Fulltime work & informal care

The role of awareness and work related care arrangements

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Abstract

Goal and Method: This study centers on full time employed informal caregivers. A Directed Content Analysis (DCA) is studied to ascertain the roles that awareness and/or self-identification as caregiver and work related care arrangements have in the manageability of combining work and care. Light is shed on the *Role Theory*, which states that combining differing roles, such as work and care will either lead to role strain or role accumulation. Furthermore, the relatively new *caregiver identity theory* is highlighted, which states that role incongruence causes stress. Furthermore the influence of the supervisor, the workplace culture and support from the personal network of the caregivers is considered. To do so, both informal caregivers and their supervisor are interviewed. In total twelve informal caregivers, five supervisors and two human resources managers were interviewed.

Results: Role awareness is not a necessary condition for managing work and care as long as care provision is accepted as part of being a parent/partner/child. Informal caregivers that do not self-identify as a caregiver and those who do both experience role strain. In addition role accumulation is experienced by both groups. Role incongruence is experienced when caregivers are not comfortable with their care tasks or when their role as caregiver and partner/parent/child are in conflict. Most caregivers that participated in this research are not aware of their role and the work related care arrangements that are available in the workplace, though this is compensated by the awareness of their supervisors. The supervisors are aware of the presence of informal caregivers in the workplace and the possible problems they could run into. Their inviting and outreaching attitude ensures that informal caregivers are offered what they need in the workplace. Other important sources of support are colleagues, psychological support and services by professionals and organizations.

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1. Introduction

In the upcoming years a big increase in the number of (fragile) elderly is expected, who are likely to be in need of care. At the same time, the active population will decrease, resulting in a lower availability of caregivers for the aging population (de Boer, Klerk & Merens, 2015). To secure care for the elderly and simultaneously control the financial sustainability of the welfare state the Dutch government promotes both participation in the labour market and providing informal care for relatives and friends (Josten & de Boer, 2015). Many caregivers combine care with employment; in the Netherlands a fifth of informal caregivers are employed. This number has grown in the past years and is expected to increase even further (Josten & De Boer, 2015). However, about 19% of informal caregivers feel overburdened from combining care and work (De Boer, Broese van Groenou & Keuzenkamp, 2010).
This study centers on full time employed informal caregivers, in which the definition of full time employment is when a person works a minimum of 36 hours a week; according to the 'Dutch' definition, informal care is provided to a person in need of help by someone from their direct social network (Oudijk et al., 2010).

Though various studies show that combining the two roles of work and care can be quite demanding, they differ in pinpointing a cause of this demand. Some point to the number of hours of care as the reason that caregivers experience a 'squeeze' between work and care (Henz, 2006) or that informal care in itself is demanding (De Boer et al, 2010). Others, however, state that when informal caregivers work more hours they tend to be especially burdened. This suggests that the number of working hours determines the demands of the combination of work and care (Frederiksen-Goldsen & Scharlach, 2006).

The problems resulting from combining work and care are that many caregivers feel too responsible and that it brings damage to their own health and independence (De Boer et al., 2010). To ease the combination of work and care, several arrangements are available, ranging from leave periods to flexible work hours (Werk & Mantelzorg, 2016). However, whether these arrangements are used depends on several conditions. One of them is the sense of awareness. In this study awareness for caregivers is seen as 'positioning one's self as a caregiver' (O'Connor, 2007, p.170) and congruence between the differing identity roles of a carer (Montgomery, Rowe & Kosloski, 2007). For supervisors it means that they know about any informal caregivers under their supervision and all work-related care arrangements. Other conditions that could influence the use of arrangements are the support a caregiver receives from their network and their workplace's culture, which rests on the shared values and

attitudes within the workplace and the underlying experiences that legitimize them (Smircich, 1983).

The goal of this study is to gain more insight into the role of awareness and work-related care arrangements in the manageability of multiple roles. The conditions that possibly influence this will also be taken into account. The study is geared towards fulltime employed caregivers; many studies have focused mainly on informal caregivers in general, but employees with care tasks are a heterogeneous group (Josten & De Boer, 2015). Informal caregivers who work full time form an interesting group because they are responding to the government's call to participate more in the labour market while caring for a relative or a friend. This study will use two perspectives from the caregiver and their supervisor respectively, showing both sides of the story. Research on the role of the employer could fill in the gaps in scientific knowledge on the perspective of the employer. Furthermore, it could contribute to policy for informal caregivers within organizations.

The master thesis design includes the following chapters; a theoretical framework, research question and choice of method, relevance of the research and time planning.

2. Theoretical framework

Working informal caregivers combine at least two important roles; working and providing care to a relative or a friend. A role is defined as; "a pattern of expectations which apply to a particular social position and which normally persist independently of the personalities occupying the position" (Sieber, 1974, p.569). In this study, various conditions for providing this care while working full time will be discussed. First of all the manageability of multiple roles will be discussed, using the *Role Theory*. Then the role of awareness and work-related care arrangements is laid out, followed by the conditions that could influence them. These entail workplace culture and the available support in one's network. The conditions that influence the manageability of multiple roles will be elaborated on through the perspectives of both the informal caregiver and the supervisor.

2.1 Manageability of combining work and care

Theories on combining multiple roles have been divided into two sides. Some theories emphasise the negative consequences of combining multiple roles while others focus on the positive outcomes. To explain the manageability of combining the roles of work and care, Dautzenberg's *Role Theory* will be used. This theory rests on two hypotheses which build on the *Role Strain Theory* (Goode, 1960) and the *Role Enhancement theory* (Reid & Hardy, 1999).

The *role scarcity hypothesis* means that people are limited in time and energy, which can cause role strain. The *role accumulation hypothesis* implies that combining multiple roles brings merits and rewards.

The *role scarcity hypothesis* states that often, playing multiple roles is stressful and conflicting (Dautzenberg, 2000). The basic premise of this hypothesis is that the limitation of resources such as time and energy, creates a need to set priorities and negotiate with other parties. As their role fulfillment extends, their available time and energy will decrease, in turn resulting in an inability to meet the expectations of all the parties involved (Grönlund, 2007). Two specific elements of the *role scarcity hypothesis* are role overload and role conflict. When demands of multiple roles are considered incompatible, irrespective of time, this will result in role conflict (Sieber, 1974). Since time and energy are limited, there is only a certain amount that can be spent on a role. This results in role overload (Sieber, 1974). Thus, working as an employee takes up a significant number of hours leaving less time for the role of caregiver, and role overload is the consequence. This is consistent with Dutch research on the experiences of informal caregivers who work full time. Findings showed that 26% of the respondents are struggling with the combination of employment and care and 19% feel heavily burdened by the situation (De Boer et al., 2010). Furthermore, this combination can result in feelings of guilt about being unable to fulfill a primary role without neglecting the other (Eldh & Carlsson, 2010). This suggests that for full time employed caregiver's time and energy are even more scarce and can result in role strain even more quickly.

However, a number of studies contradict this. For instance, a study by De Boer et al (2010) claims that more working hours do not lead to a higher burden on the individual. In fact, the number of working hours could have a positive effect. Hansen and Slagsvold (2015) found that full time work had a positive influence on informal caregivers' well-being. These findings support the *role accumulation hypothesis,* which emphasises the positive effects that the combination of multiple roles can bring. When focusing only on the negative effects of combining multiple roles, the merits and rewards are overlooked (Dautzenberg, 2000). Thus, the existence of role strain is not denied, but there are multiple compensations too (Sieber, 1974). For example, the sense of feeling needed and appreciated in a different context will extend one's self-esteem. Martire, Stephens & Atienza (1997) found that experiences in the work role can moderate the effects of caregiving stress, thereby functioning as a buffer. This is consistent with the role accumulation hypothesis, which states that a buffer is created through the privileges that may accompany a role. Additionally, a 'role spillover effect' could occur; the caregiver experience becomes less of an effort when a person has a positive employment

experience (Reid & Hardy, 1999). For instance; feeling unsafe and failing in one role can be compensated by feeling successful in another one (Grönlund, 2007); or relief is gained from the caregiving task through employment, which enhances self-esteem and provides a chance to share concerns with colleagues (Arksey, 2002).

