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General introduction and discussion

“I have the feeling there is a good basis, and that we, we can all find each other when needed. That is, I think, the most important.”

Nurse, 05122

“If there is something I will tell [...] I will discuss it with them. Sometimes I don't actually do that but the idea that you can discuss it is very nice to me.”

Partner, 06911

“This lady is an example of someone who can, especially thanks to informal care, in a frail condition, [...] continue to live independently. [...] I can close the door behind me without worrying, because I know she gets sufficient care. [...] A circle of caregivers who cooperate and complement each other.”

Household worker, 07421¹

Adequate long-term care for the ageing population is an important theme for governments, health care organizations and the general population. But how common is the situation of the lady described above? How do the care situations of older adults vary? And how can differences be explained? This dissertation will describe care networks of older adults, specifically regarding the connections between informal and formal caregivers. In this chapter I will describe the Dutch social context, introduce my theoretical framework and research questions, give an overview of the findings and end with a general conclusion and discussion.

The absolute number of older adults in need of care will increase, as well as their proportion in the general population (Glendinning & Kemp, 2006). In 2014 17 per cent of the Dutch population was 65 or older, and this number is expected to rise to 20 per cent in 2020 and to 25 per cent in 2030 (CBS Statline). The ageing of the population and policy measures responding to rising public health care costs may lead older adults to increasingly turn to informal care: policies in the Netherlands of the past decade, encourage older adults to continue to live at home, arrange their own care and mobilize informal caregivers (Da Roit, 2012; Grootegoed & Van Dijk, 2012; Schenk, Dykstra, Maas, & Van Gaalen, 2014). These policy measures are a result of the increasing tension between the generous, universalistic features of the Dutch welfare system (OECD, 2009) and its financial sustainability (Da Roit, 2012). In box 1.1 the development of the Dutch long-term care system is described in more detail.

Research on the Dutch population indicated that 11 per cent of the Dutch older population between 65 and 85 used informal care in 2012 (Swinkels, Suanet, Deeg, & Broese van Groenou, 2015). For those over 85, this was almost 35 per cent in 2008 (Plaisier, van Tilburg, & Deeg, 2011). However, labour force participation by

1 Quotes in this dissertation come from interviews held in the context of the ‘Care Networks of Frail Older Adults’ study. The numbers indicate the unique respondent numbers.

women has increased, households are smaller compared to previous decades and travel distances between family members have increased. Hence, fewer informal caregivers will be available for the growing elderly population, and might need to share the care among multiple caregivers to sustain the long-term care and avoid overburdening. With regard to the use of formal care, we know that in 2011, 12 per cent of the community-dwelling older adults between 65 and 79 used publicly-paid extramural formal care like household care, personal care or nursing care. For older adults older than 80, this was 45 per cent (Plaisier & de Klerk, 2015). Of the Dutch older care recipients aged 65 and over, 22 per cent has a mixed care network, consisting of both informal and formal caregivers (Suanet, Broese van Groenou, & van Tilburg, 2012).

As older adults will continue to live longer in the community with an increased care need, specialised formal care will be needed in addition to informal care, as a result of the aforementioned policy measures. The expectation is thus that informal and formal caregivers will more often both be simultaneously present in the care network (Geerts, 2010; Wiles, 2003). Insight into which older adults use multiple types of care, and how and why informal and formal caregivers are connected, will therefore become even more relevant.

Most studies distinguish between the use of no care, formal, informal, or mixed forms of care (e.g. Bolin, Lindgren, & Lundborg, 2008; Bonsang, 2009; Motel-Klingebiel, Tesch-Roemer, & Von Kondratowitz, 2005; Van Houtven & Norton, 2004). This, however, gives no insight in the number of individual formal and informal caregivers. As a result, the composition and size of the care network as a whole remain unknown. Furthermore, when focusing on research on cooperation between caregivers, most studies have involved only one care recipient-caregiver dyad, or one informal-formal caregiver dyad. Thus, as Sims-Gould and Martin-Matthews (2010) state, most studies neither take the broader care system into account in which multiple individuals contribute to the care provision, nor examine the dynamic and intertwined nature of informal and formal care in a homecare setting. Also Davey and Szinovacz (2008) acknowledge that a focus on only primary caregivers misrepresents important characteristics of care networks, like the structure of the network. This is problematic for a number of reasons. First, the structure of the network can add to explanations of individual behaviour in addition to individual determinants. Second, knowledge on the care networks of older

adults informs us on which types of caregivers share the care with whom. This dissertation extends prior research by taking a network perspective in explaining older adults' care use, and by examining the functioning of care networks. All in all, given the societal context in which there is a decreasing availability of informal and formal care, and the limited scientific knowledge on care networks, the aim of the current research is to describe and explain *the variation in composition and functioning of care networks of older adults, specifically regarding the interconnections between informal and formal care.*

Box 1.1 Background of the Dutch long-term care system.

Up to 2015 long-term care was to a large extent arranged through The Exceptional Medical Expenses Act (*Algemene Wet Bijzondere Ziektekosten, AWBZ*), which was enacted in 1968. To enable older disabled adults to continue to live independently and to contain costs, extramuralisation policies emerged in the 1980s (Da Roit, 2012) and continue to be employed to date. At the end of the 1980s, 11 per cent of the older adults lived in a residential setting. This percentage decreased substantially, to less than five per cent in 2010 (Garssen & de Beer, 2012). The numbers of care users at home thus increased considerably in the beginning of the millennium, leading the government to introduce measures of cost containment of home care. One measure was the introduction of the Social Support Act (*Wet Maatschappelijke Ondersteuning, WMO*), which was enacted in 2007 and gives more responsibilities to local authorities, in particular for housekeeping support. Entitlements from insurance and individual rights transformed into a subsidiarity principle in which citizens are addressed themselves to arrange their needed support. Only in case they are not able to do so the municipality intervenes. Hence, older adults live longer at home with greater care need. As of January 2015, the allocation of long-term care has been changed, placing even more reliance on self- and informal care, framed as a part of a 'participation society'. Personal care, household care and help with transport and guidance are arranged via the municipality, in which older adults are still required to regard their social network and what they can do, before any help is granted. Residential care and long-term care that is needed 24 hours per day, is ensured via the Longterm Care Act (*Wet Langdurige Zorg*). The Exceptional Medical Expenses Act disappeared completely, the Social Support Act is extended with guidance and day-care. Furthermore, the Health Insurance Act (*Zorgverzekeringswet*) covers personal and nursing care, which was financed via the Exceptional Medical Expenses Act before. Budgets for the Social Support Act and the Health Insurance Act have decreased substantially. Data used in this dissertation were collected in 2011 and 2012, a few years before the major long-term care reforms in 2015.

