a lot of activities with other elderly living in the apartments as others did. During the interview it seemed that both the elder and daughter felt proud of the fact that she was able to use a tablet. They addressed it as a 'modern' way to spend your time as elder. In some cases using the Compaan seemed to be important in shaping the imago of the elder like 'I am the 'first' with a tablet'. In the case of family Bosch the Compaan was also used by the elder as information portal to other elders that were living in the residential complex. When someone passed away in their village the church bells were ringed so that everyone would know it as a catholic tradition. Because she was able to search on the site of the church who was passed away other people came by to ask it to her. Although this seems to be specifically relevant for the elderly themselves, also the informal caregivers seem to be feeling some kind of proud or satisfaction that it has a positive effect on the elders feeling useful or confident.

"Yeah they are all surprised he? Like 'you have never been so digital'.. he because you are 85 and you are using a tablet.. [...] And is it not amazing that you are able to use it and that you can entertain yourself with it?"— Fam. Tax

"..and for her it was also.. status I believe. She is living in an eh.. in a residential complex, twenty houses, all these people have their own home.. well and she got a tablet, so she was the first with an internet connection, well she found that really cool you know.."— Fam. Bosch

(6) Control mechanism

Another very important way in which the Compaan was used in a number of systems was as a control mechanism. This seemed to be especially important in providing in the needs of informal caregivers. The Compaan then was used at distance to control the situation at the elders place by checking if the elder was doing well and checking if the elder received a message. The most important functions used for this reason were the good morning alert and the watching function. Interestingly, some informal caregivers explained that the positive way of 'checking' if everything was alright and the possibility to use it when needed was of great value to them. It was not only *possible* to use the Compaan to control the situation of the elder, but also in *specific situations* when there was a need for more control or having control in a different way. For example in the case of family Tax and Van Wijk the good morning alert was used to see if the elder stood up and in the situation of family Bosch they send a message and used the watching function to check the status of the elder. Thus the Compaan provides on the one hand a function that can be used systematically and another that can be used more indirect and occasionally.

"My older sister is living in the same village as her, she is visiting my mother regularly, but she also is a lot with vacation, so

then she is not around. And then eh.. ok how is she doing?, and then is send a message to my mother and I directly watch how long it takes her to open the message. Like 'God, is she..' yeah, really I kind of check.. and then I see 'oh within a few minutes she has read it, oke fine she is alright'” - Fam. Bosch

“The Good Morning app we use, so that I know that she stood up, and that I know that everything is oke” – Fam. van Wijk

(7) Portal to the world

An unexpected way of Compaan usage is as portal to the world. This means that it enabled elders with or without collaboration of family members to enlarge their worlds. As discussed in the paragraph about the network composition, their networks are often not very large (anymore) due to people passed away and new relationships are not build up easily. As a consequence their worlds have become smaller, especially in combination with lower mobility of many elders. It seemed that this was the reason within a system to deploy the Compaan to bring the world closer to the elder(s). The most important functionality used for this reason was internet and to a lesser extent photo's or video's. For example in a lot of cases the informal caregiver was searching with the elder on the internet for practical issues (e.g. clothes; new watch) and/or to illustrate issues where they talked about. Sometimes the photo function also was a way to enlarge the world of the elder. For example the daughter of family Van Wijk told that during the holiday she sent pictures to her mother and felt that she gave her mother a kind of entrance to another world. The Compaan was also used to enlarge the world of the elder by involving them in things they otherwise would not be able to be involved in. For example in the case of family Kramer the bad health conditions of the elder made that he was not able to attend birthday parties. However, by using the skype function a new way of being present was realized and made that he could be part it by using the Compaan.

“I said, well dad, there it is, it was in Uzbekistan, with all those tribes and so on.. and then you can show it and that kind of things, or if he needs someone, you can search it for him” – Fam. Kramer

“Especially sending pictures during the holiday was very nice. She really liked it and she also said that it gave her the feeling that she was a little bit part of it” – Fam. van Wijk

6.2 PROCESSES OF CHANGE

The Compaan is used in different ways by using different functions within each system depending on a number of reasons. Certainly common is that the entrance of the Compaan to a system led to change within the system regarding tasks, roles, ways of working and communicating. As explained in the theoretical part (paragraph 2.2.3) there are three processes that could explain processes of

change in systems: social learning, communication and self-organization. The process of learning and communication seemed to be the most important in adapting usage of the Compaan to the system. To a lesser extent also self-organization played a role. An interesting process of learning was described by a number of informal caregivers. In some systems a process of learning was especially important at the beginning to learn the elder to start using the Compaan. In other cases it was necessary to keep repeating instructions on how to use the Compaan for certain ends. Informal caregivers (and sometimes also other family members) needed to assist the elder in learning how to use the Compaan. During the interviews they talked about the importance of: ‘rehearsing’, ‘explaining’, ‘practicing’, ‘experimenting’, ‘trying’ and ‘stimulating’ which could be all related to a process of learning. Interestingly, the Compaan is developed so that it should be very easy to use for all elders, still many of them need help in using it. This seemed to be related to abstractness that some elders experienced in using the Compaan. It could be divided in the abstractness related to the use of specific functionalities and abstractness related to usage of a tablet in general. Functionalities that caused problems were the internet, news, the ‘quote of the day’, skyping, photos and the watching function. Usage of these functions was still very difficult for the elders because they were not used to techniques that enabled them to see people on a screen, have photos directly on their device or understand how others could see what they are doing on the Compaan at distance. Usage of the internet function was very difficult for almost all the elders, probably because this required a whole new way of thinking. One interviewee explained that using google was already difficult because they did not know what kind of words they needed to enter to search something.

"It is of course always difficult to, yeah where shall I go on the internet, that is for the elderly of course also... they don't know where to go, you know.."—Fam. Tax

Processes of social learning were also used aiming at developing new perspectives or modes of thinking. In this process the family members who already adapted to this thinking in digital connections were trying to learn the elder how it worked, in order to create the opportunity for usage in the system. Abstractness related to the general usage of a tablet were seen in problems with things as ‘swiping’, using a ‘touch screen’ and understanding the space and connections.

"Yeah at the beginning [...] she talked about the display, and said I am at the end of my page, so sweet. So she didn't understood that you are scrolling, you know.. totally not"—Fam. Jochems

Also processes of communication seemed to be important in changing the system towards using the Compaan. For example the daughter of family Bouw explained that she encouraged her daughter to send pictures to her grandma. However, at the same time also a process of social learning was present here, in that she tried to teach her daughter to think differently, to achieve more optimal

communication for the elder. In the same way also in other systems the contact person registered at the Compaan asked, encouraged and stimulated other members of the network to use it. These were both family members as well as friends of the elder (e.g. by sending them an invitation) and formal caregivers (e.g. asking them to participate). Other situations in which communication formed an important process in anchoring the use of the Compaan in the system was when elders did not respond to messages, alerts or the Compaan at all.

"She doesn't have to receive a message every day, but I really tried in the beginning to stimulate also to the grandchildren by saying 'well if you walk through the city', my daughter lives in Amsterdam, .. 'just make a picture, grandma loves that' [...] but I know how that works with my children, once in a while they think 'o yeah'" – Fam. Bouw

"And during a period I only got messages of the Compaan that she didn't respond [to the good morning alert].. so at some moment, I don't get stressed immediately like 'oh no', but I did say to her 'I really want you respond, because if you don't then I need to call you', because she is also old, and it has to be in her system of course" – Fam. van Wijk

Processes of self-organization were less important, but present in logic changes. For example in the situation of family Bouw, with the deaf mother, the family easily switched without a process of communication or learning to using the Compaan to communicate with their mother instead of calling the aunt to pass through that message. It was just a logic change to start using the Compaan to achieve a more optimal situation.

6.3 USAGE CONSEQUENCES

In this paragraph it will be about the consequences of the use of the Compaan. As described before the Compaan is used differently amongst systems and fulfils different roles within these systems. There are broadly four kinds of consequences of usage for informal caregivers separated: (1) feelings of control and rest; (2) more frequent and diverse communication; (3) feelings of satisfaction, happiness and less guilt; and (4) easier organization of care.

(1) Feelings of control and rest

In almost all cases the use of the Compaan resulted in feelings of control and rest amongst informal caregivers. This was mainly due to the possibilities to control the situation of the elder better and at distance. Sometimes the informal caregivers also emphasized that the Compaan made it easier and more comfortable to keep control. It required less action, provided a family with more information they otherwise would not have and it offered a more comfortable way of controlling. Sometimes it also resulted in less time needed because there was less need to visit the elder constantly. The 'good

morning' function and watching function were the most important functions that contribute to this feeling of control. Obviously this feeling of control also resulted in a feeling of rest, both for the informal caregiver(s) and other (family) members as well as for the elder. Using the Compaan resulted in having more information and more possibilities to know if the elder is doing well. It also supported the organization of care in helping to divide tasks between informal caregivers (i.e. one does not have to call or go there every day) and in checking if the elder has received a message. This prevented the informal carer from the need to call to verify if the elder got the message. These controlling mechanisms were important in almost every system, although for systems in which family members were living at a greater distance the need seemed to be even higher.

"I got the feeling that I have more control over the situation at distance, so that I don't feel the urge to visit her constantly" - Fam. Morren

"we use the agenda to put in who is going to my father, because that, it has not been long that my father is taken in the nursing home, and that is very important for her rest actually, it is now saying that I will go to my dad this afternoon, doctors' visits.. the hairdresser.. I try to eh, that the necessary things, that they will be included" - Fam. van Wijk

"That was very uncomfortable.. or I just arrived too late.. and then my mother was completely upset and I was also worried that something happened, yeah that kind of things" - Fam. Wolters

(2) More frequent and diverse communication

The second consequence related to using the Compaan in the system was more (diverse) communication. Informal caregivers explained that the diverse options that the Compaan provided to communicate made the communication more comfortable. It was for example less bothering for the elder because calling was replaced by text messages or agenda planning, resulting in more flexibility in reading the message (e.g. not necessarily need time at the same moment to communicate). But also because the communication form could be adapted to the kind of relationship that existed for example between the informal caregiver and the elder. Using the Compaan also resulted in more frequent communication in many systems during special periods (e.g. such as vacations) as well as regularly. Another example in which the Compaan helped to create a more frequent regular communication pattern was in the case of family Meijer. The son-in-law explained that the Compaan changed the communication patterns so that two sisters living at distance from the elder had more contact now. He concluded that the contact increased by using the Compaan and that it also helped to lower the burden for the other sister. Thus the Compaan supported the system in establishing more optimal communication. Furthermore in a number of cases the informal caregivers explained that using the Compaan resulted in more frequent

communication with their children (i.e. elders' grandchildren). In the case of family Bouw it even helped to communicate directly to her diseased mother instead of sending messages to the phone of her father. Consequently, her mother became more involved and 'independent'.