In general, conflicting empirical findings exist on combining work and care and it is reasonable to assume that multiple roles in employment and care are manageable up to the point when demand increases beyond capabilities (Grönlund, 2007). In addition, Montgomery et al (2007) state that both positive and negative effects exist. High levels of well-being and experienced burden can exist alongside each other.
Thus, according to the *Role Theory* the manageability of combing work and care of full time employed informal caregivers is determined by one of two things: Either role strain, in which the various roles cause stress and conflict, or role accumulation which implies that the good (such as relief and support) outweighs the bad (role strain). However, few studies about the various roles in work and informal care obligations have focused specifically on informal caregivers who also work full time, rather they focus on a general group of informal caregivers. Therefore this research will center on the group of full time workers.

2.2 Awareness of and identification as a caregiver

This research will portray two different perspectives. The concept of awareness will first be explained from the perspective of the informal caregiver and then from the perspective of the supervisor. Awareness of informal caregivers covers two different phases. The first is identification with the role of caregiver. A role identity is a self-conception of the position someone has in their social structure, based on norms and the reciprocal relationship someone has with the caregiver (Thoits, 1991). Organisations such as Mezzo and Expertise Center Informal Care [*Expertisecentrum Mantelzorg*] that are aimed at enhancing the wellbeing of informal caregivers, often point to the lack of self-identification as a caregiver. It is, however, considered as a first important step in taking responsibility for care and overseeing what needs to be done (O'Connor, 2007). Furthermore, when the identity of caregiver is rejected, informal caregiving may be hidden. This could have consequences for potential sources of support (Hughes, Locock & Ziebland, 2013).

A second step of awareness takes place after having identified oneself as a caregiver. In this phase, carers could still struggle with the multiple identities of the roles they fulfil. This can be explained through the *caregiver identity theory*, which explains that experienced stress from combining work and care is caused by the incongruence between a person's various role

identities (Montgomery et al., 2007). If the responsibilities of a caregiver are incongruent with the caregiver's definition of such responsibilities, distress is experienced. This theory centers on the role of the caregiver, but it also acknowledges the interaction with other role identities. The caregiver role merges with the other role identities that make each person unique (Talley & Montgomery, 2013). According to Settles (2004) switching between two different (role) identities with dissimilar cultures requires a bigger effort with respect to cognitive, psychological and emotional resources than switching between identities that have a similar culture. For instance, it could be easier to switch from caregiver to daughter than to switch from caregiver to full time employee.

From the perspective of the supervisor, awareness means that they know all about informal care and who among their subordinates has taken on this role. Because of differing reasons many informal caregivers do not tell their supervisor about their situation (De Boer et al, 2014). Studies concerning the combination of work and care that include the role of supervisors generally do not include the supervisors themselves. This raises the question whether knowledge of informal care will encourage supervisors to help employees manage their combination of work and care.

Thus, according to the caregiver identity theory, perceiving care as belonging to the role of mother, daughter, or another social role, hinders identification with the role of informal caregiver. This theory provides a clear explanation for stress experienced from various role identities. So far, empirical findings to support this idea are lacking. Though based on this theory the expectation is that less incongruence between the roles leads to a better manageability of work and care. Furthermore, the findings concerning self-identification suggest that awareness of one's role helps one to reach out and ask for help, which could lead to a better manageability of the work/care combination. However, it is difficult to predict a direction concerning the role of the supervisor, considering there are so few studies available.

2.3 Work related care arrangements

Concerning the work related care arrangements, both the perspectives will have light shed on them. This paragraph will start with a description of the various arrangements, followed by their possible utility and their (promoted) use.

Work related care arrangements entail paid leave, flexibility and tailored solutions. Though the arrangements concerning paid leave and flexibility are determined by law, organisations differ in their implementation. Organisations differ in the duration of leave periods or in the % of salary that is paid, and thus seem to interpret the meaning of the informal

caregiver-friendly policy in different ways (Werk & Mantelzorg, 2016). Broadly, there are three different kinds of leave concerning informal care in the Netherlands: 'crisis' leave [*calamiteiten verlof*], short term leave and long term leave. The first is meant for emergencies, ranging from a couple of hours to a maximum of two days. The duration of the short term leave is twice the number of hours an informal caregiver works. When a care situation demands more time, an informal caregiver can request long term leave which is six times the number of working hours (Werk & Mantelzorg, 2016).

Apart from requesting a period of leave, flexibility can be applied to the number of working hours and the location where an informal caregiver works. The flexible work law [*Wet Flexibel Werken*] aims to promote the possibilities of working at home or elsewhere and work hours that are convenient to informal caregivers. Apart from these legal arrangements employees can seek a solution that is tailored to their specific needs. For instance, answering private phone calls at work (Werk & Mantelzorg, 2016).

Work-related care arrangements could help informal caregivers to manage the combination of work and care. For instance, the ability to choose a location to work in order to have a positive influence on the balance between work and care. However, the risk is that caregivers often feel as though their work is never finished; there is no clear division between work and home (Lippe & Roeters, 2010). Flexible work hours could help to efficiently combine work and care, but in the case of full time employees this means that hours spent on care have to be compensated for during nights and weekends.

Moreover, the mere existence of arrangements does not guarantee that they will be used, for instance due to a lack of knowledge about them, a perceived lack of necessity to use them, or for strategic reasons (Oude Avenhuis & Kruijswijk, 2013). This raises the question of whether supervisors know about available work-related care arrangements and whether they encourage their employees to make use of them. Empirical studies on this topic are rather scarce. Only Oude Avenhuis & Kruijswijk (2013) show that supervisors are often unfamiliar with care arrangements, even though many of them consider it important that carers make use of them.

In conclusion; there are multiple work-related care arrangements which could help full time employed informal caregivers to manage their work and care roles, but this does not guarantee that all informal caregivers know about them and will make use of them. In addition, the question remains as to whether knowledge of the arrangements will motivate supervisors to encourage their subordinates to use them.

2.4 Workplace culture

Awareness of the existence of arrangements influence their use, but the workplace culture plays an important part too. Workplace culture is also known as organisational culture (Hofstetter & Harpaz, 2015) or corporate culture (Holmes & Marra, 2002). This study will use the term 'workplace culture', because it focuses on respondents from differing workplaces, not just corporate ones or organizations. Workplace culture is a multifaceted concept that is known to have been studied from differing disciplines and perspectives (Scholz, 1987), although there is little consensus about its exact constituents (Holmes & Marra, 2002). A widely cited definition is provided by Smircich (1983, p.339):

"Workplace cultures revolve around the shared values and attitudes and the shared experiences that validate them. A culture includes everything that is learned and shared by its members: its social heritage and rules of behavior, its own customs and traditions, jargon and stories".

Studies show that implementing family friendly arrangements is not enough, the workplace culture and supervisors need to be supportive of them. Employees working in an environment deemed family supportive experienced less conflict between their working and caring roles (Lapierre et al., 2008).

When the workplace culture is viewed as family friendly, employees are more likely to use the family friendly benefits (Thompson, Beauvais & Lyness, 1999). Similarly, Behson (2005) underscores the need for support and finds it more useful than formal means of support (i.e. benefits to combine work and care). In particular, environments that allow employees discretion and autonomy in the way they do their job are likely to decrease stress and conflict from combining multiple roles. Supervisors have an important role in this workplace culture. An inviting attitude contributes to opening up the dialogue about informal care (Oude Avenhuis & Kruijswijk 2013). Furthermore, showing empathy (Eldh & Carlsson, 2010) through a supporting and understanding attitude (Gautun & Hagen, 2010) havs a major impact on the ability of informal caregivers to combine work and care.