Defining care

Care is usually defined as help with (instrumental) daily activities, such as household care, personal care or nursing care. As I want to regard a broad scope of care activities that caregivers can undertake, help with administration and transport are also seen as indicators for care within this dissertation. Informal care can be defined as care given out of a social relation, like family, friends or neighbours, or as voluntary work. Formal care is provided out of a paid profession, either privately-paid or publicly-paid. Following Keating, Otfinowski, Wenger, Fast and Derksen (2003), I define care networks as the collection of individuals who provide support because of a senior's long-term health problems or functional limitations. The distinction with a support network is that caregivers in a care network take up their support because of these older adult's long-term health problems or functional limitations, which has implications for the composition and size of care networks compared to support networks, which have been studied more in detail (e.g. Litwin, 1997; Wenger, 1997). Whereas in most studies support is defined as instrumental and/or emotional, I specifically regard five types of tasks, i.e. household tasks, personal care, nursing care, help with transport and administration. Although I acknowledge the importance of emotional and social support, the focus of this dissertation is on instrumental care tasks provided.

Studying care use, networks and connections

To be able to explain why older adults use certain types of care, have certain kind of care networks and to explain how these networks function, I involve several determinants throughout my studies. To a large part, these determinants will be derived from the 'behavioral model of health service use' (Andersen & Newman, 2005), which is used in most research to study the individual determinants that are associated with care use. This model distinguishes need, predisposing and enabling factors. The need for care is the necessity of care due to sickness, and is indicated by both the physical and mental health status of the care receiver and his or her functional limitations. Predisposing factors indicate the degree to which people are willing to ask for help. Demographic features and opinions, preferences and expectations of older adults about care are classified as predisposing factors. The

third dimension contains enabling factors which make it possible to use informal and/or formal care. These factors entail the availability of caregivers, like the presence of a spouse, the number of children and income.

The behavioral model of health service use will be applied and extended in this dissertation in various ways. Within the enabling dimension the use of informal care is generally viewed as a substitute for formal care and vice versa. This limits insight in how formal and informal caregivers can complement or supplement each other in mixed care networks. The first application thus focuses on processes of task division among formal and informal caregivers within a mixed care network. Next, also within the enabling dimension I will go beyond the traditional distinction of formal and informal caregivers and study the presence of a large range of caregiver types (e.g. kin, non-kin, privately paid, publicly-paid). This enables studying processes of substitution and complementarity among groups of informal caregivers as well as among groups of formal caregivers. Furthermore, in addition to characteristics of the care user, I will also include characteristics of the caregiver, such as how they are related to the older adult, motives and type of care tasks being performed. Another contribution is that the study of care use is performed with a network perspective, which will be elaborated on next.

When studying the care networks of older adults and the connections between informal and formal caregivers in care networks, I will not only regard the individual older adult or the primary caregiver, but take dyads, as well as details of the full care network into account. I furthermore regard the care network on different levels: by studying the care network as a whole and by focussing on formal-informal connections at the dyadic level. Networks can be studied with regard to their structural, content as well as functional dimensions (Carpentier & Ducharme, 2003). Structural dimensions in network research include size, density and composition of a network. The functional dimensions entail the care that is provided, for example with regard to tasks being conducted and how tasks are divided. Content can be described by the attitudes and norms that the actors in the network hold. These norms and opinions can exert influence through the ties within the network, but also restrain actors from forming ties, for example when family values are incompatible with the values of professional caregivers (Carpentier & Ducharme, 2003). The care network as a whole will thus be studied in terms of the composition and functioning of those networks. Processes like substitution

or supplementation will surpass the informal-formal division by regarding the network and the informal and formal sub-groups as well.

The network connections that exist by definition are the connections of all caregivers with the older adult. Their relationships can range from ties with family, professional caregivers, or with volunteers. As all caregivers are tied with the older adult, the dyads *between* caregivers are by definition part of a triad including the older adult. The informal-formal caregiver connection may differ due to the characteristics of their relationship to the care recipient, but also due to the characteristics of the three actors involved. In order to study the variation among informal-formal caregiver dyads within care networks of older adults, I will move to the dyadic level. I will focus on the discussion of care among formal and informal caregivers, and study its association with characteristics of the network, characteristics of the three individual actors involved, and characteristics of the dyad between the caregivers and the dyads they form with the older adult.

Research questions

The general informal - formal connection: How are tasks divided?

I will begin by studying task division between informal and formal caregivers in mixed care networks. Different models have been developed over the years on how informal and formal caregivers divide tasks (Geerts, 2010; Lyons & Zarit, 1999; Travis, 1995). According to Cantor's *hierarchical compensatory model* (1979), choice for type of caregiver is based on preference, in which the partner, children and other family comes first, followed by non-kin, such as friends or volunteers. The formal system is used only as a last resort, when informal care is not available. Greene (1983), on the other hand, proposed with his *substitution model* that when formal services are provided, informal care decreases. Litwak (1985) described the task-specific or *complementation model*, which states that formal and informal caregivers each have capacities that are best fitted to differing types of tasks. Some tasks occur at unpredictable times requiring proximity of the caregivers, whereas other tasks require specific skills or trained caregivers (Litwak, 1985; Litwak & Szelenyi, 1969). In line with this model research revealed that help with IADL (Instrumental Activities of Daily Living) is more often given by informal caregivers, whereas help with ADL (Activities of Daily Living) is more often given by formal

caregivers (Dwyer & Coward, 1991; Wolf, Freedman, & Soldo, 1997). In *the supplementation model*, as described by Edelman and Hughes (1990) and Chappell and Blandford (1991), formal help is mainly supplementary to care delivered by informal caregivers. Both types of caregivers perform the same kind of tasks, as opposed to the complementation model. Professionals are, for example, in this case hired to help with household care, which is also done by informal caregivers. The supplementation model is likely to occur in situations where informal caregivers are unable to fully meet the care receiver's need (Travis, 1995). Noelker and Bass (1989) introduced the concept of *formal specialisation*: both types of caregivers share one type of task (e.g. household care) and formal caregivers perform one type of task by themselves (e.g. personal care). The reverse situation is also possible: *informal specialisation*, in which both types of caregivers share one type of task and informal caregivers carry out the other type of task by themselves.

As I study the task division in mixed care networks, consisting of both formal and informal caregivers, I will distinguish between the complementation model, the supplementation model, formal specialization and informal specialization. In this way I can explore which roles informal and formal caregivers can have and which types of caregivers need or do not need to tune the care. Empirical studies that include these models show mixed results, and as Geerts (2010) argues, research should not examine which model best fits reality, but rather investigate which model prevails for which older adults, given their individual circumstances. I therefore also investigated which determinants were of influence of the different types of task division. In chapter two the following research question is answered: *Which different types of task division between informal and formal caregivers are present in a mixed care network, and how are care receivers and informal caregivers' characteristics associated with these different types of task division?*

How are care networks composed?