"It has become easier.. you know, they are sending pictures more easily, or they send a message, or they skype.. and that is of course very nice. And it is also easier to .. for all those grandchildren, you know there is a lower threshold" – Fam. Kramer

(3) Feelings of happiness and satisfaction

Closely related to the consequence of more frequent and more diverse communication, informal caregivers also clearly explained that using the Compaan was not only for their own benefit but also and foremost for the elder. There was a kind of overall satisfaction and happiness that the Compaan could help the elder to do something during the day, having distraction, stimulus or being less dependent. Sometimes it even seemed as if it was a way to reduce the feelings of guilt amongst the informal carers because it provided something elders could do if they do not receive (a lot of) visits. Knowing that the elder uses the Compaan and becomes happy of it also affected the feelings of most informal caregivers. For example in the case of family Tax the daughter explained that she was happy that her mother became more involved in their lives and in the lives of her children (especially in the daily life activities). She also stated that she was happy that although her mother does not like to be involved in the activities available in the home care centrum, she now can say: *'I am oke with it, I have my tablet'*. Furthermore she explained that before they got the Compaan she always bought clothes for her mother and then took them to her asking if she liked them or not. However by using the Compaan her mother is able to participate in the searching process and therefore is more involved in the matter. Using the Compaan as portal to the world seemed to enable informal caregivers to include elders more in the process.

"I think still that it can mean a bright spot.. you know, a message just a stimulus. I am still counting, I am kept updated, although he would never express it, but I think that it is true. And for us it is also a means to active him" – Fam. Jansen

"I also enjoy it of course that she likes all the messages.. [...] I just hear that she likes it, and when I visit her and she saw a picture then she has complete stories to tell about it" – Fam. Bouw

(4) Easier organisation of care

The use of the Compaan led in most systems to support in organizing care. This was due to the reduction of time, easier communication, easier planning, easier sharing and the possibility to involve more family members, even when living at distance. For example in some systems the use of the Compaan as storage tool (e.g. of medical updates) resulted in more involvement of family members.

Obviously in systems where the Compaan was used as an organizing tool, it provided assistance in organizing the care through planning transport, controlling the well-being of the elder and in providing social support. For example in the case of family Meijer the son-in-law explained that the use of the Compaan in the system resulted in less pressure for the sister living nearby their mother, because sisters at distance also were having more contact. This also reduced the time needed for the sister living close by because she did not need to visit her mother anytime. Finally the 'improved' communication as described before also helped in the organization of care in supporting planning, sharing of information and being more involved in the life of the elder.

"And it has made organizing the care for him more easy, so for example that agenda, putting those contacts in it, so that he knows, that I know that he reads it one more time"— interview 3

"I don't have the feeling that I need to go there all the time, [...] it saves a lot of time"— interview 9

Summary

To summarize, the Compaan is used in diverse ways in accordance to the system needs. It is used to improve communication, organize care, as control mechanism, portal to the world, entertainment and as (family) storage tool. The system adapted to the use of the Compaan in these ways by mostly a process of social learning (teach the elder how to use it and to think about it) and communication (encouraging, assisting and negotiating) and to a lesser extent self-organisation. The consequences of using the Compaan helped informal caregivers in the organization of care, communication with each other and the elder, feelings of rest, control and satisfaction about the well-being of the elder.

7. NON-USE AND UNREALISED POTENTIAL

The previous part extensively discussed ways in which the Compaan is used in systems, the process of change and the consequences of usage for informal caregivers. This section discusses why the Compaan sometimes was not able to support the system. On the one hand this was due to non-use (current design and functionalities were not used) and on the other hand because of unrealized potential in usage (function/design/service aspects that have not been developed). Reasons for non-usage (7.1) and aspects of unrealized potential (7.2) will be discussed hereafter.

7.1 NON-USAGE

Based on the interviews six reasons were found that explain why some functionalities were not used in systems: *(1) no need or relevance (anymore); (2) no time, motivation or skills; (3) undesired effect on the system; (4) costs; (5) not working well and (6) lack of knowledge.*

(1) No need or relevance (anymore)

Often there was no need within a system to adapt to other ways of doing things when a system already found a way to deal with something. For example if actors within a system found a way of ensuring the medication intake or the elder read the news through a regular newspaper, there was no need to use the functionalities on the Compaan related to this. The health status of the elder, and the preferences and abilities of the members of the network determined the relevance or need to use the Compaan. However these aspects were often related to a moment in time, which made it a flexible process of use and non-use. Changes within the systems sometimes made that the use of the Compaan for certain purposes was not relevant any longer. Related to the health status of the elder, if an elder was in a relatively good condition using the medication recall was not relevant. If an elder used medication but was able to manage it, there was also no need to use medication recall. If there was formal care present the medication recall function was not needed anymore. If the family is already going with someone to visit the GP, connecting the GP to the Compaan becomes less important. So the health status of the elder influences needs within the system and therefore also the possible use of the Compaan.

Sometimes the opposite was true. The elder was at the beginning able to do many things himself but after a while certain things were no longer possible. A number of informal caregivers explained that they planned to use more functionalities when the health status of their father or mother would decline (e.g. good morning alert or medication recall). Thus also thinking about the future and being

aware of a possible changes in the health status or situation can led a need/relevance to use functionalities.

"... surely before he got the TIA we were skypeing for an hour talking with him, and then we showed him things and he was able to show things. He loved it." – Fam. de Jong

Sometimes there was no need or relevance at all to use the Compaan. For example in most cases the family was used to use WhatsApp messenger to communicate with each other. WhatsApp fitted their ways of doing better than using the Compaan so there was no need to change.

"We have a lot of contact, but we are using WhatsApp for that. I always have my telephone with me and I honestly haven't thought about using the Compaan for that.. It actually is something apart from the Compaan, that belongs to my parents" – Fam. van Wijk

(2) No time, motivation or skills

Sometimes functions of the Compaan are not just used because the elder or others were not motivated to use it or because it cost too much energy and time to implement using the Compaan in the system. Motivational issues were related to elders' characters, certain relationships or feelings of not being able to manage. Time issues were related to the energy and time needed to learn to use certain functionalities or the Compaan at all. An example of a motivational issue is that of the elder of family Morren who was not interested in playing games at all and therefore did not use this function. In the same way some types of relationships between parents and children did not provide space to use all kinds of communication channels. In a number of cases the informal caregiver explained that they did not feel the need to use for example skype, because the relationship between them and the elder had never been like having 'cosy' contact. Motivational issues played also a role in the decision not to participate in using the Compaan. In some systems there was a real need and desire for connecting the formal care members in order to intensify and enable easy communication and planning. Family De Jong thought it would be ideal if the GP could keep contact by using the video call function of the Compaan. But the GP was not able/motivated to do that. Instead after a while, his father did not respond to invitations of the GP at all and told the GP that he should come and visited him at home. Therefore the GP started to visit him at home. However, using video calling on the Compaan probably was a very good solution costing less time for the GP. In the same way other informal caregivers expressed that formal care member were not always motivated (or able) to use the Compaan.

"If care institutions would know more about it.. and.. that they desire to work with it.., you know, they all walk with their stupid notebooks" - interview 2 (391)

In some cases family members tried to use it by using someone else's account and stopped because it did not work. For example in the case of family Jansen and family Brouwer the interviewees explained that their sister(s) and brother are not connected to the Compaan because they could not work with it. They found it difficult to implement using the Compaan and after a few tries they gave up on it. However sometimes it is also about not willing at the side of the friends of the elder, whereas the main informal caregiver would like it.

"I also told it to my sister, like try it on my account.. but somehow she doesn't do it.. she doesn't have the skills to just whop add a photo" – Fam. Jansen

There were also situations in which it just cost too much time to adapt the system in such a way that using the Compaan in a certain way became useful. For example the daughter of family Tax explained that in the beginning she tried to play some games with her mother at distance. However, because it was too difficult for her mother the daughter needed to assist her which cost a lot of time. As a result they do not use it anymore. Finally related to time needed to facilitate Compaan use in general in some cases formal caregivers did not have time to help the elder with things as connecting it to electricity or turning the device on.

(3) Undesired effect on the system

Sometimes things were getting worse when functions of the Compaan were used. Due to a process of trying out a (new) function or due to an automatic installation of a new function on the Compaan (with an update) usage changes. Specifically the installation of a new functionality without the 'permission' of the informal carer seemed to be a sensitive issue. This resulted in 'distraction', 'confusion', and 'frustration' amongst both the elder as well as informal caregivers. During a number of interviews there was mentioned that the relatively new functionality 'tegeltjeswijsheden' distracted the elder, leading to question (e.g. 'from who I got this message?') or resulted in an interruption for elders writing a message.

"Well for example the quote of the day, that is only distracting him.. he can't read it, what does he need to do with that? So I put it off as well, fortunately there is the possibility to turn it off" - Fam. Jansen

Negative effects as result of trying out a new function were mostly related to unexpected reactions or haziness. The family De Jong tried out the recall function of the agenda which resulted in such an unexpected reaction. The son wanted to use the agenda to announce and remind the elder of appointments. So he and his sister added all his appointments to the agenda including the appointment for day-care. However their father did not want to go there. So the reminders resulted

in panic, him sending the taxi away and not allowing people to enter his house. Therefore the agenda was not used anymore for these appointments. Instead his daughter now got the tasks of picking him up each Thursday at 12:00 at bringing him to the day-care. An example in which trying out something that resulted in indistinctness is that of family Jochems. The daughter explained that she liked to start using the agenda on the Compaan. However her mother still used a 'normal' agenda and thus using the agenda function interfered with the 'old' way of doing things. This led to a less optimal functioning system (using two agendas) and resulted in more confusion rather than using only the paper agenda.