To sum up: The attitude of supervisors and the workplace culture an informal caregivers is important in the decision to make use of care arrangements. When informal caregivers experience support then they are more likely to use formal benefits.

2.5 Support of network

Next to conditions in the workplace, informal support influences the need for and use of work related care arrangements. Research shows that care for the elderly is largely provided by families in which adult children and their siblings play an important role (Keith, 1995). The provision of care is influenced by composition and size of the family (Matthews & Rosner, 1998; Kruijswijk, Da Roit & Hoogeboom, 2014). A higher number of siblings will generally guarantee more hours of care overall, resulting in less hours per person (Wolf, Freedman & Soldo, 1997). Yet the solidarity of siblings is shaped for a large part by the availability of sisters (Tolkacheva, Broese van Groenou & Van Tilburg, 2010). Women more often fulfil the role of primary caregiver, focusing on the more intensive tasks, while men focus on the indirect care tasks (Kruijswijk et al, 2014). Therefore, if the informal caregiver has (several) sisters, it is more likely that the intensive care tasks will be shared, whereas having brothers would reduce the amount of intensive care given.

So when a caregiver is a member of a large family with many sisters, it is likely that the burden of the care is shared, suggesting that these informal caregivers will need less time to care. According to the role scarcity hypothesis, this increase in resources should alleviate the burden of the caregiver. This, in turn, suggests that use of care arrangements is less necessary if the caregiver is supported by family members.

In conclusion, the manageability of the multiple roles of caregivers is influenced by a number of conditions. Of these conditions, awareness of and identification as caregivers, and work-related care arrangements take a central place in this research. Furthermore, the workplace culture and the role of the supervisor both arguably influence these conditions. The support a caregiver receives from their network could either decrease or increase the use of and need for work-related care arrangements.

3. Research question

The theoretical framework leads to the following question:

How do awareness and work-related care arrangements affect the manageability of full time employed informal caregivers' multiple roles?

Sub questions:

1. Does awareness of and identification with being a full time employed informal caregiver help this group in combining both roles?

2. Does knowledge of the presence of informal caregivers and the existence of work-related care arrangements encourage supervisors to help employees combine work and care?
3. Does knowledge about work-related care arrangements increase the use of care arrangements and positively influence the management of combining work and care?
4. Does an extensive support network decrease the need for work-related care arrangements and help full time employed caregivers in combining work and care?
5. What necessary elements of the workplace culture encourage employees to make use of work-related care arrangements and help them to manage the combination of work and care?

4. Research method

4.1 Type design

This research is of qualitative nature and makes use of interviews. The goal of this research is to extend and refine existing knowledge on informal caregivers by testing to see if it also applies to informal caregivers who are full time employed. The process underlying the manageability of work and care is studied through the experiences and feelings of the respondents. Therefore a deductive qualitative design is chosen: a Directed Content Analysis (DCA). The criteria for the selection of respondents are: 1) Working at least 36 hours a week. 2) Providing care for at least four hours a week. 3) Have been doing this for a period of at least three months. Caregivers that were in this situation in recent years but either work less now as a result of the care situation or are no longer an informal caregiver are also included. Given this group of people has to reflect on memories from their past, the choice is made to not include people that were in a care situation longer than ten years ago.

The categories for the data analysis are based on the themes described in the theoretical framework: combining work and care, awareness, work related care arrangements, workplace culture and support networks.

4.2 Population

This research aims for two kinds of respondents: informal caregivers and supervisors. The aim was to search for ten informal caregivers and then approach their supervisors, resulting in ten of each.

4.2.1 Recruitment of informal caregivers

To recruit informal caregiver organizations were approached that specifically provide support and information for informal caregivers, such as Mezzo, Steunpunt Mantelzorg and 'informal care realtors'[*mantelzorgmakelaars*]. Furthermore, organizations that are expected to have (indirect) contact with informal caregivers such as Zonnebloem, Alzheimer Nederland, organizations for well-being and homes for the elderly and mentally disabled were phoned and emailed. Further information on the research was sent if they knew caregivers that fitted the criteria. The organizations in turn contacted informal caregivers over the phone or via email or placed a message on social media.

Due to the broad definition used for awareness in this research, informal caregivers who presumably identified themselves as such, and informal caregivers who presumably did not were both approached. For the latter group the term 'informal caregiver' was avoided and the search was extended beyond organizations like Mezzo, where it was expected that informal caregivers were aware of their role. Additionally the personal network of the student was approached, since the recruitment via organizations was not satisfactory enough. Using a snowball technique, informal caregivers were reached who were not connected to organizations that provide support and information to informal caregivers. In total twelve informal caregivers were reached, six through organizations and six more through people from their personal network.

4.2.2 Recruitment of supervisors

Supervisors were recruited via the informal caregivers who took part in the research to ensure a match between the two. This was important considering some of the factors that were included in the research, for instance workplace culture. Before the interview took place interviewees were asked for permission to contact their supervisor. It was emphasized that no information would be shared with their supervisor. Ten informal caregivers gave permission. One caregiver was not comfortable with contacting her supervisor, and a second caregiver did not want to bother his supervisor. One of these two caregiver's colleague was also a respondent, as a consequence her supervisor could not be approached, as this would be ignoring the wishes of the caregiver that said no. Among the caregivers that did give permission there were also two colleagues. As a result, a total of eight supervisors were approached, out of which two people declined to participate. In two cases human resource managers participated instead. In total

nineteen persons participated in the research: twelve informal caregivers, five supervisors and two human resource managers.

4.3 Data collection

Data was collected through semi-open interviews, consisting of a list of questions developed beforehand. Two differing topic lists were designed, since two differing groups of respondents were interviewed. The questions are based on the theoretical framework. After collecting demographic data, the questions focused on experiences combining the roles of care and work and the conditions that help informal caregivers to do this, specifically awareness, work related care arrangements, role of the supervisors, workplace culture and their support network. The supervisors were asked about their knowledge on informal care and the work-related care arrangements, how they act upon this knowledge, and how they experience the workplace culture.

Interviews took place in a quiet setting. Before each interview started, the interviewee was asked to sign an informed consent form. To ensure the trustworthiness of the transcription of the interview a recording device was used. Additionally, the interviews were transcribed.

4.4 Data analysis

After reading the transcripts they were placed in Nvivo, where the text was coded. The categories that were established from the theoretical framework (awareness, work related care arrangements, workplace culture, support networks and supervisor) were split up into more detailed sub codes. The codes for the first round of coding (*A priori codes*) were abstracted from the theory and topic list. Examples of these codes are ‘inviting attitude supervisor’ and ‘making use of flexibility’. Further *a priori codes* and the operationalisation of them can be found in the Appendix.

In the second round of coding the assigned codes were evaluated and new codes, which are based on the transcripts themselves, were created. Additionally, existing codes were divided into subcategories. For example: ‘awareness of role’ and ‘awareness of definition’ became sub-codes of ‘awareness’, since the majority of the caregivers knew what an informal caregiver was but did not identify themselves as one. The code ‘not sharing situation’ was deleted, since it transpired that none of the caregivers hid their care situation entirely. The code trees for both employees and supervisors can be found in the Appendix.

5. *Results*

5.1 Characteristics of informal caregivers

With respect to the participants there are two groups: informal caregivers and supervisors/human resource managers. Both are detailed below.

5.1.1 Informal caregivers

Male/female	- Five male caregivers - Seven female caregivers
Person cared for:	Mother, daughter, father, aunt, sister-in-law and partner
Type of care provided	- Psychological care (such as care for an autistic husband or a borderline daughter) - Practical care tasks (such as chores around the house, preparing dinner, grocery shopping, etc) - Intensive practical care (combination of practical care and activities of daily living)
Care period	- One-two years: three caregivers - Three-seven years: five caregivers - Longer than ten years: five caregivers
Amount of care provided	- Four-ten hours: four caregivers - Twelve-thirteen hours: two caregivers - More than thirteen hours: eight caregivers
Field of work	- Industrial sector (metal and thermal engineering) - Inspection - ICT - Health care, governance or education.