The substitution, complementation and the two specialization models that serve in this dissertation as frameworks to study task division are not really suitable to further explore the composition of care networks and the informal-formal connection. Ward-Griffin and Marshall (2003), amongst others, criticize the conceptual models, for treating formal and informal care as two separate spheres, instead of regarding the intermediate domain where private and public domains inter-

sect. Another critique on these conventional models is that the older adults are neglected as potential participants in the care network, for example with regard to their organization of the care (Kemp, Ball, & Perkins, 2013). I furthermore described how the structure and other important characteristics of care networks remain unknown in most studies. Based on these considerations, I consider all caregivers involved in the care networks of older adults, as well as the older adults themselves when examining the composition and functioning of care networks. I will add to current knowledge by including a diversity of informal caregivers and a diversity of formal caregivers, and provide insight into which caregivers substitute and which complement each other, and how care networks vary in terms of diversity of caregivers and care intensity.

In the context of the current long term care reforms, older adults will need to address and stimulate their own local social network as potential informal caregivers (Grootegoed & Van Dijk, 2012; Schenk et al., 2014). Therefore, in studying the composition of care networks, I will also show the role of several psychological factors of the older adult (Blieszner, Roberto, & Singh, 2001; Bradley et al., 2002), and proximity of the local social network, in addition to other well established determinants which predict usage of care (cf. Andersen & Newman, 2005). This leads to the following research question for the third chapter: *How are the care networks of community-dwelling older adults in the Netherlands composed, how does the share of informal care vary therein and how is the variation between care networks related to individual determinants, specifically regarding psychological factors and the locality of the social network?*

In the third chapter I examine the variety of care network composition among older adults in the Netherlands. As I am specifically interested in the cooperation between informal and formal caregivers, I focus from the fourth chapter onwards on mixed care networks in which both types of caregivers (informal and formal) are present. I will study a sample of older adults with a large care need to examine specifically within these care networks what the dynamics are and how the informal-formal connection is shaped. In the fourth chapter, I will take both structural and functional aspects of the care network into account. As in the third chapter, I seek to identify care network types, and hereby also take contact and task overlap between informal and formal caregivers into account to involve functional aspects of care networks as well. Hence, my research question reads: *Which types*

of mixed care networks can be distinguished when size, composition, contact and task overlap between caregivers are taken into account, and how are the older adults' need, disposition and enabling factors associated with those types?

Caregiving dyads: who discusses the care?

So far, the informal-formal connection is explored by regarding when tasks are shared and when not, and which types of caregivers are present solely or together in a care network. In the fifth and sixth chapters the actual connection between informal and formal caregivers will be explored. Care discussion will be the outcome variable of the studies, as good cooperation starts in the first place with discussing the care. Discussion of care is defined as involving any exchange of information between two caregivers concerning the care situation of the older adult. This can be communication in case of an emergency, or consulting one another on how to deal with specific issues concerning the older adult, for example on technical, medical or social procedures. Many studies have been conducted on the evaluation of the formal-informal connection (Haesler, Bauer, & Nay, 2007), actual discussion however is not explored as much, let alone with a network perspective.

I will focus on the necessity to discuss the care, meeting opportunities (Mollenhorst, Völker, & Flap, 2011) and a shared focus (Feld, 1981). Necessity can be indicated by characteristics of the older adult. For example, older adults can decrease the necessity to discuss the care by controlling the care and communicate with all caregivers, allowing all discussion to go via them. Or, another indicator for a decreasing necessity to discuss the care in multiple informal-formal caregiver dyads is that a specific informal-formal caregiver dyad forms a bridge and informs the informal and formal caregiver subgroups, respectively. Meeting opportunities might form another explanation, such as living in the same household or providing a lot of care, which creates stimulating conditions for caregivers to meet each other and discuss the care. Finally, a shared focus, like performing the same type of task might influence whether or not formal and informal caregivers discuss the care. The research question leading in chapter five reads: *To what extent is discussion of the care between an informal and a formal caregiver in a mixed care network related to characteristics of the older adult, the care network at large and the dyads between the three actors involved?*

As described, another aspect of care networks is the content, defined by the attitudes and norms that are prevalent in the network. Hence, individual characteristics and norms of the caregivers themselves should also be taken into account. For example, informal and formal caregivers can see the ‘other’ as resource or burden (e.g. Benzein, Johansson, & Saveman, 2004; Benzein, Johansson, Årestedt, & Saveman, 2008; Hertzberg, Ekman, & Axelsson, 2003) and the display of social, emotional or affective care towards the other influences that quality of the relationship (e.g. Friedemann, Montgomery, Maiberger, & Smith, 1997; Ward-Griffin, Bol, Hay, & Dashnay, 2003). But how do their motivations and opportunities play a role when regarding their level of cooperation with other caregivers? Similar to chapter five, I take discussion of care between informal and formal caregivers as outcome variable in the sixth chapter. However, in this chapter I take the individual considerations of both types of the caregivers into account, in addition to the objective characteristics of the older adult, the care network, the dyads and individual caregivers. Prior research has shown that caregivers provide care based on different motives (e.g. Beneken Genaamd Kolmer, Tellings, Gelissen, Garretsen, & Bongers, 2008; Hoefman, 2009) and that older adults and caregivers may have different preferences (e.g. Pinquart & Sörensen, 2002; Wielink, Huijsman, & McDonnell, 1997). These conditions might be of influence on whether or not informal and formal caregivers discuss the care. Views of the formal caregivers, such as regarding the informal caregiver as a resource, a burden, a co-client or co-worker can influence the connection between the informal and formal caregiver as well (e.g. Twigg & Atkin, 1994; Ward-Griffin & Marshall, 2003). I explore in the sixth chapter what the contributions are of the individual dispositions of both types of caregivers in whether or not discussion occurs. In this chapter I regard the dyads of the most important informal and formal caregivers in the network, as they were interviewed about their dispositions. The research question is: *What are the conditions in which informal and formal caregivers discuss the care, regarding objective characteristics of the older adult, the care network and caregivers as well as individual dispositions of the caregivers?*

Data: general description

In this section a short overview is given of the various datasets that were used to answer my research questions. To study task division between informal and formal caregivers (chapter two), data from the ‘Informal Care’ study by Statistics Netherlands (CBS) and The Netherlands Institute for Social Research (SCP) were used. First, informal caregivers were identified through the Labour Force Survey collected by Statistics Netherlands in 2007. Respondents in this survey were asked whether they provided care for at least two weeks in the last twelve months for someone in their social network who needed assistance, was severely ill, had an accident or hospital admission, was chronically ill, impaired or provided care for other reasons. Those who responded affirmatively received a mail questionnaire. Of the 4484 caregivers who were identified, 2813 informal caregivers completed the mail questionnaire (de Boer, Broese van Groenou, & Timmermans, 2009). Respondents provided information on different aspects of caregiving, such as the characteristics of the older adults, their own characteristics, other informal caregivers that were available, and the formal care use.