"No no, I tried it with mom, but she also got a large paper agenda and what she is doing is putting some things there and other there, so I thought that is not working" – Fam. Jochems

(4) Costs

In some cases it was due to the costs related to adding extra members that not all family members were connected such as grandchildren, cousins or even children of the elder. The Compaan costs exist partly of a pre-set amount of money (for the device itself) and partly of a monthly amount of money (€ 12.95) that includes the service and the access for two contact persons. If a family wants to add more contact persons this costs €2.50 for each person to a maximum of €9.95 each month. During some interviews the extra costs related to gain access for an extra contract person seemed to play a negative role. It probably prevents an optimal connection of members of the network to the Compaan.

"No we didn't add the grandchildren, because that would also result in more costs I believe.. so then we thought like well we take care of it that it will be send through" – Fam. Klok

(5) Not working well

If (a function on) the Compaan was not working very well by itself obviously it affected the use of this function negatively. For example a lot of interviewees mentioned during the interviews that the skype function was not working very well. The complexity of connecting, an instable connection and the difficulty for some of the members to understand how to use it, resulted in some systems in less usage and in some other systems in non-use. In the same way also problems with the video, agenda, and logbook were mentioned. For example in the case of family Tax the agenda function was not used because it did not work practical and therefore using a traditional agenda was more suitable. The agenda did not show the whole week from Sunday to Saturday, but only a few days and started always with the present day. For a complete list of feedback on the functionalities – see *Appendix 4*.

Issues related to using the Compaan in general mentioned by informal caregivers were the difficulty of connecting new persons to the Compaan, bad connections and/or a short wire. Related to the first brothers, sisters and friends of the elder were often aged and their computer and digital skills formed a problem for them. Sometimes they were able to work with a computer or tablet but even then the process of connecting to the Compaan was too complex. The Compaan then formed a 'blockade' itself. In these cases it was clearly not about not willing (motivational aspect), but about not working.

"For others the Compaan itself is a blockade [...] ...there are some very good friends of him, who just threw in the towel" – Fam. Huisman

A bad connection was found as a problem in the first place in the connection between the systems of the formal care organizations (e.g. with hour declarations) and in the second place with Wi-Fi connections. For example in some cases the connection to the Wi-Fi was very weak and instable which made sending messages and using skype difficult.

"The only thing is that sending videos isn't working unfortunately, [...] just movies you know, because then I need to fix the whole internet connection, or choose another provider" – Fam. Morren

Furthermore a number of interviewees expressed their wish for a longer wire for the elder being able to use the Compaan more freely and place it as desired. For example people wanted to take it with them to their sleeping room, but because of the short wire and difficulty for elders to reload the Compaan they did not do that.

(6) Lack of knowledge

The last reason explaining why functions on the Compaan were not used was a lack of knowledge about possibilities by informal caregivers. This included a lack of knowledge on the existence of functionalities and or on the way functionalities could be used. During the interviews, it became clear that interviewees sometimes did not know about certain functionalities. The interviews even led to new ideas or a kind of brainstorming. For example in some cases the existence of the 'watching' function was not known at all and in another case the family did not know that they could start-up the Compaan at distance. Furthermore, in some cases the informal caregivers did not explore how to use certain functions because they thought that the elder would not be able to use it. In the case of family Tax the elder expressed during the interview that she would like to learn how to use internet, whereas the daughter told her that she would not understand that

7.2 POTENTIAL USE

During the interviews also existing needs within the systems were discussed and the role that the Compaan could play in fulfilling these needs as the Compaan would be further developed. This

unrealized potential could be related to (1) further improvement or extension of existing functionalities, design and services and (2) new functionalities, design or service elements. These potential developments will be discussed below. Furthermore the importance of ethical issues and principles in existing use and potential use addressed by informal caregivers will be discussed.

(1) Improvement and extension of existing use

In the first place, the unrealised potential of the Compaan could be connected to the feedback interviewees gave on the functionalities, design and service of the Compaan. All together the feedback expressed the desire for even more possibilities to adapt Compaan usage to suit system needs. Many informal caregivers expressed a special need related to their situation leading to a number of possible improvements. For example, related to the use of the Compaan as entertaining tool, some informal caregivers expressed the desire for more diverse games on the Compaan, being able to assist the elder in watching TV and listening to music or having a database of video's on the Compaan (e.g. 'Netflix for elders'). For example the daughter and mother of family Tax expressed that especially the game 'hangman' was far too easy. When the mother played this game this led often to feelings of anger which made her turn the Compaan off. Related to the use of the Compaan as control mechanism, some informal caregivers expressed their desire for having even more control. Especially cases in which the elder suffered from dementia informal caregivers expressed the need for more tools to control the situation or organize things at distance. Examples given were the connection of more demotics (e.g. light on/off; fall detection) to the Compaan, the use of sensors (e.g. fridge, front door) and a cautious suggestion for connecting a camera.

Related to the use of the Compaan as organizing tool some informal caregivers explained that functionalities such as the agenda and the logbook could be made more practical (e.g. easier searching, adapting, and presentation) and the usefulness of being able to scan documents (to address problems with post). Also a better connection with formal care members to the Compaan was desired by informal caregivers of elders that needed (extensive) care. In their view a (better) connection could lead to the Compaan being a more valuable caring tool including all the information, communication and planning related to the care of the elder. Related to the use of the Compaan as communication tool informal caregivers expressed the desire for more easy skype contact, the elder being able to use the Compaan as phone, being able to have groups conversations skype, the combination of skype and playing games together and an easier process of connecting new members (e.g. other prices and clear process for new members). Related to the use of the Compaan as portal to the world the most important desires were the improvement of the internet function (e.g. enable elders to use internet independently) and turning websites into 'new'

functionalities (e.g. 9292.nl, NS travel planner, food ordering etc.). Related to the overall design and functioning of the Compaan informal caregivers expressed the need for a longer wire (i.e. to improve usage), making turning on and off easier and provide a choice in look and feel (e.g. modern vs. classic). The unrealised potential related to the current service of the Compaan lies in giving more information (e.g. handbook for elders, instructions for informal caregivers) and keeping sight on the desires and needs of the users of the Compaan (e.g. importance of simplicity of the Compaan). Summarized, a lot of suggestions were given which correspond with system needs pointing at the importance of flexibility and adaptability of the Compaan.

"Yeah of what maybe could be nice, I don't know of that is possible of course, you know that they in a very simple way, because I see that that Internet, that she finds still difficult.. to find things, that maybe it could be possible to have movies via another function, .. you know for people who like that, that is of course difficult, because not everyone is interested in the same things - Fam. Klok

(2) New functionalities, design or service elements

The unrealised potential of the Compaan besides is also related to the addition of new functionalities, design or service elements. Informal caregivers expressed during the interviews what kind of ways of usage would be useful for their system. These could be summarized in three usage categories: as social network tool, specific disease supporting tool and as informational tool. Related to using the Compaan as social network tool, a number of informal caregivers explained that because the network of the elder was so small, it would be helpful if the Compaan could help elders making connections with others (e.g. new people or other Compaan users). The desire for a kind of infrastructure to facilitate this was expressed. For example the daughter of the family Klok suggested that providing the possibility to play games with other Compaan users could help her mother. Also making use of a 'pool' of Compaan users to help elders find new 'friends' seemed to be a wish of the informal caregivers.

"But that she then indeed not again needs to rely on her own children. Like I said, during the day I work at the office.. I don't have time.. and then.. pff.. you know. So that she does not rely on that, but that she can do it with other people.. that are also sitting alone behind the Compaan"- Fam. Klok

Another potential way of using the Compaan is as specific disease supporting tool. The Compaan could play a specific role for patients with a certain diseases in standardized packages on the Compaan. For example in cases where the elder suffered from dementia, there was a need for more control, whereas an elder who was very lonely was more in need of more interaction and positivity. During one of the (business) meetings (Zorgbalans, Haarlem) it was about a project in which the

Compaan was specifically used for clients with COPD. Clients were able to send their blood saturation test results directly to their nurse. Finally an additional way of using the Compaan is as informational tool. A number of informal caregivers explained that finding information to organize care for the elders was difficult. The sister of family Brouwer and the daughter of family Morren both suggested to have more information for informal caregivers on the family portal of the Compaan (not available to the elder on the Compaan itself).

Ethical issues and design principles

Besides all these potential ways to develop the Compaan, informal caregivers also pointed to the importance of ethical issues and principles in existing usage and potential usage of the Compaan. This can be seen as an important background for future developments. The ethical issues addressed by informal caregivers were privacy concerns (e.g. controlling the elder) and autonomy concerns (e.g. who decides on usage). Related to the issue of privacy, some informal caregivers struggled with telling or not telling elders about the watching function. Usage of the watching function also resulted in privacy concerns. On the one hand family members really appreciated the function because it gave them the possibility to have more control. On the other hand some interviewees expressed that they did not want to use it to respect the privacy of the elder such as in the case of family Wolters. So, enlarging possibilities to control the elder resulted in privacy issues and was an ethical border for some informal caregivers.

"I would not like to have more control over him, no, I already find this actually heavy, that I can see what he is doing.." – Fam. Brouwer

"We also considered to start using a webcam, but yeah that leads to another trajectory... that formal caregivers could feel uncomfortable.. [...] it also has a link with espionage.. and that has a.. negative sound" – Fam. Huisman

The ethical issue of autonomy when using the Compaan was about the question 'who decides'? Autonomy was related to aspects of the 'why' or 'how' behind the use of functions and about the level of autonomy the elder should remain in using the Compaan. In some cases informal caregivers saw the Compaan really as a caring tool for the family, whereas in other families the Compaan was seen as device of the elder. It was about the differences in opinion on how to use the Compaan, the risk of making the elder inactive because by manage things at distance and the need for the elder to have a final say on what he/she wants to do during the day. For example in the case of family Tax the daughter told that she really wanted to use the Compaan to have more control on the well-being of her mother, whilst the mother said during the interview that it was mainly about the pictures that could be send and the use of internet. In reaction the daughter said that it would be too difficult to

learn for her mother, whilst the mother expressed that she would like to learn it and defended herself that she got things straight still.