	- Working at well-being/volunteer organizations - Biochemistry
Number of hours working	- Twenty hours: one caregiver* - Thirty-two hours: one caregiver** - Thirty-six hours: two caregivers - Thirty-eight hours: one caregiver - Forty hours or more: seven caregivers

*Used to work full-time

**Has a family business next to her employment

5.1.2 Supervisor and human resource managers

In total five supervisors and two human resource managers participated. In the rest of the report, both human resource managers and supervisors will be referred to as 'supervisors'.

5.2 Manageability of combining work and care

Caregiver 7: *"When it's a life-threatening situation I will drop everything in favor of the care. If it is something that can be postponed…I don't take the day off to go to a birthday party. I won't. I do take a day off to go to a doctor when necessary. So, for the 'fun'-things I do not take time off and for the 'have to'-things I do".*

Role strain is a common theme among the informal caregivers interviewed for this research, though the situations and circumstances in which it occurs differ. Caregivers who feel they are in a stable care situation often only experience role strain when there is a hectic situation both in the home and at work. For caregivers that provide care out of a sense of obligation or have a complicated relationship with the care receiver it is often continuous. Role strain occurs when there is a shortage in time with respect to their tasks or time taken for themselves. When this increases and/or the care period is prolonged it will result in role overload, which affects informal caregivers' well-being. Caregivers in this position are in (desperate) need of a change in their situation, such as working less hours. However, this is not always considered a desirable solution, either because of financial reasons or because a different solution is preferred, such as a decrease in the provided care.

Emotional burden is a dominant element in role strain, it weighs heavier for the caregivers than the practical burden of providing care. Causes for this emotional burden are worries for the care receiver (in case of a decline in health) or concerns about the organization of the care. Role strain is often accompanied by feelings of guilt and responsibility. The majority of the caregivers acknowledge that care and work are not always well balanced. When there is a peak in a care period, many caregivers feel like they are less productive in the workspace. For some, caring for a loved one has led to a decrease in flexibility. For instance, when a caregiver cannot take business trips abroad without having to arrange for his wife to care for their daughter. The following quote demonstrates the experienced role strain in a hectic period.

Caregiver 8*: "...you have things to do at home, you have [daughter], also in the home there are things to do. You want time for yourself. And when it is very busy at work as well, it adds up".*

When asked how caregivers prioritize between work and care most caregivers say they prioritize home above work. However, since all caregivers have cared for at least a year but generally longer, choices had to be made to combine work and care on a daily basis. When prioritizing between work and care situations, a hierarchy in priorities appears. At the top of this hierarchy are crisis situations, in which case caregivers go home immediately. Then come important appointments for the care receiver, for which caregivers take time off or plan the appointment at a convenient time. Important appointments at work are prioritized above the home situation, when these are considered more important than appointments at home. When they are considered equally as important, home is prioritized, although arrangements are made to accommodate both appointments. Next to role strain, most caregivers also experience positive feelings towards combining work and care. When caregivers like their job it often functions as a compensation or even protection from stress experienced in the care situation, which is mostly in the form of a distraction. Work energizes them, providing a break from the care situation, and increases their self-esteem.

Caregiver 2: *"I sometimes say jokingly, but I kind of mean it: at work you can recover from sometimes being under pressure…might be the wrong word…but at home it isn't always that relaxed".*

The fact that caregivers work fulltime does not appear to make a clear difference. This is mostly demonstrated through the fact that very few consider working less to be a solution for the role strain they experience. For the caregivers that experience a role overload, the care weighs heavier than the workload. The mentality of 'just keep going' also dominates their situation and the conditions that help to maintain the balance are thus rendered more important.

To sum up, in most cases both role strain and the perks of combining work and care exist alongside each other, with peaks of role strain in the more hectic periods. Emotional burden is pinpointed as a dominant element in this respect. To organize work and care on a daily basis, a hierarchy of priorities appears.

5.3 Awareness of and identification as caregiver

Caregiver 10: *"They tell me: "You're an informal caregiver" and I say "I also am an informal caregiver". But what is an informal caregiver?"*

Knowing the definition of the term informal caregiver does not guarantee that informal caregivers identify themselves as such. Out of twelve informal caregivers, seven are aware of the definition of the word informal caregiver [*mantelzorger*], but not all of them identify themselves as a caregiver. This is generally because caregivers consider it to be normal to care for their loved one. For many it is a matter of care being included in the role of father, partner or parent. Therefore they would, despite knowing the definition, not consider themselves an informal caregiver. When care tasks are accepted as part of being a partner/parent/child caregivers will experience little incongruence. Caregivers that do not accept these tasks often experience incongruence between their roles. This is mostly the case when they have to perform tasks that they do not consider to be part of their role as a relative or partner, either because they do not feel comfortable doing it or because they lack the proper skills to perform the tasks. In these situations, these care tasks are performed by professionals instead. However, even when a caregiver generally does not experience incongruence concerning tasks, there can still be conflict between the two roles. This is demonstrated through the following quote:

Caregiver 4: *"The hardest part is that you're more of an informal caregiver at a certain moment, not more than a partner, but the caring part is more dominant than just making breakfast in bed for your partner".*

Among supervisors awareness of the definition of 'informal caregiver' and the presence of caregivers in the workplace is rather high. Supervisors understand the difficulties that could arise from combining work and care, notice the problems that caregivers run into and pick up the signals when an employee might be in a care situation, as illustrated in the next quote:

Supervisor 5: *"…I try to find that entrance with people to get them to talk. It's not up to me to put their problems on the table, but you can often tell from people that something is up. They will never directly tell you what is happening. You have to…that is a game"*

In conclusion: Role awareness is often hindered by the conviction that the provided care is a matter of course. Role incongruence arises from discomfort in performing certain care tasks or from conflicted roles. Supervisors are often aware of potential issues, this results in understanding of and sensitivity to signals.

5.4 Work related care arrangements

Supervisor 1: *"If the situation at home isn't stable, then the situation at work won't be stable either. And when the workplace doesn't contribute to the situation at home, you'll have an employee who stays home with burn out and is eliminated. So it will come back around".*

A lack of knowledge would hinder the adequate combination of work and care obligations for a larger part of the informal caregivers, if it were not for the outreaching attitude of their supervisors. Most of the caregivers did not know about the work related care arrangements that exist in their workplace. However, since for instance flexibility is generally an important element of their job, it is often not recognized as a work related care arrangement. The existence of care leave is often unknown. If it were not for the offer of the supervisor, two out of three caregivers would not have to used it.

Caregiver 12: *"Well on that account we received…because I had never heard of it before, that whole care leave…I got all at once. So I could stay home. So I stayed home for six weeks, seven weeks even".*

The type of work related care arrangement used depends on the type of care situation the

caregiver is in. Care leave is used when there is a peak in the care situation, for instance because of a surgery or a crisis. In case of the latter, 'crisis leave' [*calamiteitenverlof*] was utilized, prior to the care leave. Vacation days are used to extend the care leave when necessary. However, considering the length of the care leave (which in this case was three weeks) it is only a short term or temporary solution. Most caregivers have been providing/have provided care for several years, in which case most make/have made use of flexibility. Eight out of twelve have flexible hours, they can start later, leave earlier or choose to finish a task at another time. Additionally, many caregivers have autonomy concerning their agendas and can plan their own appointments, as illustrated by this quote:

Caregiver 5: *"Yes, I do have control over my own schedule. If I want to work an hour longer, I'll work an hour longer. If I want to leave an hour early, I'll leave an hour early"*

The type of job can hinder flexibility, though in the case of flexible hours supervisors often allow workers to leave early or, for instance, leave during lunch and compensate for this later. Working from home, however, is rendered impossible when employed in the industrial sector or in care of the elderly.

