Governing informal care

An exploration of informal care in the Dutch health care system

Leonoor Gräler

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Funding

The research project was supported with a grant provided by the Netherlands Organisation for Health Research and Development (ZonMw, project number 60-63900-98-652).

ISBN 978-94-6510-047-0

Cover by: Margreet Borgman (www.oranjeboven.nl)
Printed by: ProefschriftMaken (www.proefschriftmaken.nl)

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Sturen op mantelzorg

Een verkenning van mantelzorg in het Nederlandse zorgsysteem

Thesis

to obtain the degree of Doctor from the
Erasmus University Rotterdam
by command of the
rector magnificus

Prof.dr. A.L. Bredenoord

and in accordance with the decision of the Doctorate Board.
The public defence shall be held on

4 October 2024 at 10:30 hrs

by

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Table of contents

CHAPTER

1

General introduction

The text of the introduction has been reviewed and edited with the assistance of Grammarly's AI-powered writing assistant.

An account of informal care

The topic of this thesis is informal care. Informal care is the usually voluntary and unpaid care and support that is delivered by those in a pre-existing relationship with someone with a chronic illness, disability or other long-lasting care need due to ill health or aging (Hoefman et al., 2013). In the Netherlands, where the research in this thesis is situated, over one-third of the population of 16 years and older provides informal care (De Boer et al., 2020). Of those who provide care, about a quarter of them deliver over 8 hours of care per week for longer than three months. On average, informal caregivers provide 7 hours of care per week for five years. The tasks informal caregivers take on are diverse, from helping in the household and helping with administration or emotional support, to providing medical care such as administering injections.

Who provides what type of care and how many hours is influenced by several factors. First and foremost, it is prompted by the needs of the care recipient. However, it is also influenced by other factors such as feelings of reciprocity, affection, family values, caregiving obligations, and personal characteristics and circumstances (Zarzycki et al., 2022). Furthermore, importantly, caregiving trajectories do not necessarily stay stable (Verbakel & Glijn, 2023). Relationships can change, the needs of the recipient can change, and the circumstances of both the caregiver and care recipient can change.

The first time I came into contact with informal care was in my twenties. As a student, every Saturday afternoon, I took a local train into the countryside of the beautiful north of the Netherlands, where J lived. There, I provided care for J who had had Parkinson's disease for over ten years at the time I met her. J was a self-confident, strong-headed, and empathic woman, whom I would grow very fond of in the years to come. She lived with her husband. He had been providing care for her all that time, along with friends and family. Throughout time this had become a 24/7 activity, because of the increasing needs of J. Luckily, they had the means to call in help. I was part of that help, an untrained clumsy student who lived an unregular life, taking the wrong trains, breaking dishes, and wearing ripped jeans on the job. However, it was precisely our two worlds colliding that made our dynamic interesting. It made visible what I took for granted, in both my life and that of J and her family.

When I started working for J, seeing her family and friends taking care of her, I learned that bearing the burden (and joy) of caring for a loved one is much more than putting on clothing and providing someone with food on set times (which can both be straining enough in itself!). It is also arranging other caretakers, keeping track of doctor schedules, providing medicines, ordering medicines, financial administration to prove to the government funds are spent as intended, paying the caretakers accordingly, being constantly vigilant in case of a fall or an irregular need, and being there emotionally for your loved one who is severely ill. Furthermore, it is balancing care with having a life of your own, having a job, maintaining a social network, and retaining some sense of privacy amid all the helpers in your house and your relationship. Lastly, this all happens within a context of grief and worry: losing your loved one as you knew them, seeing them grieve over the loss of autonomy, feeling guilty for not being able to solve it all, and worrying about what is yet to come on an unpredictable timeline.

The way care was provided for J, could be described as desirable from the perspective of policy makers. She was able to stay at home for a long time, and pressure was taken off the formal care system. However, it became clear to me that this was not to be taken lightly. It required being resourceful and being skillful in organizing it all. This is where my interest in informal care sparked. Researching this topic has provided me with more insight into the world of informal care. In this thesis I want to convey these insights, hoping it may spark others' interest as well.