"I find it also, I have with my sister also.. very much.. in the, we have been in the trajectory of to what extent do you take over issues and are you going to decide, thing, fill in .. that something is good, eh, my father is still very capable of expressing things and my mother also quit well, but yeah"– Fam. Bouw

Finally, also the meetings with local governments and health care organizations led to discussions about these ethical issues of privacy and autonomy. During these conversations a number of policy advisors asked if the elder would be in control and what kind of information family members had access to when using the Compaan. Regarding the design principles informal caregivers expressed a few aspects that they found important in using the Compaan. Especially the simplicity of the Compaan was seen as a great advantage of the Compaan. Therefore working with opting on-off for functionalities was very important. With the introduction of the new function 'tiles wisdom' the company had chosen for an automatic opt on after installation. As mentioned before this led in some cases (family Jochems and Jansen) to distraction and confusion. On the other hand in general informal caregivers found further development of the Compaan important. They seemed to prefer a balance between improvements that matched the need of the elder and environment, at the same time keeping the simplicity. Informal caregivers for example expressed the importance of having no logins for the elder. Furthermore aspects addressed by informal caregivers were the difficulty for elders of using different devices (e.g. a phone, remote controls, and the Compaan), to deal with changes (e.g. a new update of the Compaan) and the fear of elder to let the Compaan being turned on (e.g. fear for short circuit).

Summary

Summarized, sometimes the Compaan was not used in the system. Reasons were: no need or relevance for it (anymore), people did not have time, skills and or motivation, it had an undesired effect on the system, it cost too much, it did not work well or because of a lack of knowledge. In other situations using the Compaan could be valuable but was not possible because existent functionalities, design elements, or service aspects limited successful usage or because functions, design elements or service aspects were not available or developed. This unrealized potential gives possible opportunities for development in the future and shows the importance of connecting to system needs. Ethical issues and principles in existing use and potential use of the Compaan were seen by informal caregivers as an important aspect in future developments. Important issues were the level of privacy (e.g. controlling the elder) and the level of autonomy (e.g. who decides).

8. CONCLUSION AND DISCUSSION

This is the first study that assessed how using the Compaan could lead to support informal caregiving and to take a systemic approach looking from the perspective of the informal caregiver. Both informal caregiving as well as Compaan usage takes place in a system including a network of actors around the elder. It is through the actions of members of the network that change within systems can be achieved. Usage of the Compaan thus should fit these system conditions and needs. Informal caregivers within these systems find themselves in many situations that could lead to excessive levels of stress, tiredness, and feelings of responsibility resulting in feelings of burden. However they are playing an important role in achieving high quality and efficient long-term care for elderly living independently at home. Therefore it is necessary to find ways to improve the facilitation of informal caregiving in order to minimize the experienced burden as a result of providing care. The use of technologies, such as the Compaan, could be an important way to achieve this.

Main findings

The results of this study showed that there is a great diversity in network composition, roles and tasks of actors, needs within systems and in experienced burden related to informal caregiving. Common was the need for more adequate communication. The usage of the Compaan also varied across systems but could be divided in partly enlarging means of informal carer to manage the situation (as communication tool, control mechanism and care organization tool) and partly increasing autonomy and well-being for the elder (entertainment tool, family storage tool, status object, portal to the world). This usage pattern was achieved by processes of (social) learning and communication and to a lesser extent self-organization. Using the Compaan led in most cases to a combination of feelings of rest and control, improvement of communication, easier organization of care and feelings of happiness and satisfaction for informal caregivers. The results also showed explanations for non-use of the Compaan. These were the absence of need or relevance (anymore) to use it, no time, motivation or skills, an undesired effect on the system, costs, not working well and/or because of a lack of knowledge. Compaan usage potentially could lead to even more support for informal caregivers (and systems) which could be realized by improvement of existent and the development of new functions, design, and service elements. However, in this further development ethical constraints (autonomy and privacy) as raised by informal caregivers should be taken into account. To summarize, a great diversity in network composition and system conditions was present, leading to different usage, consequences and diverse suggestions for potential development.

Conclusion

The central question of this study was to find out in what way the Compaan could support informal caregiving in eldercare seen from a systemic perspective. The relations between informal caregivers, formal caregivers and the elder were complex, diverse and changing. Usage of the Compaan provided in some cases the opportunity to enable actors within the elders' network to become more actively involved resulting in a better division of tasks amongst network members. This helped in some cases in reduction of time spend on care, increased feelings of rest, better division of tasks and thus seemed to lower the burden related to care. The Compaan also made it possible for actors to take a more supportive role in the system. Although the division in social-, support- and care network turned out to be less useful in practice, Compaan usage enabled actors to adopt more supportive (or even caring roles). Using the Compaan could thus also provide support to the system by enabling more actors of the network to become involved in caring, lowering the burden related to caregiving (Tokacheva et al., 2011).

The Compaan also provided a special opportunity to systems in using it in diverse ways according to the system needs. By using the Compaan in these to the system adapted ways, corresponding to the network possibilities, informal caregiving could be supported (e.g. assisting caregiving in such a way that it corresponded with the needs and possibilities). Overall the importance of the flexibility and adaptability of the Compaan to the specific needs within and uniqueness of a system could be seen as very important. The results showed that the changes within the system (e.g. in health status, needs, distance etc.) and the uniqueness of each system explained the need for flexibility and adaptation. Only because the Compaan provided enough structure for usage and at the same time enough space for adaptation to the system, it could be used in such diverse cases and in diverse ways. This flexibility was created on the one hand by the possibilities given by the Compaan to switch on and off functions, and the facilitation using functionalities in different ways. On the other hand it was due to the way families were responding to the diverse functions that created adapted usage fitting the system needs. Thus, a constant process was going on in which the system adapted to changes (e.g. health status, (temporary) distance). This enabled the system to (start) use the Compaan and to help create a system in which informal care could be given more easily.

Although the Compaan already seems to provide relevant support to systems (and especially informal caregivers) it could potentially become even more supporting. Seen from a systemic perspective aspect of hardware (device), software (modes of thinking) and orgware (infrastructure and environmental conditions) are all important in achieving the full potential of an innovation. Hardware related problems found were problems with existing functions (e.g. skype process is difficult) and problems with the design (e.g. short wire). Related to the software problems were a

lack of motivation (e.g. of members to connect), a lack of knowledge (e.g. about existing functions on the Compaan), modes of thinking (e.g. elderly do not understand internet) and ethical issues (e.g. privacy and autonomy). Lastly orgware related contributions to the unrealized potential of the use of the Compaan were bad connections (e.g. with systems of formal care), the lack of infrastructure for network expansion (e.g. need for internet, e-mail, computer skills) and costs (e.g. adding new contacts). These issues partly explain the unrealized potential of usage of the Compaan. Interestingly, feedback of informal caregivers on the Compaan was mostly based on creating opportunities to deal with specific (other) needs within the system. Thus, it also requires the provision of even more space to adapt the use of the Compaan in line with the constantly changing needs within a system, to realize the unrealized potential. Therefore the incorporation of users' feedback will remain important in the further development of the Compaan to become an even more successful innovation in line with the theory of system innovation (Leeuwis & Aarts, 2011). In the end, this could provide even more opportunities to support informal caregiving within a system.

Discussion

Scientific relevance

From the analysis it became clear that every system and within the system the network around the elder differed on many aspects: relationships, distance between actors, division of tasks, involvement in care, skills, modes of thinking and feelings of burden. Despite of this diversity in systems there was a common need for more adequate communication as explained in chapter 5. This need resulted from differences in communication habits, level of independence of the elder, feelings of shared responsibility, the occurrence of life events and distance between actors. Little research has been done on the needs that informal caregivers and elders have that can led to usage of a tool such as the Compaan. Although, the Compaan is unique in its user-friendliness (especially for elders) and got an online family-portal (enabling family members to manage usage at distance), there is a lack of studies on ICT usage to support informal caregivers (and caring families). Research that is available often focussed on identifying opportunities for using ICT to support informal caregivers (McHugh et al., 2012; Chi, & Demiris, 2015; Bosch & Kanis, 2016; Kinney et al., 2003), or especially the effects of using technology (Demers et al., 2016; Finkel et al., 2007; Thompson et al., 2007; Lauriks et al., 2007; Magnusson, Hanson & Borg, 2004). These studies often also incorporated informal caregivers related to a specific caring situation (e.g. caregiving to elder with dementia) rather than including informal caregivers in general, or focussed on large groups of caregivers and thus concluded on a more general level. This study is unique in focussing on informal caregiver's usage of an ICT tool in practice.

However, studies that did focus on the opportunities of ICT or technology in supporting informal caregivers suggested opportunities in the area of encouraging meaningful interactions (Bosch & Kanis, 2016; McHugh et al., 2012) and when living at distance (Benefield & Beck, 2007). This corresponds with the aspects related to the need for more adequate communication in systems as found in this study.

This research furthermore showed that the same device, the Compaan, is used differently amongst systems corresponding to their uniqueness and great diversity. The Compaan was used to: communicate, organize care, as (family) storage tool, provide entertainment, as status object, as control mechanism, and portal to the world. Other studies aiming at identifying opportunities for ICT to support informal caregivers found that it could be helpful in arranging support needed, avoiding social isolation, meaningful social action, and the capturing of precious moments (McHugh et al., 2012; Bosch & Kanis, 2016). This present study confirms the idea that technology could help informal caregivers in arranging the support needed (e.g. organization of care, increased control), avoid social isolation of the elder (by communication) and the relationship with the elder (e.g. more (diverse) communication, involvement and storing memories). No studies were available that found that ICT could provide support in enlarging the world of the elder as being used as portal to the world or as status object. Probably these results are also contributing to avoiding social isolation of the elder or in having meaningful interaction (using internet to shop together). More research should be done to understand the usage of tools, such as the Compaan, to understand how usage contributes to the system.