Working flexible hours and working from the home indulges caregivers with numerous benefits, such as saved time and maintaining the balance or even avoiding burn out, although flexibility also has a downside. Some report that their workdays are extended beyond their ability to keep functioning. Attending care tasks during the day results in having to work until late at night. Since a full time workweek is already completely filled, there are not many other possibilities to compensate for missed hours in work. This induces role overload.

Though all supervisors know that their company provides certain work related care arrangements they do not know the exact details of them. Only the human resource managers do. The arrangements offered are generally dictated by the collective agreement [*CAO*] and are often reduced to (un)paid leave. Some supervisors find the existing work related arrangements very minimal. Additionally, they state that every person and situation is different. Therefore, arrangements are mainly handled in three different ways. 1) providing additional arrangements, 2) loose interpretation of the existing arrangements and 3) tailored solutions. Additional arrangements include possibilities such as 'buying' care leave. When interpreting arrangements loosely, supervisors/human resource managers follow the law, but interpret it in a way that the caregiver will benefit most, for example, by allowing care leave when a person is hospitalized. However, tailored solutions are used the most. Many supervisors will discuss the situation with

the employees and look for the best solution together, keeping in mind the situation and the employee. This coincides with the experience of the majority of the caregivers.

Thus most caregivers are not aware of the arrangements that they could use, or are not aware that flexibility they make use of is considered as one of the work related care arrangements. However, supervisors point them in the direction of care leave when this is needed. Both flexibility and care leave make a difference in the manageability of combining work and care, though it is used in varying situations and has varying benefits.

5.5 Workplace culture

Supervisor 6: *"But to use solutions is sometimes to listen, think with somebody and talk. And it doesn't even have to be that they make use of all kinds of arrangements".*

When caregivers feel comfortable with their workplace culture, they are more likely to share their situation with their colleagues or supervisor. Three caregivers perceive their supervisor as not having an inviting attitude. In these cases caregivers will not bring their situation to the fore, though they will not hide it either. Many informal caregivers are positive about the atmosphere in the workplace. Only three out of twelve consider the atmosphere in the workplace (partly) unpleasant, either because they experience a culture of fear or because of unsympathetic colleagues. Both result in not being completely open about their personal situation.

Caregiver 10*: "...there are some who will stab you in the back: 'we'll work overtime then!' And those things can sometimes all at once become too much".*

Sharing domestic issues results in feeling understood and supported. In most cases caregivers can count on support. Both colleagues and supervisors feel that this atmosphere encourages employees to seek help or to make use of work related care arrangements. Most caregivers consider that their supervisor has an inviting attitude. The majority uses words like 'empathic', 'approachable' and 'compassionate' to describe them. Supervisors generally see their own attitude as inviting by being open, empathic and devising solutions for their employees. They are understanding when their employees are less productive as a result of the care situation they are in, or that they are less flexible or available. In respect to the relationship that employees have with their supervisor, multiple values come to the fore. Both trust and a sense of responsibility from the caregiver is important to supervisors. The latter

is specifically important when a more reactive policy towards employees is applied. In the eyes of supervisors, it is also up to the employee to come forward with their story and ask for help when they need it. Trust seems to be based on a reciprocity principle. Caregivers often feel that they need to compensate for time off by handing in their overtime hours or vacation days. However, supervisors tend to expect a different type of compensation. They trust their employees with solutions and arrangements and in return expect their employees to be honest about their situation and not to abuse the solutions handed to them.

In conclusion: most caregivers view their workplace culture as pleasant. Sharing their situation with colleagues or their supervisor makes them feel understood and will often result in advice or solutions to help manage their situation. In this matter a principle of reciprocity arises, where trust from the supervisor is repaid with compensation for 'unproductivity' from caregivers.

5.6 Support of network

Caregiver 4: *"Yes, it's just the accommodation. Practically, logistically speaking, to help each other accommodate it all".*

The support provided and the intensity of that support depends on numerous things, such as geographical distance to the care receiver, the relationship with either caregiver or care receiver and whether network members are capable of understanding the sort of care the receiver needs. However, the number or the gender of siblings does not seem to affect the support received. Though the siblings that do provide support are mostly sisters, many sisters do not help out (much). Also whether care is provided for a child, a parent or partner does not appear to influence the decision from the network to support the caregiver.

All the informal caregivers that participated in this research are either the main caregiver to the person they care for or they share this care equally with their partner. In general, caregivers receive three types of support from their network 1) incidental practical support 2) structural practical help and 3) psychological support. Additionally, many feel supported by services from professionals or organizations, although the effects of the support given can vary in each individual care situation. For caregivers that feel that their care situation is stable, often incidental practical care can be sufficient, although when they are the main caregiver who feels alone in their caring, it will not make a big difference. The care tasks that others perform will

be complementary and will not relieve the caregiver's burden. Structural practical support can substitute part of the care provided.

Two types of support seem to make the biggest difference for the caregivers. The first is psychological support from people in their network. This is mostly a chance to talk, to receive advice, or to undertake activities as a form of distraction. The caregivers that reported an emotional burden and also received psychological support, also reported less role strain than the caregivers that did not receive psychological support.

Caregiver 9: *"I have a sister who I am very close with. And she was there from the beginning. From the start. She really was a big help".*

Another source of help that stands out concerning making a difference in the manageability of combining work and care is professional support. Half of the caregivers report receiving professional support, such as a general practitioner who is willing to pay house visits, home care professionals, support groups, daytime activities [dagbesteding] and a guesthouse for disabled children [logeerhuis]. This frees caregivers from certain tasks and results in time for themselves or their partner. The difference that incidental or structural support can make in manageability depends on the way this support is experienced. The sources of support that might make the biggest difference are professional support and psychological support. The latter mostly accommodates the emotional burden that many caregivers experience.

6. Conclusion and discussion

This final chapter answers the research question: *How do awareness and work-related care arrangements affect the manageability of full time employed informal caregivers' multiple roles?* After answering the various sub-questions, a general conclusion will be given, after which, shortcomings will be discussed and recommendations are made.

6.1 Awareness and manageability of combining work and care

Awareness is not a necessary condition for managing the roles of work and care, as long as a caregiver accepts the care tasks as part of being a partner/parent/child of the care receiver. Furthermore, this gives caregivers less incongruence and therefore less stress. Caregivers that do not identify themselves as caregivers or simply reject the role, show the same insights into their situations as the ones that do. This contradicts the findings of O'Connor (2007), who states

that awareness is a condition for taking responsibility for care and overseeing the tasks that need to be completed.

According to the *scarcity hypothesis*, caregivers will experience stress and conflict as a result of managing differing roles (Dautzenberg, 2000). In relation to this theory recent research has found that all caregivers experience or have experienced role strain, irrespective of their awareness of their role as caregiver.

Also *role accumulation* (Dautzenberg, 2000) does not appear to be linked to awareness. If anything, the ability to combine work involves a set of requirements such as professional help for the care receiver, flexibility in the workplace, an understanding supervisor and a positive attitude of the caregiver. The workplace atmosphere, and whether people like their job is also an important factor. It offers compensation in the form of energy and distraction, provides an income and makes people proud. This coincides with the 'spillover effect' as described in the *role accumulation hypothesis* (Reid & Hardy, 1999). The findings in this research coincide with the findings of Montgomery et al. (2007) who found that experienced burden and high levels of well-being can exist alongside each other. The *caregiver identity theory* states that stress from combining work and care is caused by the incongruence between a person's various role identities (Montgomery et al., 2007). In relation to this, the current research found that distress from role incongruence was experienced in two types of situations: first through the performance of tasks that caregivers do not consider to be part of their role as a relative or partner and second through the conflict between the differing roles of relative/partner and caregiver.