This thesis aims to provide insight into the current policies and practices surrounding informal care. The expectations of informal care from policymakers as a solution to a plethora of societal problems are high. However, involving informal caregivers comes with a range of challenges in the care of older people. Here above, I started by zooming in on a personal story to make the subject of this thesis more tangible. Now I will zoom out and connect this experience to the broader context and bodies of literature (Nicolini, 2009).

The policy context of informal care involvement

European countries face a major challenge regarding the financial sustainability of public long-term care (LTC) for their aging populations (Norton & Stearns, 2009). In 2050, the percentage of old persons is expected to have more than doubled compared to 2000 (Rowland, 2009), putting pressure on the working population to finance care for older people. Furthermore, this demographic change causes workforce shortages, including in health care (OECD 2020).

Therefore, governments turn to informal care as a solution to these challenges (Pavolini & Ranci, 2008).

There are at least three arguments to focus on informal care as a solution to the challenges mentioned above (Deusdad, Pace & Anttonen, 2016; Da Roit, Le Bihan, & Österle, 2007; Eichler & Pfau-Effinger, 2009). First, informal care is believed to be less costly than formal care from a public finance perspective, because informal care may substitute paid professional services (e.g. Kehusmaa et al., 2013). Second, informal caregivers could, for the same reason, mitigate personnel shortages. Finally, informal care is at the same time expected to contribute to quality of care as informal caregivers can contribute to personalized care, because of the personal relationship and specific knowledge of the care recipient informal caregivers have (McCormack & McCance, 2006; 2010).

The consequences of informal care involvement

Involving informal care has consequences for the relationship between professionals, care recipients and informal caregivers. Although informal care may increase the possibility for older people to age at home (Kemp, Ball & Perkins, 2013), better accommodate personalized care (McCormack & McCance, 2006), and give a sense of purpose to caregivers (Burgess, Kemp & Bender, 2022), there are also negative consequences of informal caregiving: informal caregivers may choose to or have to reduce their working hours or stop working altogether to provide care (Nguyen & Connelly, 2013; Van Houtven, Coe & Skira, 2013). Furthermore, providing informal care may reduce the physical and psychological health of caregivers (Pinquart & Sörensen, 2003; Lindt, Van Berkel & Mulder, 2020).

Also, the consequences are often borne by specific groups (Pinquart & Sörensen, 2007). One of the most affected groups is women, as they provide more care than men and, at the same time, are being pressed to increase their labour participation (Goijaerts, 2022; Kruse & Jeurissen, 2021). Authors have argued that policies build on an ideal of pre-government involvement, where "informal was the norm", obscure such inequalities and forgo the intimacy that is required for care (Da Roit & De Klerk, 2014). Therefore, it is important to gain insight in the consequences for different groups and support each of them accordingly. In this thesis, I research the heterogeneity among informal caregivers in terms of outcomes, and the relationship between available support arrangements and outcomes.

Furthermore, the involvement of informal caregivers requires changes in professional care. Informal caregivers often provide care in complex networks, which often also include professionals (Jacobs et al., 2016). This requires some form of collaboration, which is notoriously difficult and important because values, ideas about task division, and norms about quality of care can differ (Burgess et al., 2022; Wittenberg et al., 2018). What care looks like and what the role of informal caregivers should be is, therefore, not set in stone but, rather, negotiated in the relationship between professionals and informal caregivers (Kemp, Ball & Perkins, 2013). To provide more insight into how care is negotiated in daily care practices, in this thesis, I look at the consequences of providing care for informal caregivers and their relationship with professionals.

All in all, it seems that the involvement of informal caregivers is easier said than done. In this thesis, I want to focus and explore two reasons behind this. First, providing informal care requires resources such as money, time, ability, a social network, and health (Broese-Van Groenou & De Boer, 2016). Not everyone may have these resources available to the same extent, and care needs and who is burdened with care to what extent may be unevenly spread across the population. Therefore, I will close in on the heterogeneity of informal caregivers, as well as the support arrangements that should help mitigate the burden. Second, the involvement of informal caregivers requires collaboration between professionals and informal caregivers (Kemp, Ball & Perkins, 2013), which is difficult because of the different values they may uphold and the new tasks and roles this prompts. Therefore, it is important to look at how collaboration is done in practice and to what consequences.