In order to study the composition of care networks of community-dwelling older adults in the Netherlands, data from the Longitudinal Aging Study Amsterdam (LASA) are involved for the third chapter. LASA is an on-going multidisciplinary cohort-sequential study on the physical, cognitive, emotional and social functioning, as well as the care use of older adults in the Netherlands (Huisman et al., 2011). It is a national survey, as respondents were selected from three representative, culturally distinct regions, also varying in level of urbanization. LASA aims to study determinants, consequences as well as changes over time in these five domains of functioning, and interrelate them. The first data collection took place in 1992, in which respondents born between 1908 and 1937 were included. The sample was drawn from 11 Dutch municipalities which differed in level of urbanization and religion. Both in 2002-2003 and 2012-2013 a new sample was included, born in 1938-1947 and 1948-1957, respectively. Since 1992 follow-ups are held every three years. Data are collected by a personal interview, a separate medical interview and questionnaire. For the third chapter data of the 2011-2012 wave is used, stemming from the first two cohorts, in which 1308 older adults were

interviewed. Those older adults were selected who received some sort of care, leading to a sub-sample of 491.

As for the fourth, fifth and sixth chapter, data were collected in the context of the ‘Care Networks of Frail Older Adults’ study in the Netherlands (Broese van Groenou, Jacobs, Zwart-Olde, & Deeg, 2015; Jacobs, van Tilburg, Groenewegen, & Broese van Groenou, 2015). This work is supported by The National Care for the Elderly Programme as commissioned by the Dutch Ministry of Health, Welfare and Sport (grant number 314080302), and is a smaller local study in which data were collected from multiple actors in the care networks of older adults. Older adults in need of care were identified via eight homecare and three voluntary care organizations in Amsterdam and surroundings in 2011. From the homecare organizations team- and case managers together with professional caregivers approached older adults who were, according to them, cognitively able to participate in a face-to-face interview, aged 65 or older, and who received care from at least two types of caregivers, i.e. informal caregivers (family/friends or volunteers) or professional caregivers.

The main focus of the study was to identify the care network, but information on the physical, cognitive, emotional and social functioning was provided as well. Furthermore, the older adults answered questions about other care use such as day care, hospital admissions, the evaluation of the care provision, perceived control of care, quality of life and open-ended questions about the start of the care, alternatives for care provision, what to do in cases of emergency and plans for the future. Finally, the older adults were asked to identify the most important caregivers of which at least two different types (both informal and formal) were approached for an interview. In total 94 informal caregivers (of which 11 volunteers) and 102 formal caregivers were interviewed, providing details about their own characteristics and living situation, views on caregiving, preferences, and open-ended questions in which they evaluated the care. They could also identify other caregivers and indicate with whom in the network they discussed the care, as the older adult might forget some caregivers and may be less aware of the connections between caregivers (Koehly, Ashida, Schafer, & Ludden, 2015). Many stakeholders were included during this study, which is elaborated in

Box 1.2. Interaction with stakeholders

As a part of the ‘Care Networks of Frail Older Adults’ study, multiple stakeholders were involved, including older adults themselves, informal and formal caregivers, managers from care organizations, policymakers from city councils and the national government, representatives from health insurance companies and lobby organizations for informal caregivers and volunteers, and several medical doctors and researchers in the field of geriatrics, care, and welfare. They gathered three times in varying combinations and commented on the research plans and directions, design of the study, questionnaires, and the form and content of the non-scientific output: various reports and brochures were written, aimed at and disseminated to direct users and the general population (van Wieringen, Broese van Groenou, & Groenewegen, 2014; Zwart-Olde, Jacobs, & Broese van Groenou, 2013a; Zwart-Olde, Jacobs, Broese van Groenou, & van Wieringen, 2013b). Other interaction with the field occurred as well: several lectures were given to stakeholders and the broader audience. Given the large reforms in the long-term care sector, it was important to reflect with these stakeholders on the consequences these reforms had for the research project, and how the results of the research project could be interpreted in light of these reforms. The societal implications of the results of the dissertation are partly based on these activities, of which an overview can be found in the appendix.

Chapter overview

The composition and functioning of care networks are explored in several ways, divided into different studies which are summarized in table 1.1. The major findings are summarized per chapter.

Summary of the findings

Chapter 2: Task division in mixed care networks

The functioning of mixed care networks was regarded on a dyadic level by regarding types of task division and relating them to characteristics of the care receivers and informal caregivers. The four types of task division (the complementation model, the supplementation model, formal specialisation and informal specialisation) were compared in mixed care networks. I found the supplementation model, in which informal and formal caregivers perform the same type of tasks, to be most prevalent in the model. When tasks were divided the informal caregivers more often provided household care and formal caregivers provided personal care. Children and those using privately-paid help were more likely to comple-

Table 1.1 Overview of the dissertation

Goal	Data	Methods	Results
Chapter 2 Relate several determinants to various forms of task division like complementarity, supplementation, informal – and formal specialization	SCP, data from Labour Force Survey 2007 N = 458 caregivers Dependent variable: Four theoretically driven task division types	Multinomial logistic regression with Average Marginal Effects	Intensity of care provision, informal caregivers' motives and presence of privately-paid help distinguish between type of task division
Chapter 3 Describe prevalent types of older adults' care networks based on caregiver diversity and relate differences to various determinants	LASA wave 2011-12 N = 491 Dependent variable: Four types of care networks using six indicators of different caregiver types	Latent class analysis, multinomial logistic regression	A privately-paid, partner, larger informal and formal care network were distinguished; perceived control, preference for informal care, education, income as well as locality of different social network types differentiated between the network types
Chapter 4 Explore how structural (size, composition) and functional features (contact, task overlap between informal and formal caregivers) contribute to different types of mixed care networks	CNFOA, 2011-2012 N = 74 Dependent variable: Four network types using two structural and two functional indicators	Principal Component Analysis, subsequent F-tests and Chi-square tests	A small mixed care network, small formal network, large mixed network and large formal network were distinguished. ADL-level, memory problems, social network, perceived control and level of mastery differed
Chapter 5 Examine discussion of care between all potential informal-formal caregiver dyads in a care network and relate this to conditions of the older adults, the care network structure, and the caregivers	CNFOA, 2011-2012 N = 2150 (level 1, dyad observations); 1020 (level 2, dyads); 410 (level 3, care-givers); 74 (level 4, older adult/ network characteristics) Dependent variable: Discussion of care	Multilevel logistic regression	In 26% of the dyads discussion occurred, which was the case when both caregivers performed multiple types of tasks, the informal caregiver was co-residing and contact within the informal and formal sub-networks was higher
Chapter 6 Relate discussion of care to individual dispositions of caregivers (next to objective characteristics of the older adult, care network and caregivers	CNFOA, 2011-2012 N = 112 Dependent variable: Different types of informal caregivers. Discussion of care	Descriptive, F-tests and chi-square tests	Discussion especially occurs when informal caregivers are strongly motivated to keep the older adult at home, dispositions of the formal caregiver did not matter