6.2 Knowledge and encouragement of informal caregiver by supervisor

Awareness of both informal caregivers in the workplace and work related care arrangements encourages supervisors to help employees manage their combination of work and care. This help entails searching for suitable solutions, use of arrangements such as flexibility and in some cases care leave.

If supervisors are aware of both the definition of the word 'informal caregiver' and the presence of caregivers in the workplace, then sensitivity to circumstances that could cause caregivers could struggle to share their situation seems to be a logical consequence of this. It is, however, the attitude of the supervisor that imposes a positive influence on the ability of employees to combine work and care. Since supervisors sincerely want to know if their subordinates are experiencing difficulties in managing the combination of work and care they will not only pick up signals, but will often approach their employees to obtain more

information. The combination of awareness with an outreaching and inviting attitude of the supervisor results in advice, accommodating possible solutions and offers of work related care arrangements for the employee.

Oude Avenhuis & Kruijswijk (2013) found that supervisors are often unfamiliar with work related care arrangements. This contradicts the findings in the current study, though supervisors (excepting human resource managers) do not always have detailed knowledge on them. It is the manner in which supervisors apply the arrangements which makes a difference for the informal caregivers' manageability of combining work and care. The focus on employees' needs instead of the arrangements shows that the relationship is deemed more important than the actual rights that caregivers have. The principle of reciprocity in which a supervisor offers not only trust, but also solutions, and is repaid by loyal, hardworking employees illustrates that fact.

6.3 Knowledge and usage of work related care arrangements

Knowledge of the work related care arrangements would lead to usage of them, which influences the management of combining work and care. However, if it were not for the outreaching attitude of the supervisor, in many cases a lack of knowledge would hinder the adequate combination of work and care obligations for a larger part of the informal caregivers. Many caregivers did not know which work related care arrangements existed in their workplace, though many did not recognize flexibility as one of them. Differing arrangements render differing results. In the case of care leave, caregivers were given space to accommodate a peak in their caregiving.

Flexibility however, accommodates the needs of caregivers in combining work and care in the long term. Caregivers feel that this will help them to maintain a balance, especially with respect to the long term. Though it also contributes to role strain, flexibility often requires the employee to work the hours that are spent on care. This can result in an overload of the roles, given that caregivers need to give up their evenings or weekends in order to do so.

6.4 Support of network and combining work and care

The question of whether extensive support networks decrease the need for work related care arrangements is difficult to answer based on the data in this research. Caregivers have somebody that provides (incidental) support, though this is not enough to deem it extensive. Regarding care for parents, studies have found that whether care is provided depends on the composition and size of the family (Matthews & Rosner, 1998; Kruijswijk et at, 2014) and that

the solidarity of siblings is largely shaped by the presence of sisters (Tolkacheva et al, 2010). However, the current research shows that though the siblings that provide support are mostly sisters, many sisters do not help out (extensively). Only one case shows that the availability of sisters resulted in an extensive network for the care receiver, which resulted in a decrease in role strain for the caregiver.

Whether the support given helps caregivers in combining work and care depends strongly on both their own situation and the support given. Incidental support is enough in situations where caregivers feel that they have control over the situation, whereas it is not the case if the caregiver is suffering the consequences of role overload. The two types of support that could be deemed most important in this research are psychological support and professional services. The first because it addresses the emotional burden experienced by many, an element that many consider to be heaviest when combining work and care. The latter because it has an considerable influence on the ability to combine work and care. It relieves caregivers of certain tasks, frees time for caregivers to rest and/or can help in arranging appointments.

6.5 Elements of workplace culture, care arrangements and combining work and care

Various elements of the workplace culture are important in the encouragement of employees to make use of care arrangements, and even more in helping them to manage the combination of work and care. According to Thompson et al. (1999) employees that experience the workplace culture as family friendly will be more likely to avail themselves of family friendly benefits. This coincides with the findings of this study, though few know about the arrangements. However, the workplace culture is considered to encourage employees in asking for help or at least discuss their situation. Studies have pointed towards the advantages of granting employees autonomy (Behson, 2005), an inviting attitude of a supervisor (Oude Avenhuis & Kruijswijk, 2013) and showing empathy (Eldh & Carlsson, 2010). The findings of this research correspond with that. Supervisors with an inviting attitude are approached more often when caregivers cannot manage the combination between work and care. Furthermore, the general atmosphere and empathic colleagues with whom caregivers can share their situation are important. An understanding environment in the workplace could in that sense be considered a source of support in itself, considering the personal outlet, advice and distraction it offers them. Altogether, it encourages caregivers to seek help and make use of arrangements when these are known.

6.6 General conclusion

Though awareness is not a necessary condition for the manageability of combining work and care, it does have an important role with respect to the knowledge and use of work related care arrangements. However, whether this knowledge resides with the caregiver or not does not matter as long as awareness of caregivers in the workplace encourages supervisors to reach out to them. Work related care arrangements are important to the manageability of combining work and care. Care leave is a means of accommodating a peak in the care situation and flexibility can maintain the balance in combining work and care in the long term. Another condition for combining work and care is an inviting and safe workplace culture, which provides a compensation for the care that caregivers provide. Whether support provided from the network influences the use of work related care arrangements is still undecided given the lack of extensive networks in this research. However, psychological support is deemed important, considering it provides answers to the emotional burden many caregivers experience.

6.7 Discussion

This research centers on full time employed informal caregivers, a rather complicated respondent group to reach. Difficulties in the recruitment were mostly that organizations did not want to help, since they were overloaded with requests from students. The ones that wanted to help generally knew plenty of working informal caregivers, but often nobody that worked fulltime. Furthermore, informal caregivers with a full time job frequently stated they were too busy to participate in my research. Even though the student was flexible with regard to setting a time, date and location for the interview.

6.7.1 Shortcomings

Many supervisors that were approached and agreed to participate in this research were considered empathic supervisors with an inviting attitude. However, it is unlikely that every caregiver is satisfied with their supervisor. Therefore a positive bias arises. Furthermore, data on the influence of an extensive network is lacking, considering only one caregiver had an extensive network. This prevents drawing a conclusion on the influence of extensive networks.

6.7.2 Recommendations

This is a minor qualitative research, to present a more representative research more participants are recommended. Further recommendations include a quantitative research to diminish the chance of politically correct answers and/or include supervisors that are less praised by their employees. Furthermore, to gain more knowledge on the requirements for a fruitful

combination of work and care, further research is recommended concerning (the influence of) extensive networks. Research should be extended to include less flexible jobs, since flexibility has a big influence in maintaining the balance in the long term. Finally, this study paints a clear picture of the manageability of combining work and care of fulltime employed informal caregivers. However, this knowledge could be extended by comparative research of full time and part-time employed informal caregivers.

Since caregivers state that professional support is among their biggest sources of support, a recommendation concerning policy is to (keep) invest(ing) in services from professionals and 'replacement care' [*respijtzorg*]. This creates a means to satisfy the government's desire to combine work and care, by providing options for the relief of caregivers so that they can maintain the balance in the long term.

Concerning organizational policy it is recommended that supervisors are aware of signals that their employees might be overcompensating as a result of 'unproductivity' caused by their care situation. An open conversation on this topic could really help an employee. The experiences from supervisors in this study could serve as examples of 'best practices' for that.

7. References

Arksey, H. (2002). Combining informal care and work: supporting carers in the workplace. *Health & social care in the community*, *10*(3), 151-161.

Montgomery, R.J.V., Rowe, J.M., & Kosloski, K. (2007). Family caregiving. In: Blackburn, J. A., & Dulmus, C.(eds) *Handbook of Gerontology. Evidence-based approaches to theory, practice, and policy* (p. 426-446). Hoboken, NJ, USA: John Wiley & Sons.