The main question

Given the challenges described before, it is important to think about how to include informal caregivers in a way that does justice to all the parties involved, now and in the future. This means considering the complexity behind informal care, including among other things the (distribution of) burden of care, and the interaction between professionals and informal caregivers.

Therefore, involving informal caregivers requires political and organizational choices about how to distribute resources and burdens, and who has a say in the provision of care. These aspects are important to study because they can have a big impact on care recipients, informal caregivers, and professionals, but also because it requires making political choices for which it is important to know how these choices unfold in practice. Therefore, the main question of this thesis is:

What can we learn from current informal care policies and care practices in the Netherlands for future endeavors to better involve informal caregivers in care?

I highlight two aspects when answering this question. First, I look at the national and municipal policy levels to see how policies affecting informal caregivers relate to informal care outcomes. Second, I zoom in on the practices in daily care to further unravel how collaboration takes shape. Therefore, this thesis is divided into two sections based on the following sub-questions.

1. *How are national and local government policies related to informal care outcomes?*
2. *What does the involvement of informal caregivers mean for how care is negotiated between professionals and informal caregivers in practice?*

I start by looking at informal caregivers using quantitative methods, describing how government decision-making is related to the number of informal caregivers, intensity of care, and burden of care. Then, in the second part, I zoom in more closely on the practice of informal care inclusion in terms of how caregivers negotiate care with professionals and co-construct care trajectories within the dynamic network of care recipients, using qualitative methods. In the following, I elaborate on these sub-questions.

Sub-question 1: Governmental policies and informal care

Chapters 2 and 3 are about specific aspects of the relationship between national and municipal policies and informal care outcomes.

The first level I focus on is national government. Since the 1970s, informal care has been on the policy agenda in the Netherlands (van der Lyke, 2000). It is, therefore, important to study how different policies and institutional arrangements impact informal caregivers. For example, the influence of national context for informal care was shown by previous literature comparing countries with different institutional arrangements (e.g., Bom & Stöckel, 2021; Miyazaki, 2023; Courtin et al., 2014; Viitanen, 2007). Bom and Stöckel (2021) found that, compared to the Netherlands, a larger proportion of informal caregivers in the UK provided medium and intense care. They link this difference to the fact that the Netherlands has a more generous long-term care scheme, thus putting less pressure on informal caregivers. Besides influencing the percentage of informal caregivers, policies also influence who takes up the role of informal caregiver (Schmid, Brandt & Haberkern, 2012) and to what extent they are burdened or supported (Courtin et al., 2014). Below, I go into the two topics of study, specifically focusing on the impact of government policies on informal caregivers in this thesis.

The COVID-19 pandemic

The global public health crisis posed by the COVID-19 pandemic from 2019-2022 made understanding the heterogeneous effects of policy on informal caregivers, and how support could be tailored, very pressing. Studies showed that the COVID-19 pandemic heavily influenced informal caregivers (Klarenz-Dant & Comas-Herrera, 2020). However, they also showed that this influence was not the same for everyone (e.g. Raiber & Verbakel, 2021). For example, in the Netherlands, people who provided care for someone in a nursing home might have decreased hours of caregiving because of constraints to entering the nursing home, while those who provided care for someone in the same household, may have increased caregiving to mitigate the scaling down of professional care to only the most necessary care (SCP, 2020).

Nevertheless, no study has provided an overview of which caregivers were affected how by COVID-19 in the Netherlands. The analysis will explore the extent to which informal caregivers were affected by the pandemic and the policies in response to the pandemic and how the effects varied across different types of caregivers. This information will be crucial in developing tailored policies and interventions that cater to the unique needs of informal caregivers during pandemics and other crises. Ultimately, the study will contribute to a better understanding of how policy can be developed to support informal caregivers.