When thinking about the consequences of ICT usage in care settings, the results of this study showed that using the Compaan could support informal caregivers in the facilitation of (more) diverse communication with the elder and others, in organizing care around the elder, in having control over the situation of the elder and in feelings of rest and satisfaction as explained in chapter six. In line with these findings the systemic review of Chi and Demiris (2015) on the use telehealth tools to enhance care to family caregivers, also concluded that they may benefit from increased and more efficient communication. Furthermore the study of Czaja and Rubert (2002) concluded that the use of technology could provide support by facilitating tasks such as daily (health) checks and reminders of appointments or medication alerts. Some studies found that the use of ICT to support informal caregivers in having contact with other caregivers was useful (Lundberg, 2013; Czaja & Rubert, 2002). Results of this study also showed the importance of using ICT for this reason but also to connect with the elder. So, ICT usage seems to be supporting for informal caregivers in communication and organization of care. None of the studies reported the supporting effect or opportunity of knowing that the elder is doing well by informal caregivers. Probably this has not been recorded because the

Compaan is a specific device in providing the opportunity to monitor at distance and stimulates contact in a special way. However, other studies concluded that information technology in general has a promising role in alleviating distress or depression among caregivers (Lopez-Hartmann et al., 2012; Finkel et al., 2007; Eisdorfer et al., 2003; Czaja & Rubert, 2002). This study provided more detailed answers on how informal caregivers could be supported by using ICT tools, such as the Compaan, also indicating the different ways of ICT usage within in systems (including informal caregiving).

This study showed that Compaan usage was adapted in such a way that its usage fulfilled in system needs and that further improvement of such a device lies in looking at unfulfilled needs. McHugh et al. (2012) also concluded that consulting caregivers to ensure that technology design is grounded in an understanding of the needs is of importance. The results also indicated that the flexibility of the Compaan explains the success of usage within a system, thereby underscore the importance of customization. Other research, including two systemic reviews, also indicated the importance of factors such as flexibility and adaptations as requirement for solutions in the caregiving context (Bosch & Kanis, 2016; Lopez-Hartmann et al., 2012; Chi & Demiris, 2015). However, these studies did not explain why these factors were so important and how this flexibility should be achieved as explored in this study. Looking from a systemic perspective to innovation as done in this study provided to be helpful to achieve this as proposed by Leeuwis and Aarts (2011).

Finally, the importance of ethical issues in further development of ICT tools were addressed by informal caregivers in this study. Results showed that aspects as privacy and autonomy could play an important role in the usage of the Compaan. This is line with other research that also pointed to factors as privacy, confidentiality and autonomy (Kaplan, & Litewka, 2008; Magnusson, 2004). The concept of responsible innovation could be useful here, pointing to the importance of inclusion of users in development and a responsive process to incorporate user's feedback (Stilgoe, Owen & Macnaghten, 2013). Systemic innovation theory could be seen as very useful in understanding the needs, adopting process, usage and consequences of a tool, but does not pay attention to ethical concerns in the development of the tool as well as in the process of adapting usage to the system needs. However, many informal caregivers in this study pointed to important ethical issues that limited the (future) usage of the Compaan (e.g. not willing to use camera to control, although there is a need for more control). To ensure flexibility and adaptability and at the same time be aware of ethical constraints, asks for an incorporation of attention for ethical constraints in the co-evolutionary process. Using the framework as proposed by Stilgoe et al. to prevent developments contrary to important ethical principles, could be a valuable addition to the theory of system innovation.

Societal relevance

As local governments in the Netherlands have become responsible for supporting informal caregivers, and informal caregiving often comes with (excessive) feelings of burden, the results of this study provide interesting insights in the diversity of elderly caregiving systems, showing the need for tailored and flexible supporting strategies. Tools that cannot provide this space will probably be less suitable to support systems. Whereas the use of technologies are seen as important way to support (informal) caregivers, knowledge about important aspects of these technologies could be very valuable in selecting (and subsidize) useful technologies. The results of this study showed that the Compaan is such a flexible tool, and its usage can contribute to a system that supports informal caregiving. As mentioned in the introduction the sorts of informal care most given are emotional support, assistance with visits, domestic help and assistance with administrative matters (Mot, 2010). It seems that the Compaan could provide assistance for all of these sorts of care, except for domestic help. This study also showed diverse, but existing feelings of burden related to providing informal caregiving. The burden of informal caregiving results not only in concerns for individuals and families, but also to larger society because of health problems of informal caregivers themselves (Arno & Memmott, 1999). Therefore it is very important to decrease feelings of burden to ensure high quality and efficient (elder) care in the future. Based on this study the Compaan could be seen as valuable tool in supporting informal caregivers, thereby possibly lower feelings of burden.

Strengths and weaknesses

This research showed that taking a systemic perspective result in relevant and interesting findings. One is able to understand needs, usage, problems with usage and potential directions for development taking into account context factors (e.g. formal connection is desired, but not working). In addition, the adoption of a network perspective in this study also helped to indicate how and why actors within the network of the elder used the Compaan. Another strength of this study the collection of data by means of 16 semi-structured interviews providing the opportunity to examine issues in detail and depth. Interviews were carried out relatively systematically and amongst a reasonable homogeneous group of participants. This provided rich and relevant data on the specific population of elders receiving informal care and formal care. However, one should note that this is a specific population. For example usage of the Compaan is based on elders with someone around them who can assist them. For elders who do not have children, grandchildren or others that could fulfil this role, using the Compaan is difficult. Furthermore, the main focus was on elders who got also some form of formal care, but elders could also rely solely on informal care. However, the achievement of a point of data saturation positively influences the validity of this study (Fusch, & Ness, 2015). Furthermore, by using a combination of data methods (triangulation of measure), the

use of an interview guide and coding based on cites influences of personal biases in the interpretation of data which could negatively influence the reliability of the results, have been limited. A general weakness of qualitative research lies in the presence of the researcher during the data collection that could have led to issues of anonymity and confidentiality. Some interviewees could have felt less comfortable to (negatively) speak about their parent(s), especially when recorded. There has been tried to limit these feelings by assuring anonymity to all others except for the researcher, assuring recordings usage only for the present study and the conduction of the interview at the desired place of the interviewee. Also the presence of a partner or an elder during some of the interviews could have led to the interviewee feeling less comfortable to share his or her opinion or positively to more relevant data. Finally the study has been carried out in collaboration with the company behind the Compaan. This study aimed to provide an impression of important system needs, aspects and consequences of usage of the Compaan from the perspective of informal caregivers (as users). Therefore owners and employees were not involved in the data collection, data analysis and report writing. Also no financial (or other) compensation was present.

Implications and recommendations

Although the results showed that the Compaan is already very flexibility and adaptable to specific systems, still there are more extensions of this flexibility and adaptability possible which could help to achieve unrealized potential usage. Future research should try to understand how technologies such as the Compaan could become even more flexible to further increase possible adaptations to specific systems needs and changes in this needs over time. Research should also focus on understanding how such technologies could be the most supportive from the perspective of the entire network (e.g. elder, formal care and informal caregivers). In the end it is the balance of all these perspectives on how such a supportive (ICT) tool could be the most supportive that can lead to an optimal design. In general more research on specific tools is needed to understand and compare usage, consequences and potential of tools in practice. For other companies working in the field of technologies to support elders and their environment it is recommended to ensure that devices provide enough space to adapt it to specific needs. This could be achieved by providing the opportunity to set functions on/off and by incorporating (potential) user-feedback in a process of constant development. Also enabling (easy) connections between all relevant actors in the care network of the elder could be a valuable development (e.g. for Compaan try to enable formal caregivers to connect to the Compaan). Furthermore, elders who do not have close family members are probably extremely in need of connection with others, but cannot use the Compaan solely (no assistance in family portal). The company behind the Compaan could also take into account this

population and develop a specific portal for these elders, in which formal care members or the company itself could provide assistance. In general the Compaan seemed to be developed from the perspective of elder users. However, to make the Compaan even more suitable for informal care givers (as well as elders and formal caregivers) the company could look at the entire environment around the elder. This leads to questions such as: 'What is important for usage by informal caregivers?', 'What is important to use the Compaan for formal caregivers?', and 'How could these aspects be incorporated while still keeping an easy-to-use product for elders?' Thereby ethical issues should be taken into account in the development process as proposed in this study. Overlooking the implications of ignoring ethical issues could lead to non-use (e.g. privacy of elder and respecting authority of users). For care organizations the results of this study underline the potential benefit of the usage of tools such as the Compaan. More attention to identifying such tools such and providing opportunities to use such tools, could be helpful to support collaboration with the elder and its environment. Informal caregivers clearly expressed a desire for a connection with formal care in using the Compaan to share information, communicate and organize care. Care organizations could use this information to develop new ways of working that support informal caregivers in these needs. Finally, for local governments this study could provide valuable information to take into account when thinking about/selecting (ICT) tools to support informal caregivers of elderly. It also give insight in how systems of care operate and underscore the value of looking at the entire care system.