Behson, S. J. (2005). The relative contribution of formal and informal organizational work–family support. *Journal of Vocational Behavior*, *66*(3), 487-500.

De Boer, A., Van Groenou, M. B., & Keuzenkamp, S. (2010). Belasting van werkende mantelzorgers. *TSG*, *88*(6), 313-319.

De Boer, A., De Klerk, M., & Merens, A. (2015) Vrouwen, mannen en de hulp aan (schoon)ouders. Retrieved from http://www.scp.nl/dsresource?objectid=38551&type=org

Dautzenberg, M. G. H. (2000). *Daughters caring for elderly parents* (Doctoral dissertation, Maastricht university). Retrieved from http://pub.maastrichtuniversity.nl/aa13230c-ab63-4bed-8cfd-ca0cdafa2ba2

Eldh, A. C., & Carlsson, E. (2011). Seeking a balance between employment and the care of an ageing parent. *Scandinavian journal of caring sciences*, *25*(2), 285-293.

Fredriksen-Goldsen, K. I., & Scharlach, A. E. (2006). An interactive model of informal adult care and employment. *Community, Work and Family*, *9*(4), 441-455.

Gautun, H., & Hagen, K. (2010). How do middle-aged employees combine work with caring for elderly parents? *Community, Work & Family*, *13*(4), 393-409.

Grönlund, A. (2007). More control, less conflict? Job demand–control, gender and work–family conflict. *Gender, Work & Organization*, *14*(5), 476-497.

Goode, W. J. (1960). A theory of role strain. *American sociological review*, 483-496.

Hansen, T., & Slagsvold, B. (2015). Feeling the squeeze? The effects of combining work and informal caregiving on psychological well-being. *European Journal of Ageing*, *12*(1), 51-60.

Henz, U. (2006). Informal caregiving at working age: Effects of job characteristics and family configuration. *Journal of Marriage and Family*, *68*(2), 411-429.

Hofstetter, H., & Harpaz, I. (2015). Declared versus actual organizational culture as indicated by an organization's performance appraisal. *The International Journal of Human Resource Management*, *26*(4), 445-466.

Holmes, J., & Marra, M. (2002). Having a laugh at work: How humour contributes to workplace culture. *Journal of Pragmatics*, *34*(12), 1683-1710.

Hughes, N., Locock, L., & Ziebland, S. (2013). Personal identity and the role of 'carer'among relatives and friends of people with multiple sclerosis. *Social science & medicine*, *96*, 78-85.

Josten, E., & De Boer, A. (2015). Mantelzorg en betaald werk bij vrouwen en mannen. *Tijdschrift voor Arbeidsvraagstukken, 31(4),* 414-429

Keith, C. (1995). Family caregiving systems: Models, Resources, and Values. *Journal of Marriage and the family*, 57, 179-189

Kruijswijk, W., Da Roit, B., & Hoogenboom, M. (2015). Elasticity of care networks and the gendered division of care. *Ageing and Society*, *35*(04), 675-703.

Lapierre, L. M., Spector, P. E., Allen, T. D., Poelmans, S., Cooper, C. L., O'Driscoll, M. P., ... & Kinnunen, U. (2008). Family-supportive organization perceptions, multiple dimensions of work–family conflict, and employee satisfaction: A test of model across five samples. *Journal of Vocational Behavior*, *73*(1), 92-106.

Matthews, S. H., & Rosner, T. T. (1988). Shared filial responsibility: The family as the primary caregiver. *Journal of Marriage and the Family*, 185-195.

Martire, L. M., Stephens, M. A. P., & Atienza, A. A. (1997). The interplay of work and caregiving: Relationships between role satisfaction, role involvement, and caregivers' well-being. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *52*(5), S279-S289.

O'Connor, D. L. (2007). Self-identifying as a caregiver: Exploring the positioning process. *Journal of Aging Studies*, *21*(2), 165-174.

Oude Avenhuis, A. & Kruijswijk, W. (2013) Aandacht voor mantelzorgers werkt! Retrieved from http://www.expertisecentrummantelzorg.nl/Site_EM/docs/pdf/Aandacht_voor_mantelzorg_werkt.pdf

Oudijk, D., De Boer, A., Woittiez, I., Timmermans, J. & De Klerk, M. (2010) Mantelzorg uit de doeken. Retrieved from http://www.scp.nl/Publicaties/Alle_publicaties/Publicaties_2010/Mantelzorg_uit_de_doeken

Reid, J., & Hardy, M. (1999). Multiple roles and well-being among midlife women: Testing role strain and role enhancement theories. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *54*(6), S329-S338.

Scholz, C. (1987). Corporate culture and strategy—The problem of strategic fit. *Long Range Planning*, *20*(4), 78-87.

Settles, I. H. (2004). When multiple identities interfere: The role of identity centrality. *Personality and Social Psychology Bulletin*, *30*(4), 487-500.

Sieber, S. D. (1974). Toward a theory of role accumulation. *American sociological review*, 567-578.

Smircich, L. (1983). Concepts of culture and organizational analysis. *Administrative science quarterly*, 339-358.

Talley, R. C., & Montgomery, R. J. (Eds.). (2012). *Caregiving Across the Lifespan: Research• Practice• Policy*. New York, USA: Springer Science & Business Media.

Thoits, P. A. (1991). On merging identity theory and stress research. *Social psychology quarterly*, 101-112.

Thompson, C. A., Beauvais, L. L., & Lyness, K. S. (1999). When work–family benefits are not enough: The influence of work–family culture on benefit utilization, organizational attachment, and work–family conflict. *Journal of vocational behavior*, *54*(3), 392-415.

Tolkacheva, N., van Groenou, M. B., & van Tilburg, T. (2010). Sibling influence on care given by children to older parents. *Research on Aging*, *32*(6), 739-759.

Van der Lippe, T., & Roeters, A. (2010). En win-win situatie: de positieve relatie tussen werk en privé. In; A. van den Broek & Cloïn (red.), *Komt tijd, komt raad?* Essays over mogelijkheden voor een nieuwe tijdsorde (pp. 79-90). Den Haag: SCP

Werk & Mantelzorg (2016). CAO Inspirator. Retrieved from https://docs.google.com/viewer?url=http://www.werkenmantelzorg.nl/%2FUserFiles%2Ffiles%2Falgemeen%2FWM_CAO_INSPIRATOR_juni_2015.pdf

Werk & Mantelzorg (2016). Wet en Regelgeving. Retrieved from http://www.werkenmantelzorg.nl/stichting/wet-en-regelgeving

Wolf, D. A., Freedman, V., & Soldo, B. J. (1997). The division of family labor: Care for elderly parents. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *52*(Special Issue), 102-109.