LASA: Longitudinal Aging Study Amsterdam; SCP: The Netherlands Institute for Social Research; CNFOA: the Care Networks of Frail Older Adults study

ment the care activities, and informal caregivers who were strongly motivated usually performed more types of tasks. The results reveal that there is a difference between the complementation model and formal specialisation on the one hand, and informal specialisation and the supplementation model on the other, where in the latter models care is often provided for more hours and for a longer period of time, the caregivers are more strongly motivated, and privately-paid help is less often used compared to the former models. Hence, privately-paid caregivers help informal caregivers or replace the tasks of the formal caregivers.

Chapter 3 and 4: Distinguishing care network types

In the third chapter I aimed to distinguish care network types, regard the share of informal care and explore how the variation between the care networks was related to several individual determinants. I used a latent class analysis with caregiver types as indicators, and revealed four types of care networks. The *privately-paid network* type is characterized by a presence of a privately-paid caregiver, the absence of informal care and by older adults having relatively good health, many financial and social resources, and in control of life and care. In the *partner network* the older adults always had a partner or resident child, providing many hours of care by often only one caregiver. In 76 per cent of the cases they provided care without any form of formal care (either privately-paid or publicly-paid). The older adults in the partner network were relatively young, they had moderate functional limitations and relatively often preferred informal care. The *larger informal network* is characterized by older adults who receive help from relatively many informal caregivers (children, other family and non-kin), have moderate functional and cognitive limitations, children and other relatives living nearby, and a preference for informal care. Older adults with a *formal care network* have a high care need based on age and health, low personal and social resources and are thus strongly dependent on formal care.

Need, predisposing and enabling factors varied between the networks: having children nearby was associated with higher odds of receiving informal care in the larger informal network, but this effect was not found for other types of informal caregivers. Although older adults in the partner care network relatively often had friends and other non-kin close by, the partners, helping a lot of hours and with a lot of different types of tasks, provided the care solely. This suggests they might

need to be stimulated to overcome a ‘request scruple’ and share the care with other potential informal caregivers, to prevent overburdening. Psychological indicators of the capability to mobilize informal caregivers did not prove to have an effect in the informal network, suggesting that possibly informal caregivers themselves mobilize others. Older adults in the formal care network had a high care need, few social network members and their perceived control of care was low, indicating this is a vulnerable group in times of cutback in formal care.

From the fourth chapter onwards I focused on mixed care networks. First of all, I studied the network level, and took both structural (size, composition) and functional characteristics (task overlap, discussion) into account to reveal network types. Four networks were identified: a *small mixed care network* with older adults often living alone and with relatively little (I)ADL disabilities and a low level of mastery, a *small formal network* with mostly a residing caregiver and more formal caregivers, in which much discussion occurred, the older adult having a high sense of mastery and relatively many ADL disabilities, a *large mixed network* with relatively many kin and non-kin caregivers and little contact between the informal and formal caregivers, in which the older adult had few disabilities, and a *large formal network* with many formal caregivers, in which the older adults had a relatively small social network and many ADL disabilities.

The networks resembled the network types I derived in the third chapter, in which the amount of informal caregivers present seemed to be dependent on marital status, and the number of formal caregivers present dependent on care need and age: if a partner was present, he or she provided a lot of care, without any other informal caregivers. When the care need was high and the older adult was relatively old, the social network was relatively smaller and more formal care was involved. The privately-paid network was not present in the fourth chapter. These networks were almost always consisting of solely privately-paid caregivers, performing help with household tasks. This network type could not come up in the fourth chapter due to our selection criteria, which were aimed at mixed care, resulting in a sample of older adults who used both informal and formal care. Furthermore, the sample of both chapters differed substantially, in which the latter had a larger care need.

Chapter 5 and 6: Care discussion in informal-formal caregiver dyads

In chapter five, I studied the extent to which discussion of care between informal and formal caregivers was related to characteristics on the network level, to the older adult and to characteristics of the caregivers involved. In this study I found that in 26% of all informal-formal caregiver dyads discussion occurred. This was more likely when the caregivers performed more types of tasks, the informal caregiver was residing with the older adult and contact within the formal and informal sub-network was higher. Neither the perceived control of the older adult nor the need for care appeared to matter a great deal for whether or not discussion of care occurred. Higher education turned out to be a better indicator: higher education was related to less discussion suggesting that more highly educated older adults possibly serve as a bridge, i.e. that the communication occurs via the older adults. The fact that occurrence of discussion in the informal and formal subgroups was positively related to the occurrence of discussion between an informal and formal caregiver suggests that in-group discussion might generate questions which need to be discussed with the other caregiver. Another explanation could be that in-group discussion empowers a caregiver to discuss the care with the other type of caregiver, in terms of advice or emotional support.

Finally, in chapter 6 I again focussed on discussion of care, but took individual dispositions into account as well to study their association with the occurrence of discussion. Given the small number of dyads and large number of determinants, I performed bivariate analyses in the sixth chapter. These revealed that discussion with a formal caregiver mostly occurred when the informal caregivers were residing with the older adult or provided a lot of care (increased meeting opportunities), or when they were strongly motivated to keep the older adult at home. Although those dyads were selected which were reported by the older adult as most important, informal-formal caregiver discussion again only took place in about half of the dyads. Especially when there was no residing caregiver, rarely discussion with a formal caregiver occurred, which thus possibly needs to be stimulated more. I could tentatively conclude that the formal caregivers are focussed on preventing overburdening, as they mostly discuss the care with residing caregivers. The individual disposition of the formal caregivers seems not to be important, which might indicate that care provision is very task-oriented, which implies or does not imply

care discussion, but might hinder the professional to discuss the care with informal caregivers when something else than their core task comes to mind.