REFERENCES

- Ahrweiler, P., & Keane, M. T. (2013). Innovation networks. *Mind & Society*, 12(1), 73-90.
- Andersson, S. (1998). *The network perspective: Its origin and differences to the marketing management approach*. PhD, Entrepreneurship and Small Business Research Institute (ESBRI), Stockholm, Sweden.
- Arno, P.S., & Memmott, M.M. (1999). The economic value of informal caregiving. *Health Affairs*, 18(2), 182-188. DOI: 10.1377/hlthaff.18.2.182
- Barer, B. M., & Johnson, C. L. (1990). A critique of the caregiving literature. *The Gerontologist*, 30(1), 26-29.
- Barrett, P., Hale, B., & Butler, M. (2014). *Family care and social capital: Transitions in informal care*. London: Springer.
- Barrett, A.E., & Lynch, S.M. (1999). Caregiving networks of elderly persons: Variation by marital status. *The Gerontological Society of America*, 39(6), 695-704.
- Benefield, L.E., & Beck, C. (2007). Reducing the distance in distance-caregiving by technology innovation. *Clinical Interventions in Ageing*, 2(2), 267-272.
- Boer, A. de, (2005). *Kijk op informele zorg*. Sociaal en Cultureel Planbureau (SCP), Den Haag.
- Borgatti, S.P., Mehra, A., Brass, D.J., & Labianca, G. (2009). Network analysis in the social sciences. *Science*, 323, 892-895.
- Bosch, L. B. J., & Kanis, H. (2016). Design opportunities for supporting informal caregivers. In: Proceedings of the 2016 CHI Conference Extended Abstracts on Human Factors in Computing Systems, 2790-2797.
- Brodsky, J., Resnizki, S., & Citron, D., (2006). Issues in Family Care of the Elderly: Characteristics of Care. Burden on Family Members and Support Programs, Myers-JDC-Brookdale Institute, Israel.
- Centraal Bureau voor de Statistiek (CBS). (April, 2013). 220 duizend Nederlanders voelen zich zwaar belast door mantelzorg. Press release of 22 April 2013, nr. PB12-027. Consulted on 3 June 2016 on: <https://www.cbs.nl/nl-nl/nieuws/2013/17/220-duizend-nederlanders-voelen-zich-zwaar-belast-door-mantelzorg>
- Centraal Bureau voor de Statistiek (CBS). (2015). *Zorguitgaven stijgen met 1.8% in 2014*. Consulted on 19 april 2016 on: <https://www.cbs.nl/nl-nl/nieuws/2015/21/zorguitgaven-stijgen-met-1-8-procent-in-2014>
- Chi, N. & Demiris, G. (2015). A systemic review of telehealth tools and interventions to support family caregivers. *Journal of Telemedicine and Telecare*, 21(1), 37-44.
- Consolvo, S., Roessler, P., Shelton, B.E., LaMarca, A., Schilit, B., Bly, S. (2004). Computer-supported coordinated care: Using technology to help care for elders.
- Czaja, S.J., & Rubert, M.P. (2002). Telecommunications technology as an aid to family caregivers of persons with dementia. *Psychosomatic Medicine*, 64, 469-476.
- Demers, L., Mortenson, W.B., Fuhrer, M.J., Jutai, J.W., Plante, M., Mah, J., & DeRuyter, F. (2016). Effect of a tailored assistive technology intervention on older adults and their family caregiver: A pragmatic study protocol. *BMC Geriatrics*, 16(1), 1.
- Eisdorfer, C., Czaja, S.J., Loewenstein, D.A., Rubert, M.P., Argüelles, S., Mitrani, V.B., & Szapocznik, J. (2003). The effect of a family therapy and technology based-intervention on caregiver depression. *The Gerontologist*, 43(4), 521-531.
- Elzen, B., Barbier, M., Cerf, M., & Grin, J. (2012). Stimulating transitions towards sustainable farming systems. In I. Darnhofer, D. Gibbon, and B. Dedieu (Eds.), *Farming Systems Research into the 21st Century: The new dynamic* (chapter 19). Dordrecht: Springer Science.
- Elzen, B., & Wieczorek, A. (2005). Transitions towards sustainability through system innovation. *Technological Forecasting & Social Change*, 72, 651-661.
- Finkel, S., Czaja, S., Schultz, R., Martinovich, Z., Harris, C., & Pezzuto, D. (2007). E-Care: A telecommunications technology intervention for family caregivers of dementia patients.

- American Journal of Geriatric Psychiatry*, 15(5), 443-448.
- Fusch, P.I., & Ness, L.R., (2015). Are we there yet? Data saturation in qualitative research. *The Qualitative Report*, 20(9), 1408-1416.
- Giebers, H., Verweij, A., & Beer, de, J. (2013). *Vergrijzing wat zijn de belangrijkste verwachtingen voor de toekomst?* In: Volksgezondheid Toekomstverkenning, Nationaal Kompas Volksgezondheid. Bilthoven: RIVM. Geraadpleegd op 18 april 2016 op:
<http://www.nationaalkompas.nl/bevolking/vergrijzing/toekomst/>
- Griffiths, A. (13 April 2013). Can technology fill the elderly care gap? *The Telegraph*. Consulted on 21 April 2016 on:
<http://www.telegraph.co.uk/active/9983886/Can-technology-fill-the-elderly-care-gap.html>
- Harlton, S., Keating, N., & Fast, J. (1998). Defining eldercare for policy and practice: Perspectives matter. *Family Relations*, 47(3), 281-288.
- Havens, B., Donovan, C., & Hollander, M. (2001). Policies that have positive or negative impacts on informal care in Canada. *Paper presented at the International Association of Gerontology, Vancouver*.
- Heaney, C.A., & Israel, B.A. (2008). *Chapter 9: Social networks and social support*. In: Health behavior and health education: Theory, research, and practice, Glanz, K., Rimer, B.K., & Viswanath, K. (Eds.). San Francisco: Jossey-Bass.
- Hiemstra, E., & Woudstra, Y. (2015). *Vrijwilligerswerk en informele zorg binnen de transitie*. Partoer: Provincie Friesland.
- James, N. (1992). Care = organization + physical labour + emotional labour. *Sociology of Health and Illness*, 14(4), 488-509.
- Kaplan, B., & Litewka, S. (2008). Ethical challenges of telemedicine and telehealth. *Cambridge Quarterly of Healthcare Ethics*, 17, 401-416
- Keating, N., Otfinowski, P., Wenger, C., Fast, J., & Derksen, L. (2003). Understanding the caring capacity of informal networks of frail seniors: a case for care networks. *Ageing and Society*, 23(1), 115-127.
- Kilelu, C. W., Klerkx, L., & Leeuwis, C. (2013). Unravelling the role of innovation platforms in supporting co-evolution of innovation: contributions and tensions in a smallholder dairy development programme. *Agricultural systems*, 118, 65-77.
- Kinney, J.M., Kart, C.S., Murdoch, L.D., & Ziemba, T.F., (2003). Challenges in caregiving and creative solutions: Using technology to facilitate caring for a relative with dementia. *Ageing International*, 28(3), 295-313.
- Klerk, M., de, Boer, A., de, Plaisier, I., Schyns, P., & Kooiker, S. (2015). Informele hulp: Wie doet er wat? Omvang, aard en kenmerken van mantelzorg en vrijwilligerswerk in de zorg en ondersteuning in 2014. *Sociaal en Cultureel Planbureau, Den Haag*.
- Knoke, D., & Kublinski, J.H. (1982). *Network analysis*. Beverly Hills: Sage Publications.
- Kruijswijk, W., Hermans, M., & Rooijen, H., van (2016). *Mannen en mantelzorg, niet te missen!* Movisie and Emancipator, Utrecht.
- Leeuwis, C. & Aarts, N. (2011). Rethinking communication in innovation processes: Creating space for change in complex systems. *Journal of Agricultural Education & Extension*, 17(1), 21-36. DOI:10.1080/1389224X.2011.536344
- Litwin, H., & Attias-Donfut, C. (2009). The inter-relationship between formal and informal care: a study in France and Israël. *Ageing Society*, 29(1), 71-91.
- Loket gezond leven. (2015a). Decentralisatie overheidstaken. Consulted on 2 June 2016 on:
<https://www.loketgezondleven.nl/gezonde-gemeente/gezondheidsbeleid-maken/wettelijke-kaders-gezondheidsbeleid/decentralisatie>
- Loket gezond leven. (2015b). Publieke gezondheid en de transitie. Geraadpleegd op 2 June 2016 on:
<https://www.loketgezondleven.nl/gezonde-gemeente/gezondheidsbeleid-maken/wettelijke-kaders/decentralisaties/publieke-gezondheid-en>
- Lopez-Hartmann, M., Wens, J., Verhoeven, V., & Remmen, R. (2012). The effect of caregiver support interventions for informal caregivers of community-dwelling frail elderly: a systemic review.