Support arrangements

Governments aim to mitigate care burden by offering support arrangements for informal caregivers. However, there is only limited evidence that they are successful in reaching caregivers (Courtin et al., 2014). There have been various types of support services studied, including respite care (van Exel et al., 2006), psychoeducational interventions (e.g., Frias et al., 2020; Murfield et al., 2022), and digital support (e.g., Henoch et al., 2020). However, these support services have not been able to unequivocally demonstrate a positive effect among caregivers. For instance, Van Exel et al. (2006) found that respite care was expected by informal caregivers to decrease their subjective burden, but informal caregivers were hesitant to use services. Similarly, Henoch et al. (2020) found that digital support was considered suitable for the population of informal caregivers, while they preferred face-to-face meetings.

As a result, it is not uncommon that support arrangements remain underused (Brodaty et al., 2005; Choi et al., 2023; De Boer et al., 2020). This may be attributed to the fact that these arrangements do not always meet the needs of informal caregivers (Barrett et al., 2014; Henoch et al., 2020), or informal caregivers may not be aware of the support services available to them (Feijten et al., 2017). Furthermore, for organizations that have to arrange the support, it can also be challenging to identify informal caregivers at an early stage (Spit et al., 2023).

In the Netherlands, the task of supporting informal caregivers has been decentralized to the municipal level in an attempt to better tailor services to the needs of caregivers. However, there is a lack of understanding regarding whether municipalities are successful in reaching informal caregivers and the effectiveness of their efforts. Chapter 3 of this study aims to provide a deeper understanding of the relationship between municipal support and informal care outcomes.

Sub-question 2: Organizational policy, professionals and informal care

Together, chapters 4 and 5 provide insight into how care organizations and professionals involve informal caregivers. They focus on how care is negotiated between professionals and informal caregivers within convoys of care.

Professionals working in care organizations have to collaborate with informal caregivers, as care is often provided in networks of both informal caregivers and professionals (Jacobs et al., 2016). However, this collaboration between professionals and informal caregivers is complex because of differences in expectations about roles and care (Twigg & Atkin, 1994; Nies, 2017). Research shows that, from the perspective of informal caregivers, their expertise and effort are not acknowledged enough and divisions of responsibilities are unclear (Wittenberg et al., 2018). On the other hand, although informal caregivers can be of help, they can also be perceived as a burden to professionals (Hertzberg, Ekman & Aksselson, 2003).

Furthermore, the institutional context adds to the complexity, as it influences how informal caregivers are perceived and what professionals can do. For example, how teams of professionals in a home care setting were organized influenced the involvement of informal caregivers by these professionals. Professionals in smaller teams with less task division, but more clarity about responsibilities involved informal caregivers more (Van Wieringen, Broese-Van Groenou & Van Groenewegen, 2015).

It is important to gain more insight into the mechanisms at play when including informal caregivers in formal care practices. I will provide such insight by teasing out how professionals and informal caregivers negotiate care together and what consequences these negotiations have.

Micropolitics

Chapter 4 examines the relationship between professionals and informal caregivers in care for older people as a dynamic and negotiated undertaking, following the convoys of care model (Kemp, Ball & Perkins, 2013). As the boundaries between professionals and informal caregivers are ambiguous and roles are sometimes overlapping, care becomes organized within their relationship. The qualities of this relationship have consequences, for example, for collaboration and communication (e.g., Kemp et al., 2018), moral decision-making (Kemp et al., 2022), and the quality of the relationships of care recipients to other people (Ciofi et al., 2022; Fitzroy et al., 2022). Furthermore, research has shown that some informal caregivers are better at captaining care and relationships with professionals, gaining micro advantages over those who are not (Gengler, 2014).

Although this shows that the negotiations between professionals and informal caregivers have consequences for how care is organized and how resources are distributed, little research has taken on an explicitly political lens. Therefore, in Chapter 4, I look at the micropolitics within convoys of care for older people to see how professionals and informal caregivers organize care.

The role of mundane objects

While listening to the stories of professionals and informal caregivers about their relationship, I noticed how informal caregivers often mentioned the role of mundane objects, such as clothing, doormats, and toothbrush holders as impacting this relationship. To informal caregivers, these objects were very important. Mundane objects have been shown to take an important role in the organization of care (Buse, Martin & Nettleton, 2018). Exemplary studies have focused on how competing values of what comprises good care are worked out through the food practices in nursing homes (Mol, 2010), how women in nursing homes use their handbags to negotiate a private space (Buse and Twigg, 2014), and the role of clothes to negotiate dignity and identity (Twigg, 2010; 2013). Furthermore, objects such as the laundry create rhythms in care homes because of the sequential actions the laundry requires (Buse et al. 2018; Lloyd, 2020).