My overall research question was to gain insight in *which different types of task division between informal and formal caregivers are present in a mixed care network, and how care receivers and informal caregivers' characteristics are associated with these different types of task division*. The care networks varied from smaller sizes to larger sizes, and also in the share of formal care, depending on different determinants like marital status, care need and income. Interconnections between the informal and formal caregivers were also related to a variety of determinants, again marital status, but also the informal caregivers' dispositions, types of tasks that were performed, structure of the network and other dyadic connections in the network.

Discussion

Several conclusions can be drawn from this dissertation. First of all, I regarded traditional models of the informal-formal connection and showed that, following Geerts (2010), different forms of complementation and supplementation can occur simultaneously in task division, depending on the individual circumstances of the older adult and the caregivers. In this chapter on task division I was also able to gain detailed insight into complementation and supplementation processes between different types of formal caregivers in mixed care networks. Privately-paid caregivers were often available in the complementation model and performed the same tasks as informal caregivers. Hence, the privately-paid workers supplemented the informal caregivers with IADL tasks and complemented the formal, publicly-paid caregivers. When formal care helped with IADL tasks, the odds of receiving privately-paid care decreased, which was also found by Broese van Groenou et al. (2006) for older adults in the Netherlands.

When moving to the studies on the composition of the care network, I was not only able to study substitution or complementarity between informal and formal caregivers, but also to gain more specific insight into which caregivers were present together and into who did or did not discuss the care. I found that the relationship type with the older adult is important: partners usually provide the

care alone, which is also found in other studies as well (e.g. Keating & Dosman, 2009; Li, 2004). Hence, there appears to be a substitution effect between them and other informal caregivers. When a partner was present, they usually were the main caregivers as well, indicating that partners are the first to be involved (cf. Cantor, 1979). Other informal caregiver types, such as children, neighbours or friends, more often shared the care amongst each other, but also with formal caregivers, suggesting more complementarity between these types of caregivers. Non-kin rarely provided care, indicating that filial obligations and other social norms still influence the likelihood for an individual to provide care. When specific tasks were needed, like personal care or nursing care, formal caregivers were more often present. Hence, the task dependency model of Litwak (1985) applied as well, albeit mostly for the high-skilled care tasks. In short, processes of substitution or complementation were shown to not only emerge between informal and formal care, but also within the informal or formal groups. Hence, applying a network perspective to these traditional models further increased our insight into which caregivers do or do not share the care.

In both studies on network types I found the same kind of networks, namely a network in which the older adults were not so physically frail and had a small network, a partner network, in which a partner was providing a lot of care, sometimes with the presence of formal care, a larger informal network, in which care tasks such as administration and help with transport were provided, and a formal network, with many formal caregivers, sometimes present together with informal caregivers. Of course, these care situations are no fixed situations: networks are an evolving collection of people (Kemp et al., 2013). Although the care networks were not studied through time, the results of both studies do reveal the dynamic nature of the care process: how care networks develop through time is dependent on the availability of a spouse or other co-resident caregiver, the availability of other informal caregivers (mostly children) in the social network, income and care need.

When mixed care networks were studied in detail, I found that discussion and task-sharing occurred more often with co-residing caregivers such as partners or resident children, indicating the importance of the relationship type and the meeting opportunities (Mollenhorst et al., 2011). Relationship type, a dyadic feature of the caregiver in relation to the older adults, thus seemed to be largely influential

regarding the functioning of the network. Furthermore, it is well established that network research can explain individual outcomes (Borgatti, Brass & Halgin, 2014; Borgatti, Mehra, Brass & Labianca, 2009). How the informal-formal connection was shaped did indeed appear dependent on network characteristics. The presence of other caregivers and the discussion within other dyads in the network was related to more discussion between informal and formal caregivers. Individual characteristics of the caregivers and older adults themselves also played a role. For example, dispositions of the informal caregivers were also related to the functioning of the network, such as the motives of the informal caregivers. The disposition of the formal caregivers did not appear to play a large role, type of tasks performed by the formal caregivers did. Hence, individual behaviour can not only be explained by regarding individual actors, but a number of other explanations add to the explanatory power of the functioning of care networks: the size and composition of the network, characteristics of the dyad with the older adult, individual characteristics of the caregivers and older adults, both objective features (e.g. tasks or hours of care provided) and subjective features (opinions and motivations), and the connections between the non-focal dyads.

All in all, applying and extending the determinants of the ‘behavioral model of health service use’ (Andersen & Newman, 2005; Bradley et al., 2002) proved to be useful to not only explain the care use of older adults and the involvement of various types of informal and formal caregivers, but also to relate to processes of substitution and complementation within mixed care networks. Involving multiple types of informal and formal caregivers informed on which types did or did not share the care. Furthermore, individual determinants from the behavioural model were also related to the connection of informal and formal caregivers. Applying the behavioral model to care users and caregivers simultaneously, proved to be a valuable extension as well.

Whereas establishing the size of personal social networks is relatively common in social sciences, establishing the size of a care network has not been done very often. In addition to investigating the variance in size of care networks, I investigated a variety of ties, and how these ties affected each other (cf. Borgatti et al., 2009). The dependent variable of two studies was the discussion of care, which can be seen as a relation indicated by interaction. I regarded similarities by means of a shared focus (Feld, 1981), as indicated by task overlap. Also, I regarded the social

relation of the informal caregiver to the older adult, and the professional relation of the formal caregiver to the older adult. Because of these mixed composed care networks, the ties to the older adults in need of care varied from being a kinship tie with a likely large affective dimension, to a relationship with professional values. These in turn were related to the occurrence of interaction between two caregivers. In the chapters with the network typology as the outcome variable, I aggregated within-group dyadic discussion, i.e., the interaction among informal caregivers themselves and formal caregivers themselves, as well as the number of individual caregivers, to establish the number and proportion of various caregiver types. In short, dyadic information like relationship types, aggregated dyadic information like within-group discussion, and aggregated individual information like number of caregivers, were related to outcomes on the dyadic level (i.e. occurrence of informal-formal care discussion) and on the network level (i.e. network typologies). Although network analysis is not applied in its traditional form, the studies in this dissertation are among the first in which care networks are studied in detail, upon which future research could possibly build.

Limitations and suggestions for future research

Several limitations can be identified from this dissertation, and suggestions for future research can be derived from them. For all studies I had the availability of cross-sectional data only. Therefore, I could not establish which social relations transfer into care relations, or what transitions occur in care networks over time. Longitudinal research among a larger group of frail older adults and over a longer period of time would be needed to establish the transitions that occur in care networks. Allen, Lima, Goldscheider and Roy (2012) studied care transitions and took the presence of secondary informal and formal caregivers into account, but did not regard the entire care network. By obtaining full care network details, the stability of care networks might be related to the size and composition of the network, whether caregivers can take over each other's tasks and thus form a safety net, or whether new caregivers get involved and disappearing caregivers get replaced.