- International Journal of Integrated Care*, 12.
- Ludwig, W., Wolf, K., Duwenkamp, C., Gusew, N., Hellrung, N., Marschollek, M., Wagner, M., & Haux, R. (2012). Health-enabling technologies for the elderly: An overview of services based on a literature review. *Computer Methods and Programs in Biomedicine*, 106(2), 70-78.
- Lundberg, S. (2014). The results from a two-year case study of an information and communication technology support system for family caregivers. *Disability and Rehabilitation: Assistive Technology*, 9(4), 353-358.
- Maarse, J.A.M., & Jeurissen, P.P. (2016). The policy and politics of the 2015 long-term care reform in the Netherlands. *Health Policy*, 120, 241-245.
- Magnusson, L., Hanson, E., & Borg, M., (2004). A literature review study on information and communication technology as a support for frail older people living at home and their family carers. *Technology and Disability*, 16(4), 223-235.
- McHugh, J.E., Wherton, J.P., Prendergast, D.K., & Lawlor, B.A. (2012). Identifying opportunities for supporting caregivers of persons with dementia through information and communication technology. *Gerontechnology*, 10(4), 220-230.
- Ministry of Public Health & Sports. (September, 2014). *De toekomst agenda informele zorg en ondersteuning*. Consulted on 1 Juni 2016 on:
http://www.expertisecentrummantelzorg.nl/Site_EM/docs/pdf/Toekomstagenda-informele-zorg.pdf
- Ministry of Public Health & Sports (June, 2014). *De maatschappij verandert. Verandert de zorg mee?* Policy publication, Schippers, E.I & Van Rijn, M.J, Den Hague.
- Mot, E. (2010). *The Dutch system of long-term care*. CPB Netherlands Bureau for Economic Policy Analysis. The Hague, Netherlands.
- Movisie. (Aug., 2013). *Feiten en cijfers informele zorg*. Utrecht.
- Movisie. (N.D.). *Samenspel tussen formele en informele zorg*. Promotie document samenspelscan. Expertisecentrum Mantelzorg. Consulted on 8 June 2016 on:
<https://www.movisie.nl/artikel/samenspel-scholing-belangrijk-ondersteuning-mantelzorgers>
- Noelker, L.S., & Browdie, R. (2014). Sidney Katz, MD: A new paradigm for chronic illness and long term care. *The Gerontologist*, 54(1), 13-20. DOI: 10.1093/geront/gnto86
- Oldenburg, B., & Glanz, K. (2008). *Chapter 14 Diffusion of innovations*. In: Health behavior and health education: Theory, research, and practice, Glanz, K., Rimer, B.K., & Viswanath, K. (Eds.). San Francisco: Jossey-Bass.
- Oudijk, D., Boer, A. de, Woittiez, I., Timmermans J. & Klerk, M. de (2010). *Mantelzorg uit de doeken*. Den Haag: SCP.
- Oudijk, D., Woittiez, I., & de Boer, A. (2011). *More family responsibility, more informal care? The effect of motivation on the giving of informal care by people aged over 50 in the Netherlands compared to other European countries*. *Health Policy*, 101, 228-235.
- Owen-Smith, J. (n.d.). *Network theory: The basics*. Consulted on 21 June 2016 on
<http://www.oecd.org/sti/inno/41858618.pdf>
- Peetoom, K., Lexis, M.A.S., Joore, M., Dirksen, C.D., & De Witte, L.P. (2016). The perceived burden of informal caregivers of independently living elderly and their ideas about possible solutions. A mixed methods approach. *Technology and Disability*, 28(1), 19-29.
- Pickard, L., Wittenberg, R., Comas-Herrera, A., Davies, B., & Darton, R. (2000). Relying on informal care in the new century? Informal care for elderly people in England to 2031. *Ageing and Society*, 20, 745-772.
- Powell, W.W., White, D.R., Koput, K.W., & Owen-Smith, J. (2005). Network dynamics and field evolution: The growth of inter organizational collaboration in the life sciences. *American Journal of Sociology*, 110(4), 1132-1205.
- Rijksinstituut voor Volksgezondheid en Milieu. (n.d.). Infographic. Consulted on 18 april 2016 on:
<http://www.gezondheidszorgbalans.nl/Infographics>
- Rijksinstituut voor Volksgezondheid en Milieu (2013). 220 duizend Nederlanders voelen zich zwaar belast door mantelzorg. Consulted on 18 april 2016 on:

- http://www.rivm.nl/Documenten_en_publicaties/Algemeen_Actueel/Nieuwsberichten/2013/220_duizend_Nederlanders_voelen_zich_zwaar_belast_door_mantelzorg
- Rijksoverheid, a. (n.d.). *Ouderenzorg: Kwetsbare ouderen*. Consulted on 18 april 2016 on: <https://www.rijksoverheid.nl/onderwerpen/ouderenzorg/inhoud/kwetsbare-ouderen>
- Rijksoverheid, b. (n.d.). *Hoe is de zorg en ondersteuning per 2015 georganiseerd?* Consulted on 1 June 2016, on: <https://www.rijksoverheid.nl/onderwerpen/zorg-in-zorginstelling/vraag-en-antwoord/organisatie-zorg-en-ondersteuning-per-2015>
- Rijksoverheid. (2 July 2014). *Schippers en Van Rijn: door e-health betere zorg en meer eigen regie*. Consulted on 21 april on: <https://www.rijksoverheid.nl/onderwerpen/ouderenzorg/nieuws/2014/07/03/schippers-en-van-rijn-door-e-health-betere-zorg-en-meer-eigen-regie>
- Rijksoverheid. (2 July 2014). *Rapport: De maatschappij verandert. Verandert de zorg mee?* Consulted on 21 April 2016 on: <https://www.rijksoverheid.nl/onderwerpen/ouderenzorg/documenten/rapporten/2014/07/02/de-maatschappij-verandert-verandert-de-zorg-mee>
- Rogers, E. M. (1986). *Communication technology* (Vol. 1). Simon and Schuster
- Rosenthal, C.J., Martin-Matthews, A., & Keefe, J.M. (2007). Care management and care provision for older relatives amongst employed informal care-givers. *Ageing & Society*, 27, 755-778.
- Rotmans, J. (2006). *Societal innovation: Between dream and reality lies complexity*. Erasmus University, Rotterdam.
- Scheffers, M. (2010). *Sterk met een vitaal network. Empowerment en de sociaal netwerkmethodiek*. Bussum: Coutinho.
- Sing Nam, H. (2004). *Exploring the relationship between formal carers, informal carers and carees during the elder-care process*. Masterthesis. Lingnan University.
- Steyaert, J. en R. Kwekkeboom (2012) *De zorgkracht van sociale netwerken*.
- Stilgoe, J., Owen, R., & Macnaghten, P. (2013). Developing a framework for responsible innovation. *Research Policy*, 42, 15-68-1580.
- Struijs, A. (2006). *Informal care: The contribution of family carers and volunteers to long-term care*. Council for Public Health and Health Care, Zoetermeer, the Netherlands.
- Thompson, C.A., Spilsbury, K., Hall, J., Birks, Y., Barnes, C., & Adamson, J. (2007). Systematic review of information and support interventions for caregivers of people with dementia. *BMC Geriatrics*, 7(1), 18.
- Timmermans, J., De Boer, A., & Iedema, J. (2005). *De mantelval: Over dreigende overbelasting van de mantelzorger*. Sociaal en Cultureel Planbureau, Den Haag.
- Timonen, V. (2009). Toward an integrative theory of care: formal and informal intersections. In: Human development and the lifespan: Antecedents, processes and consequences of change, Roberto, K.A., & Mancini, J.A., (Eds.). Lanham: Lexington.
- Thesaurus Zorg & Welzijn. (2016). *Voorbeeld van termen rond mantelzorg: Centrale verzorgers*. Stimulansz. Consulted on 8 June 2016 on: <http://www.thesauruszorgenwelzijn.nl/tr6566.htm>
- Tolkacheva, N., Broese van Groenou, M., de Boer, A., & van Tilburg, T. (2011). The impact of informal care-giving networks on adults children's caregiver burden. *Ageing and Society*, 31, 34-51.
- Trott, P. (2012). *Innovation management and new product development* (5th ed.). Pearson: Edinburgh Gate.
- Van de Bunt, G.G. & Nencel, L. (2012). Social research methodology.
- Van Rooijen, M., Goedvolk, R., & Houwert, J., (2013). A vision for the Dutch healthcare system in 2040: Towards a sustainable, high-quality health care system. *A report of the World Economic Forum, in collaboration with McKinsey & Company*.
- Verbeek-Ouddijk, D., Woittiez, I., Eggink, E., & Putman, L. (2014). Who cares in Europe? A comparison of long-term care for the over-50s in sixteen Europe. The Hague: The Netherlands Institute for Social Research (SCP), June 2014.
- Vilans. (n.d.). ICT toepassingen voor mantelzorgers.

- Visser-Jansen, G., & Knipscheer, C.P.M. (2004). *Services for supporting family carers of elderly people in Europe: Characteristics, coverage and usage*. National background report for The Netherlands, Eurofamcare. Vrije Universiteit Amsterdam.
- Vreugdenhil, M. (2012). Nederland participatieland? De ambitie van de Wet maatschappelijke ondersteuning (Wmo) en de praktijk in buurten, mantelzorgrelaties en kerken. *Dissertation, Faculty of Social and Behavioral sciences, UvA-DARE, UvA*.
- VWS. (2007). *Beleidsbrief Mantelzorg en vrijwilligerswerk 2008-2011: Voor elkaar*. Ministry of Health, Welfare and Sport, The Hague.
- Wallance Williams, S., Williams, C.S., Zimmerman, S., Munn, J., Dobbs, D., & Sloane, P.D. (2008). Emotional and physical health of informal caregivers of residents at the end of life: The role of social support. *Journal of Gerontology*, 63B(3), 171-183.
- Walker, A.J., Pratt, C.C., & Eddy, L. (1995). Informal caregiving to ageing family members: A critical review. *Family Relations*, 44, 402-411.
- Wenger, G.C. (1991). A network typology: From theory to practice. *Journal of Ageing studies*, 5(2), 147-162.
- Wieringen, M., Broese van Groenou, M., & Groenewegen, P. (2014). *Hoe thuiszorgorganisaties samenwerking organiseren: Visies, praktijken en dilemma's*. Rapportage over de samenwerking van thuiszorgmedewerkers met mantelzorgers en andere organisaties. Amsterdam: Vrije Universiteit.
- Wong, A., Kommer, G.J., & Polder, J.J. (2008). Levensloop en zorgkosten: Solidariteit en de zorgkosten van vergrijzing. Rijksinstituut voor Volksgezondheid en Milieu (RIVM) rapport.
- Worcester, M. I., Archbold, P., Stewart, B., Montgomery, R., & O'Connor, K. (1990). Family coping: Caring for the elderly in home care. *Home health care services quarterly*, 11(1-2), 121-185.
- Yates, M. E., Tennstedt, S., & Chang, B. H. (1999). Contributors to and mediators of psychological well-being for informal caregivers. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 54(1), P12-P22
- Young, D., Borland, R., & Coghill, K. (2010). An actor-network theory analysis of policy innovation for smoke-free places: Understanding change in complex systems. *American Journal of Public Health*, 100(7), 1208-1217.

APPENDIX

APPENDIX 1 – THE COMPAAN



Family portal

APPENDIX 2 – MODELS DESCRIBING THE ELDER (CARE) NETWORK

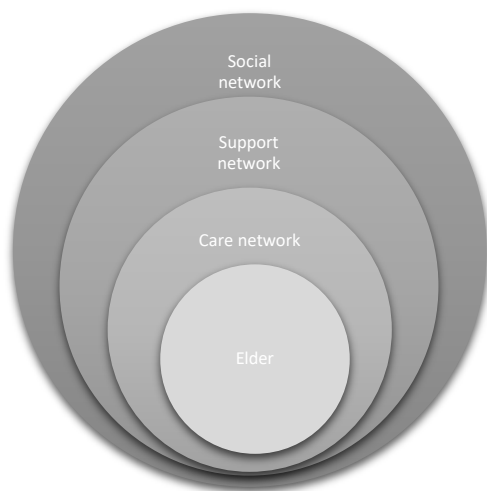


Figure 1 - Conceptual distinction between social-, support- and care networks around the elderly based on Keating et al. (2003).