Appendix

I. Operationalisation of codes

A priori code	*Operationalisation*
A priori codes informal caregivers	
• Acceptance of role	• Acceptance of their role as either caregiver or partner/parent/child.
• Incongruence of roles	• When the role of mother/daughter/partner etcetera does not 'match' with the role of informal caregiver
• Awareness of role	• When an informal caregiver identifies themselves as such
• Role strain	• Experiencing stress from combining the roles of work and care
• Guilt	• Experiencing guilt from not being able to spend time on one role as a result of spending time on another one
• Compensation	• Experiencing certain perks at the workplace that compensate for the care situation
• Feeling responsible	• Feeling responsible for the person cared for
• Making use of flexibility	• To work from home or apply flexibility to the working hours
• Not sharing situation	• Not telling about the care situation at work
• Unaware of arrangements	• Caregiver does not have knowledge of work related care arrangements
• Making use of leave	• Making use of the care leave provided by the workplace
• Support	• Experiencing support from work or personal network
○ Psychological support	○ Receiving support through talking, phone calls etcetera
○ Practical support	○ Receiving support in the form of practical tasks
• Intensive care tasks	• Providing care tasks such as helping with ADL
• Sharing care	• When the care for a person is shared equally
• Inviting attitude supervisor	• When a caregiver feels like they can approach their supervisor with their private situation
• (un)safe environment	• When a caregiver feels like they cannot share their situation at the workplace

• Feeling understood	• When a caregiver shares their situation and people (colleagues) respond in a way that helps them
***A priori codes* supervisors**	
• Awareness definition	• Supervisor is aware of what an informal caregiver is and what the care they provide entails
• Awareness caregivers in the workplace	• Supervisor is aware that among the employees in the workplace, some provide care for a loved one
• Recognizing reasons not to tell	• Supervisor recognizes the reasons that employees might have for not sharing their situation in the workplace
• Aware of possible 'hidden' caregivers in the workplace	• Supervisor is aware that not all informal caregivers share their situation at work and might therefore not know all the caregivers in the workplace
• Aware of arrangements	• Supervisor knows which work related care arrangements are available in the workplace for caregivers to use
• Offers tailored solutions	• Offer solutions that are tailored to the needs and situation of the caregiver
• Inviting attitude	• Supervisor is empathic and interested in hearing about his/her employee
• Recognizes signals	• Supervisor is sensitive to signals

II. Topiclist informal caregivers

Introduction

- Introduce myself
- Explain what the interview entails (goal, method, duration, anonymity and confidentiality)
- Ask for permission to record the interview

Demographic information

- Age
- Gender
- Number of brothers and sisters
- Marital status
- Number of children

Context

- Relationship to the person cared for
- Illness/condition of the person cared for
- Type of job
- How many hours of work
- How many hours of care
- Duration of care
- Care tasks

Awareness

- Could you tell me what an informal caregivers is?
- Do you consider yourself to be an informal caregiver? Why (not)?
- Who in your personal environment knows about your care situation?
- Which tasks do you consider to be part of being a partner/parent/child and which tasks belong to the role of caregiver according to you?
- How do you experience providing care?
- Which care tasks do you provide at the moment that you don't feel comfortable with?
- How do you consider the changeover between work and care? (in general)
- What influence do you think you own attitude has on combining work and care?

Combining different roles

- Could you tell me something about how you combine work and care?
- How do you experience combining work and care?
- What do you think about your job?
- How do you deal with the different obligations that work and care bring along?
- Do you like your job? What do you like about it?
- Does your work influence the way you feel? In what way?
- Does your work influence the care situation? How?
- Does the care situation influence how you feel? In what way?
- What do you like about providing care?
- How do you prioritize between work and care?

Informal care arrangements

- What do you know about work related care arrangements in general?

- Could you tell me which work related care arrangements are available at your work?
- Have you ever made use of work related care arrangements?
- Do you make use of flexible working hours/locations?
- How come you (do not) make use of this?
- Did you ever make arrangements with your supervisor to accommodate your care situation?
- If so, how did this change your situation?

Workplace culture

- Could you tell me about the atmosphere in your workplace?
- Who knows about your care situation?
- How do they respond to this?
- How much autonomy do you experience in the workplace?
- How would you describe your supervisor? (specifically concerning his/her attitude)
- Do you experience support or empathy from you supervisor?
- What are reasons to share (or not share) your care situation at work?
- How does the atmosphere at work contribute in your choice to (not) make use of certain work related care arrangements?

Care network

- Could you tell me something about which persons from your personal network could provide support for you to care for [name of care receiver]?
- Are they involved in the care provided? If so, how?
- How is the collaboration between you and possible other caregivers?
- What influence does the support received have on the pressure caused by combining work and care?
- Would you make less/more use of arrangements if you would receive less/more support from your network?

Conclusion

- Resume the most important themes
- Thank you for the interview
- Would you like to read the thesis report?

III. Topiclist supervisors

Introduction

- Introduce myself
- Explain what the interview entails (goal, method, duration, anonymity and confidentiality)
- Ask for permission to record the interview

Personal data

- What is your age?
- What is your position?

Context

- How many people do you supervise?
- In what kind of organisation do you work?
- How many hours a day do you work?

Awareness

- Could you tell me what an informal caregiver is?
- Do you have any personal experience with informal care?
- How many informal caregivers do you think are among your employees?
- Do you think it is possible that there are more, but that they do not come forward with this?
- What do you think about informal caregivers within the workplace?
- How do you deal with them?

Combining different roles

- What is your vision on combining (informal) work and care?
- What problems do you encounter with employees that combine work and care?
- How do you deal with that?

Work related care arrangements

- Can you tell me which arrangements are available within your organisation/company?
- What do you think about the existing arrangements?
- In what way do you apply them?
- Do you offer employees tailored solutions?

Workplace culture

- Can you tell me something about the atmosphere in the workplace?
- What is your reaction when an employee shares details about their personal life?
- How do you think your employees would describe you as a supervisor?
- What could be reasons for informal caregivers not to share their care situation at work?
- How does the atmosphere in the workplace contribute to (not) making use of arrangements according to you?

Conclusion

- Resume the most important themes
- Thank you for the interview

- Would you like to read the thesis report?

IV. Code tree informal caregivers

1. Awareness
   - Awareness of definition
     - Unaware of definition
   - Awareness of role
     - Unaware of role
   - Incongruence of roles
     - Caused by tasks
     - Caused by conflict between roles
2. Combining work and care
   - Role accumulation
     - Compensation
     - Daily life prioritizing
     - Prioritizing home above work
     - Sharing care as a solution
     - Working less as a solution
       - Working less not a solution
   - Role strain
     - Care influences work negatively
       - Decrease in flexibility
       - Decrease in productivity
     - Emotional burden care
       - Feeling responsible
       - Feeling Guilt
     - Financial worries/negative financial consequences care
     - High work pressure
     - Role overload
     - Shortage in time
     - Hectic situation at home and work
3. Support network
   - Main caregiver
   - Sharing care
   - Little support
     - Complicated family relationship
   - Incidental practical support
   - Structural practical support
   - Source of professional help
   - Psychological support
4. Work related care arrangements
   - Autonomy
     - No autonomy
   - Aware of arrangements
     - Unaware of arrangements
   - Making use of flexibility
     - Negative effects of flexibility
     - No flexibility available
     - Positive effects of flexibility
   - Making use of leave
   - Tailored solution
     - Compensating with overtime

    - Using vacation days to extend leave period
5. Workplace culture
    - Safe environment
        - Experiencing space from work to care
        - Feeling understood
        - Good atmosphere
        - Protecting workplace culture
        - Sharing situation
            - Selective sharing of situation
    - Unsafe environment
            - Un-understanding colleagues
            - Workplace culture of fear
    - Supervisor
        - Inviting attitude
            - Reciprocity
            - Understanding supervisor
        - Uninviting attitude

V. Code tree supervisors

1. Awareness
   - Aware of possible ‘hidden’ caregivers
     - Recognizes reasons not to tell
     - Unaware of possible ‘hidden’ caregivers
   - Awareness caregivers in the workplace
     - Recognizing signals
   - Awareness definition
   - Importance of knowing
   - Problems with caregivers
     - Emotional burden care
     - Physical burden care
2. Work related care arrangements
   - Care leave
     - Paid care leave available
     - Unpaid care leave available
   - Dealing with arrangements
     - Additional arrangements
     - Tailored solutions
       - limitations
     - Wide interpretation of existing arrangements
   - Flexibility
     - Flexibility in location
       - No possibility to work from home
     - Flexibility in working hours
       - No possibility for flexible hours
3. Workplace culture
   - Attitude supervisor
     - Inviting attitude
     - Outreaching towards employees
     - Reactive policy
     - Responsibility caregiver
     - Trust is important to supervisor
   - Safe atmosphere workplace
     - Safe environment
     - Culture helps to seek help
   - Unsafe atmosphere work
     - Un-understanding colleagues