Another implication of the lack of longitudinal data is that I could not establish the causality between the individual determinants and care network type, for example between health deterioration and the composition and functioning of the care networks, or when older adults would make the transformation to another

type of care network. Specifically the care trajectories of the older adults within the formal care networks could be regarded, who were identified as a risk group, to investigate who will provide the care when the care need increases. Furthermore, gathering data on both the social network and the care network provides information of who in a social network does actually provide care. Longitudinal research may establish how specific characteristics of the social relation (e.g. kin, non-kin, duration of the relation, intimacy) matter for the transition to a care relation.

A second limitation is that only older adults who had no or few cognitive problems were interviewed. Therefore, it remains unknown how care networks of cognitively impaired older adults in the Netherlands are composed. A recent multi-actor study by Koehly, Ashida, Schafer and Ludden (2015) provides information on care networks of older adults suffering from Alzheimer in facility settings in the United States. Control of care, the capabilities to arrange one's own care or the older adults' function as a bridge between informal and formal caregivers, are all characteristics that do not, or to a lesser extent, apply to cognitively impaired older adults. Therefore, it is important to compare the composition and functioning of care networks of cognitively impaired older adults, for example those suffering from dementia. We know from previous studies that cognitive disfunctioning leads to fewer continued and new contacts in the social network (Aartsen, van Tilburg, Smits, & Knipscheer, 2004; Broese van Groenou, Hoogendijk, & van Tilburg, 2013). Research on the care networks of cognitively impaired older adults would provide insight in whether these networks are smaller in size as well compared to cognitively healthy older adults, specifically regarding the share of informal caregivers. Regarding the functioning of the networks, knowledge would be gathered on how care networks of older adults with declining cognitive abilities (need to) change, for example regarding a greater need for connection between caregivers.

The third limitation is related to the concept of 'assistive care', as explained and studied by Sims-Gould and Martin-Matthews (2007), which is help given to other caregivers allowing them to fulfil their tasks. For example, the informal caregiver can prepare a meal, which the formal caregiver can give to the older adult. Hence, informal caregivers prepare the conditions for the formal caregivers to fulfil their tasks. I regarded the tasks the caregivers provided to the older adult, but not any form of assistive care amongst the caregivers themselves, which, in addition to discussion of the care, could have been another dimension of the cooperation

that occurs between caregiver dyads. Furthermore, I limited the care network to caregivers who all provided help to the older adult, and because of this selection the supportive networks of the caregivers remain invisible. It did show, in this way, all caregivers directly involved and as a result provided information on the number of people the older adult sees, and what primary tasks are needed. But another implication is that the assistive care, or indirect care, remains invisible (Koehly et al., 2015; Kruijswijk, Da Roit, & Hoogenboom, 2014). Including these caregivers who do not provide the care directly to the older adult, would possibly lead to larger care networks estimations.

Next, I included individual attitudes and preferences as indicators of dispositional factors of care use and care provision in studying a selected sample of formal-informal caregiver dyads. As we did not interview each caregiver within the entire network, I could not take the preferences of other network members into account. Especially in close networks with a lot of strong relationships, norms and values are shared within the group (Coleman, 1990), which can influence the individual behaviour. In line with this, Silverstein and Bengtson discuss consensus as a dimension of intergenerational solidarity (1997), which could also apply to caregiver and caregiver-care recipient dyads. Shared norms could facilitate interaction and vice versa, and further research could gain insight in how consensus plays a role in the functioning of care networks. Knowing this would possibly be another explanatory variable of why some connections came about in the caregiving dyads, and why some caregivers did not discuss the care. Furthermore, the most important caregivers reported on all dyads in the network. When collecting full network data, the level of discussion would not be derived from the ego-networks of those who are interviewed, but collected from every individual themselves, improving the accuracy of whether or not discussion occurred between two caregivers.

As I only used Dutch data, a final limitation is that results are limited to the Dutch context. Therefore, variation in policies, cultural norms and beliefs and its effects on older adults' care networks cannot be established. Also, arrangements and availability of support for caregivers vary between countries and could be of influence on the composition of care networks. Cross-national comparisons of the composition of care networks and the linkages between informal and formal caregivers are therefore important steps in research on care for older adults. As was shown in the empirical chapters, several individual characteristics of both the older

adults and the caregivers are crucial for the composition of the care network, but also for the connections between the caregivers. For example, the type of caregiver (partners behave very differently in the care networks compared to other types of informal caregivers) or the health situation of the older adult (which is related to the number of formal caregivers and the level of perceived control of care). These aspects may play out differently depending on national context, and important to consider in every study on care networks of older adults.

Societal implications

Data were collected before the major long-term care reforms in the Netherlands that were introduced in January 2015. Since then, several care tasks have been shifted from a national level to a municipality level, and from being entitlements (rights) to being services older adults can apply for. Moreover, even more reliance is placed on informal care. These reforms will change the amount of formal care that is available, but might also influence the norms and values of older adults and (potential) informal and formal caregivers, which subsequently might affect the propensities of older adults to involve informal and/or formal care. The general discourse over the last years of the Ministry of Health, Welfare and Sport is that informal and formal caregivers should be connected properly and that multiple informal caregivers in the neighbourhood should be involved (VWS, 2013, 2015). This dissertation revealed that the connection between informal and formal caregivers is currently only prevalent in the case of residing caregivers, and marginally existing in the case of only non-resident caregivers. Furthermore, it is still mostly family that provide the care. This dissertation has various societal implications for older care receivers, informal and formal caregivers, as well as for managers and policymakers in the long-term care sector that do apply to the current situation. Most of them are derived from the empirical chapters, but some implications are informed by the various activities of knowledge dissemination. An overview of these activities can be found in box 1.2 and the appendix. I discuss the most important societal implications below.

As for the older adults, variety in the care networks proved to be related mostly to care need, marital status, the social network and income status. Partners or resident others were found to provide a lot of care by themselves, and in the case of residing caregivers often no other informal caregivers were present, despite the

presence of proximate social network members who could possibly take up a role as informal caregiver. Although older adults have more friends and other non-kin in their network compared to years before (Suanet, van Tilburg, & Broese van Groenou, 2013), these network members do not take a share in the care provision. Co-residing informal caregivers are particularly at risk of becoming overburdened, as they rarely share the care and provide many hours of care themselves. They, together with the older adult, might need to overcome a request scruple (Linders, 2009), i.e. a hesitation to ask help from others, such as neighbours, friends or volunteers. Furthermore, if not done so already, older adults and their partners could regard their willingness and financial resources to involve privately-paid care, to relieve and avoid overburdening of the partner.