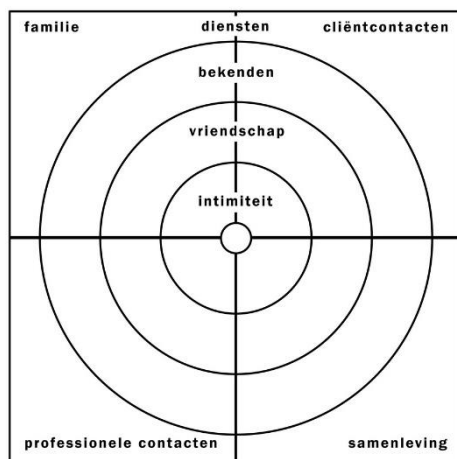


Figure 2 - Networkcircle of Lensink (Movisie).

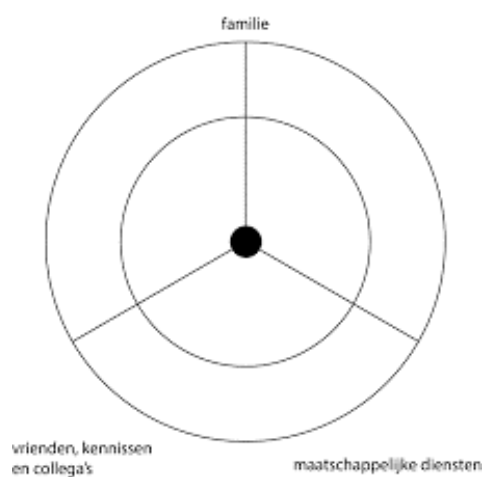


Figure 3 - District ecogram as part of the social network method (Scheffers, 2010).

APPENDIX 3 – INTERVIEW QUESTIONNAIRE

A. Demographic

- > background (education, work, family situation)
- > education
- > family size?

B. Background information

- > Why using Compaan?
- > Who is the care-receiver (age/problems)
- > Why did you choose to provide informal care?

C. Networks [understanding the caring situation and relationships]

- > described the important actors in the network
 - > number of people that are involved
 - > number of people connected to the Compaan
 - Who are these people?
 - Who is not connected to the Compaan, but is important in caregiving?
- > understand the relationship between the different actors
 - > which formal caregivers are involved?
 - > how many informal caregivers?
 - > who are this?

D. Support for informal care [in what way does the functioning of the network influences the use of the Compaan for system change in supporting and facilitating informal caregiving?]

Types of support given (before and after Compaan use)

- > Who provides physical support?
- > Who provides emotional support?
- > Who organizes/manages care?
- > Who provides this care out of profession?
- > Who provides this care out of relationship (family/friend/neighbours?)
- > How was this before the Compaan? All the actors/tasks
- > If task division changed, did it led to... (lead to more efficient system, time reduction, better manageable?, distance less a problem?)
- > In case of change of tasks, how did you achieved that?

[find out which actors pay a role, find out what role, find out how the new tasks division facilitated informal caregiving]

Experiences of burden

Do you experience some kind of burden related to caregiving?

How would you describe the burden related to the informal caregiving?

(four levels)

What causes this feelings of burden?

time/financial burdens/social isolation/the sandwich generation/little support/relationship with care-receiver/collaboration with others/ managing care/feelings

How was this before the use of the Compaan?

APPENDIX 4 – FEEDBACK COMPAAN

A. FEEDBACK ON DESIGN

1. Recharging can be made more easy by using a charging mat. No need for a wire, makes it easier to use the Compaan flexible and enable elders to do it themselves or formal caregivers (costs less time). Another option is to make the wire longer, so that it can be used more freely.
2. Design of the Compaan: the rubber button on top falls out quickly, the standard on the back falls out quickly, it could be an improvement if it would be foldable. A bit a rough design, could be further improved.
3. Turning the Compaan off is difficult for many elders because there are two ways to turn it off which leads to diffusion, and because the button is hard to find.
4. Big pictograms are ideal for the elders to use, however it could be further improved by making it possible to choose which pictograms are presented on the first and second 'page' because swiping is still difficult for most elders.
5. Touch pen could be more sophisticated (smaller) to make it easier to use and not a double function (writing and touching with the same pen).
6. Option to use a wireless apart keyboard. This offers an opportunity for people to see it as a type machine and it takes less space on the screen (pop-up keyboard results in loss of screen space). Provide the possible to choose the level of complexity of the keyboard (with all kinds of symbols, or only letters/numbers; on alphabetic order).
7. Use of functionalities are separated and not interrupted by incoming messages. When a new message comes in making sure that the elder returns back to what he or she was doing.

B. FEEDBACK ON FUNCTIONALITIES

1. **Games:** option to choose a degree of difficulty when playing games, more diverse games and being able to play games and at the same time skyping. Make it easier to play games at distance (e.g. clear instructions for the elder and an alert if the elders wants to play a game for the contact person).
2. **Skype:** make the process less complex, and more user-friendly, bigger screen of the person who you are skyping with if possible (from the elder). Some informal caregivers explained the wish for having group conversations when using skype.
3. **Internet:** give option to display more favourites than six, sometimes the screen is too small and then things are not visible (e.g. example mentioned about the ING site); internet works difficult because of the 'in-between-button' of internet, would be more easy if the favourite could be directly a pictogram on the screen.
4. **Agenda:** making it more easy to scroll through the agenda, bigger arrow to click on, give a weekly overview starting with Sunday or Monday (instead of the 'current' day), less space for one day is not a problem because elder's have not that much appointments. Opportunity to select colours for certain kind of appointments or contact persons (yellow is GP, green is daughter etc.). Make it easier to change or remove things in the agenda.
5. **Logbook:** enable making adjustments to saved notes, enable searching in the logbook, and make it more clearly by opportunities to create more structure.
6. **Photos:** digital photo frame is a nice function, make it easier to upload more photos at once
7. **Quote of the day:** for some elders it lasts to long on the screen, or the opposite they are not able to find it back.

8. **Messages:** make it more easy to send a message and select to whom, suggestions given were with using pictures (e.g. profile picture) or to make it more like WhatsApp (e.g. conversations with a person organized together). Make it easier to clean up the send and incoming messages.
9. **Watch functionality:** enable informal caregivers to really take over the screen or to see what the elder is doing real life.

C. FEEDBACK ON COMMUNICATION // SERVICE

1. **Information provisioning:** informal caregivers would like to receive more information for themselves (about the latest updates; privacy of data etc.) and also for the elder in the form of a paper manual or instruction cards. Furthermore in one case the informal caregiver explained that it would be nice if more promotion material was included to make others enthusiastic.
2. **Development:** most informal caregivers liked the further development of the Compaan, however a number of them also said that the Compaan should in the end be kept simple.
3. **Communication:** Other ways to communicate about the possibilities of using the Compaan for informal caregivers. Often they did not know about all the possibilities of using the Compaan (e.g. start up at distance).
4. **Service:** informal caregivers expressed their satisfaction with the service. Possible developments could be extended possibilities to have contact (e.g. chat/WhatsApp or more information on site/brochure), having another visit at the elder after for example two years to refresh information and check Compaan status.
5. **Costs:** Most informal caregivers did not find the costs related to the Compaan a problem. However, in some cases it led to avoiding of connecting more actors. A suggestion was to not calculate extra costs per extra user, but per message send. (During one interview it also became clear that the Compaan was too expensive for a friend of the informal caregiver).
6. **Autonomy:** No automatic opt-in: a number of informal caregivers explained that they did not liked the automatic installation of new functionalities. They wanted to be always in charge of changes on the Compaan.
7. **Privacy:** Password for family portal, there was one case in which the informal caregivers expressed concerns related to privacy issues, because she did not have an automatic email to change her password. Probably this could be helpful to create feelings of trust when this would be adapted.

D. SUGGESTIONS ON NEW FUNCTIONALITIES

1. **Control functionalities:** Connection of more domotics (e.g. sensors, cameras or detection tools, alarm button for alarming family directly with SMS, phone call or message in case of emergency)
2. **Computer functionalities:** such as excel, word and being able to print from the Compaan (e.g. Bluetooth connection with printer), being able to connect an USB.
3. **Online functionalities:** A special app for YouTube or YouTube made more easy to use for elders to watch videos and listen music. Making it possible to bank online with a special app or site for elder who are able to do that. A travel planning app for public transport or taxis.
4. **Entertainment functionalities:** book readings (aloud), music tool (e.g. playlists, kind of Spotify), integrating remote controls on the Compaan (for TV/radio), Netflix for elders.
5. **Information functionalities:** providing information for informal caregivers about caregiving, respite care, useful organizations, website and contact addresses etc.
6. **Communication functionalities:** a 'normal' phone function on the Compaan (e.g. easier to use one device for the elder)
7. **Caring functionalities:** being able to turn on the TV or music at distance by family members or

scheduling of it in the agenda, with asking permission from the elder. Being able to scan documents with the Compaan (e.g. during skype) to quickly share important post. A meal deliverance service was said to be useful.

8. **Social functionalities:** elders being able to connect with other Compaan users during playing games or in a chat program. Or a kind of Facebook for elders.

GENERAL ON ELDER DESIGN

The interviews showed the following general principles that could be relevant to keep in mind with elder design:

- passwords are a problem for most elderly, online opportunities requiring a password therefore are often too difficult. Providing easier (and safe) solutions for this is important (e.g. online banking, shopping with account).
- messages on voice will be difficult because many elders have difficulty with speaking clearly and if they make a mistake it will be difficult for them to understand
- remote controls and phones give a lot of problems, this could be an opportunity to develop the Compaan
- changes are difficult, meaning that starting to use new functionalities is difficult. One should think about a clear introduction of new functionalities for elders.
- elders want to turn off devices out of fear