Nevertheless, in the convoys of care model, only human actors are taken into account. Therefore, in Chapter 5, I studied the objects and the role they play in professional-informal caregiver interactions.

Reading guide

Summing up, this thesis addresses the question of what we can learn from current informal care policies and care practices in the Netherlands for future endeavors to better involve informal caregivers. In the next four chapters, I will discuss different themes concerning this research question. Chapters 2 and 3 will focus on governmental policies and circumstances, answering the sub-question: how do the national and subnational policies influence informal care outcomes? Chapters 4 and 5 will revolve around care organizations and professionals, answering the sub-question: what does the increased involvement of informal care mean for how care is negotiated between professionals and informal caregivers in practice? In the discussion chapter, I will summarize and reflect on my findings and highlight the main implications for policy and practice.

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CHAPTER 2

Informal care in times of a public health crisis: objective burden, subjective burden and quality of life of caregivers in the Netherlands during the COVID-19 pandemic

This chapter was published as:

Gräler, L., Bremmers, L., Bakx, P., van Exel, J., & van Bochove, M. (2022). Informal care in times of a public health crisis: Objective burden, subjective burden and quality of life of caregivers in the Netherlands during the COVID-19 pandemic. Health and Social Care in the Community, 30(6), e5515–e5526. https://doi.org/10.1111/hsc.13975

Abstract

In the Netherlands, about one-third of the adult population provides unpaid care. Providing informal caregiving can be very straining in normal times, but the impact of a public health crisis on caregivers is largely unknown. This study focuses on the question how caregiver burden changed following the COVID-19 pandemic, and what characteristics were related to these changes. We use self-reported data from a sample of 965 informal caregivers from the Netherlands three months into the pandemic to investigate how the objective burden (i.e., hours spent on caregiving) and the subjective burden had changed, and what their care-related quality of life (CarerQol) was. We found that on average the subjective burden had increased slightly (from 4.75 to 5.04 on a 0-10 scale). However, our analysis revealed that some caregivers were more affected than others. Most affected caregivers were women, and those with low income, better physical health, decreased psychological health, childcare responsibilities, longer duration of caregiving, and those caring for someone with decreased physical and psychological health. On average, time spent on care remained the same (a median of 15 hours per week), but certain groups of caregivers did experience a change, being those caring for people in an institution and for people with a better psychological health before the pandemic. Furthermore, caregivers experiencing changes in objective burden did not have the same characteristics as those experiencing changes in perceived burden and quality of life. This shows that the consequences of a public health crisis on caregivers cannot be captured by a focus on either objective or subjective burden measures or quality of life alone. Long-term care policies aiming to support caregivers to persevere during a future crisis should target caregivers at risk of increased subjective burden and a lower CarerQol, such as women, people with a low income and people with childcare responsibilities. Such policies should consider that reducing objective burden may not necessarily lead to a reduction in subjective burden for all caregivers.

Introduction

Against the backdrop of rising health care expenditures, governments emphasize the need for informal care (Pavolini & Ranci, 2008). However, providing informal care can be very time consuming and perceived as burdensome (Bom, Bakx, Schut, & Van Doorslaer, 2019). Increased caregiver burden has negative consequences for care-recipients, sustainability of health care systems and societal costs. Burden of informal care can be exacerbated by events that increase stress factors or complicate routines. Such events can be changes in the health or the financial situation of the caregiver, changes in health of the care recipient, or an increase in other responsibilities (Pearlin, Mullan, Semple, & Skaff, 1990). The COVID-19 pandemic was a crisis in which many of these factors collided, affecting informal caregivers in many ways (Lorenz-Dant & Comas-Herrera, 2021). However, there may be differences among caregivers with regards to how they were affected. This has been understudied, while this knowledge is important to tailor interventions to support caregivers in times of a crisis.