For the single older adults with no residing caregivers, the care situation appeared to be very different. Often children were providing the care, and they seemed to mobilize other informal caregivers. Given this role of the children, older adults could discuss their wishes regarding care provision with their children in time, pay attention to their social network and address the preferences towards potential informal care, formal care or privately-paid care. As for non-resident caregivers, there was little discussion with formal caregivers. The informal caregivers could discuss the care more and share expectations about the involvement and tasks all caregivers provide, possibly at the start of the care.

Formal caregivers were shown to discuss the care rarely with non-resident informal caregivers. Moreover, they are not always aware of all caregivers involved in the network. Discussion seems to be merely dependent on the type of tasks the formal caregivers perform, and not on their individual motives, indicating that the formal caregivers are merely task-oriented. Policy asks from formal caregivers to connect more to informal care (VWS, 2013), which requires formal caregivers to regard and adjust themselves to the unique circumstances of every older adult. In the case of residing caregivers, this is attention towards the risk of overburdening, in the case of non-residing caregivers, it implies more connection with the informal caregivers. Therefore, it is important for formal caregivers to identify all (potential) caregivers and make contact with at least one of the informal caregivers and discuss the care on a regular basis, or at the time of a change or health deterioration.

As for the home care organizations, the ‘Care Networks of Frail Older Adults’ study found that organizational policies and work processes are neither adjusted sufficiently to structural cooperation between informal and formal caregivers, nor that a clear vision is developed of who an informal caregiver is and what they ought to do and not do (van Wieringen et al., 2014). These policies and practices could be developed in order to instruct formal caregivers in what they should do and not do and how they could involve and cooperate with other caregivers. Another strategy to enhance discussion of care is to stimulate less task differentiation (i.e. professionals who can perform multiple kinds of tasks), which leads to smaller teams and more cooperation with informal caregivers (van Wieringen, Broese van Groenou, & Groenewegen, 2015). Furthermore, most informal caregivers indicated that they do not need to discuss the care very frequently, but found it important to be able to reach the formal caregiver or care organization when needed. Currently this was not the case in many organizations. Hence, care organizations could facilitate proper accessibility for the informal caregivers. As care discussion did not often occur for non-resident caregivers, and formal caregivers were not aware of all caregivers present in the care network, digital and technical tools, such as websites or graphic tools such as an ‘genogram’ (Kruijswijk et al., 2014), could be used to identify the care network and facilitate cooperation between the caregivers.

I studied various types of informal and formal caregivers in care networks of older adults. Hardly any volunteers were found to be present in the care networks, and the volunteers who did get involved did so particularly for those older adults who had no other informal caregivers providing care. Volunteering organizations could stimulate and develop ways to support other informal caregivers, for example by enlarging the care network with volunteers to alleviate the caregiver burden. Of course, this should not go at the expense of older adults who do not have any form of informal care at all. Furthermore, the volunteers indicated that they preferred to limit themselves to their care task, and not to interfere with the care tasks of the other caregivers. In pursuing the aim of connecting the various caregivers the wishes and boundaries of the caregivers involved should be respected.

Other important organizations are health insurance providers, which can facilitate the cooperation between informal and formal caregivers by providing the financial means allowing formal caregivers to invest time in the relationship with informal caregivers. Often health care professionals and managers from health care orga-

nizations expressed their willingness to involve informal care, but mentioned the financial restraints to do so (van Wieringen et al., 2014). Therefore, it is important for health insurance companies to create the space for these opportunities, even more now they have the responsibility for a wider range of long-term care tasks.

City councils currently arrange much of the long-term care. They have an important role in arranging the connection between care recipients, informal caregivers, interest groups for informal caregivers, care- and voluntary organizations and insurance companies, in order to adjust the care. The rise of the number of community initiatives (Hurenkamp, Tonkens & Duyvendak, 2006) in which older adults are gathered themselves to arrange long-term care, are also developments for city councils to take into consideration.

All parties involved, including national governments, should be aware of the group of older adults who risk a lack of care in times of austerity measures. The network typologies revealed a network type consisting of relatively frail older adults with a great care need, many formal caregivers, a small social network and a low income. In the mixed care network study 28% of the older adults had this type of network, for the larger care network study, it was 35%. The number of older adults will rise, especially those of 80 years and older, and the number of older adults with multimorbidity and a large need for care will rise as well (Schram, de Waal, de Craen, Deeg, & Schellevis, 2008). Hence, the number of adults might rise in this risk group, that does not have the social or financial resources to arrange the care when publicly-paid formal care withdraws. They need to be ensured they keep receiving the care they need.

The government aims for older adults that they (be helped to) invest in a support network (VWS, 2015), but this has to be applied to the extent that older adults are willing and capable to do so. Prior research revealed that a national discourse with an emphasis on ‘control of care’ (*eigen regie*) and ‘self-reliance’ (*zelfredzaamheid*) had the effect that those in need of care felt the pressure to be independent, and felt ashamed for being dependent of others for their daily functioning. Involving informal caregivers instead of formal care may be experienced as a loss of autonomy and independence (Grootegoed, 2013). Older adults may experience the increased dependence on their personal networks as a problem and view autonomy as not being overly dependent on one’s own social network. Hence, state support can be viewed as a way of staying autonomous (Grootegoed & van Dijk, 2012).

Therefore, the group of older adults who possibly avoid care that is needed because they do not want to involve informal care, is another risk group to consider.

Extramuralisation policies cause older adults to live longer at home. This also appeared to be the wish of older adults: most older adults in the 'Care Networks of Frail Older Adults' study indicated that they would not like to move to a residential setting. Bloem and van Tilburg (2006) showed however that for a certain group of older adults who did move, feelings of loneliness actually decreased. These were older adults who were relatively older, less often had a partner, more often used formal care and more often had cognitive problems. Their psychological welfare seems important to consider when they do stay at home. Indeed, most informal and formal caregivers in the 'Care Networks of Frail Older Adults' study, in answering the question who they missed in the care network, indicated that they missed someone to do social activities with them. More or different types of instrumental care were not missed as much. Hence, the social welfare of older adults is an important point of focus as well.

All in all, the concept of a 'participation society' as we see today, seems not to be very applicable for those who need it the most. Also for caregivers it remains to be seen if other informal caregivers will and are capable to take up the care tasks, as it is still mainly the family who provide informal care. Furthermore, with the exception of partners, other informal caregivers confine themselves to specific household tasks or administration, and for relatively few hours per week. Further knowledge on what motivates informal caregivers to take up care and specific care tasks, and how they can be activated, remains important, in order to move towards an inclusive caring society.