In this paper we will answer the following research questions: how did the burden of informal caregivers change following the COVID-19 crisis? And how was this burden related to characteristics of caregivers, care recipients and the caregiving situation? We used self-reported data to study to what extent caregivers experienced a change in burden three months into the COVID-19 pandemic in the Netherlands. Firstly, we explored which caregiver characteristics were related to a change in the number of hours spent on caregiving (i.e. objective burden). Subsequently, we analyzed how characteristics related to changes in the perceived burden from caregiving (i.e. subjective burden). Lastly, we investigated care-related quality of life during the pandemic. By combing objective burden, subjective burden and quality of life measures, it is not only possible to see which caregivers were most affected by the pandemic, but also the ways in which they were affected.

We contribute to the literature by identifying which characteristics relate to changes in objective and subjective burden during the COVID-19 pandemic. Prior research shows that during the pandemic informal caregivers experienced changes in responsibilities as well as in mental, physical and financial health (de Sousa, Sequeira, Ferré-Grau, & Araújo, 2022; Greaney, Kunicki, Drohan, & Cohen, 2020; Lorenz-Dant & Comas-Herrera, 2021). These consequences differed for caregivers with different characteristics. Studies from various countries show that gender (Lorenz-Dant & Comas-Herrera, 2021; Raiber & Verbakel, 2021; Zwar, König, &

Hajek, 2022), age (Budnick et al., 2021; Hofstaetter, Judd-Lam, & Cherrington, 2022), employment (Truskinovsky, Finlay, & Kobayashi, 2022), living situation of the care recipient (Prins, Willemse, Velden, & Pot, 2021; Smaling, Tilburgs, & Achterberg, 2022), relationship to the care recipient (Tur-sinai, Bentur, & Fabbietti, 2021) and network (Allen, Uekusa, & Alpass, 2022) were important characteristics that distinguish how caregivers were affected. Studies in the Netherlands found that there were differences between men and women, and between those in different relationships to the care recipient (Prins et al., 2021; Raiber & Verbakel, 2021; Smaling et al., 2022; Tur-sinai et al., 2021). Previous literature thus shows that consequences differed across countries, which may be due to differences in measures, COVID impact and health care system (Lorenz-Dant & Comas-Herrera, 2021; Santini, Socci, Fabbietti, Lamura, & Teti, 2022; Tur-sinai et al., 2021). In the Netherlands, there were relative large increases in informal care and decreases in formal care compared to other countries (Tur-sinai et al., 2021).

Despite the growing body of research on informal care during COVID, so far, no studies seem to have investigated how objective burden, subjective burden and quality of life were related during the pandemic, and whether this relationship differs between groups. Therefore, in this paper, we study the question: To what extent were informal caregivers affected during the COVID-19 pandemic in the Netherlands, and to what extent did that differ between informal caregivers with different characteristics?

Conceptual model

Caregiver burden measurement

Caregiver burden represents the overall consequences of caregiving (Pearlin et al., 1990). In this paper, we focus on objective burden, subjective burden, and care-related quality of life. The *objective burden* of care is the burden of care measured by the time spent on caregiving. However, time spent on care may not necessarily reflect how the caregiving burden is perceived (i.e. *subjective burden*) (Montgomery, Gonyea, & Hooyman, 1985). According to the caregiver stress process model (Pearlin et al., 1990), subjective burden is the result of the emotional evaluation of aspects directly related to caregiving itself (e.g., needs of the care recipient, time spent on caregiving), which is mediated through aspects secondary to the care process such as difficulty combining caregiving with other activities and responsibilities, or economic strains. Furthermore, demographic factors, such as gender, and socioeconomic status (e.g., gender, socioeconomic status) influence both the time spent on caregiving, but also directly influence how caregiving is perceived. By combining measures of objective burden and subjective burden, groups who provide a lot of care and groups who experience a lot of burden can be distinguished.

Finally, subjective burden may not capture the overall impact of caregiving on all life domains relevant to caregivers. Quality of life is conceptually different from subjective burden (Chappell & Reid, 2002; Yates et al., 1999). It captures the effect of the appraisal of the caregiving situation on overall well-being and is influenced by both aspects directly or indirectly related to caregiving and aspects beyond the caregiving process (Chappell & Reid, 2002). To measure care-related quality of life, we use the CarerQol, which is a caregiver-specific quality of life measure (Brouwer, Van Exel, Van Gorp, & Redekop, 2006; Hoefman, Van Exel, & Brouwer, 2013). The dimensions of this instrument consist of satisfaction, the relationship with the care recipient, psychological well-being, ability to combine daily activities with care, financial well-being, support network, and physical well-being. All dimensions are specifically asked in the context of informal caregiving. Care-related quality of life is strongly associated with objective and subjective burden, but also encompasses a broader set of potentially relevant impacts of caregiving on the overall quality of life of caregivers.

Caregiver characteristics and COVID-19

Based on the work of Pearlin et al. (1990), Yates et al. (1999) and Chappell and Reid (2002), we discuss characteristics associated with objective burden, subjective burden and care-related quality of life that are relevant in the context of COVID-19. COVID-19 may have influenced both the characteristics as well as their relationship to the outcome. We distinguish three groups of characteristics: care recipient's need for care, caregivers' dispositional and restrictive characteristics and help from others. In this section, we will discuss the potential effects of the pandemic on caregivers based on these characteristics.

Care recipient's need for care

Characteristics of the care recipient are related to variation in the demand for care and include the health of the care recipients and the nature of the condition (Chappell & Reid, 2002; Pearlin et al., 1990; Yates, Tennstedt, & Chang, 1999). Whereas the first two determine how much and what care is needed, the latter determines among whom the care is potentially divided. A health decline during the pandemic would increase the need for care. Furthermore, how caregivers experienced the pandemic may be related to the nature of the condition of the care recipient, because psychological conditions and physical conditions may have been experienced differently by caregivers. The changes in health during the pandemic and the nature of the condition before the pandemic are therefore expected to be related to the caregiver outcomes.

Caregiver dispositional and restrictive characteristics

Demographic and socioeconomic characteristics are associated with caregiver outcomes (Chappell & Reid, 2002; Pearlin et al., 1990; Yates et al., 1999). The pandemic may have influenced the relationship between these characteristics and the consequences of caregiving. For example, older caregivers may have felt more at risk. This may also be the case for the relationship between health of the caregiver and outcomes. Caregivers who were already struggling with their health may have been less inclined to care or experienced more stress, because of their own health risk. Furthermore, the psychological and physical health of caregivers may have changed during the pandemic (Park, 2020).

Another dispositional characteristic is the relationship between the caregiver and care recipient, because it implies certain expectations with regard to caregiving (Fletcher, 2020). This includes the type of the relationship and its duration (Chappell & Reid, 2002; Pearlin et al., 1990; Yates et al., 1999). Both affirm the obligation and willingness to care felt within a relationship, which may be related to changes in caregiving tasks during the pandemic. For instance, most informal caregivers who stopped proving care, provided care for less than 10 hours a week on average (Rodrigues, Simmons, Schmidt, & Steiber, 2021). However, those with strong ties often provide more intensive informal care (de Boer, de Klerk, Verbeek-Oudijk, & Plaisier, 2020). Therefore, we expect that the relationship between the caregiver and care recipient is of importance in how the pandemic was experienced and whether informal caregivers changed the amount of time spent on caregiving.

Whether the informal caregiver lives together with the care recipient (SCP, 2020) and the travel distance (White, 2020) may have also had an influence, because contact with people from outside the household was restricted and care homes were closed for visitors (SCP, 2020). This made it difficult to provide care outside the household, while within the household it was difficult to escape the caregiving situation.

Finally, caregiver outcomes are related to responsibilities such as work or childcare. These other responsibilities not only influence the time available for caregiving, but also how caregiving is experienced (Pearlin et al., 1990). Combining work and caregiving could have become more complicated during the COVID-19 crisis (Lafferty et al., 2021). Furthermore, time spent on childcare may have intensified due to school closures and home schooling. We expect that caregivers with children experienced an increased subjective burden, as prior studies show that childcare responsibilities affect subjective burden (Koopman, Heemskerk, van der Beek, & Coenen, 2020). To conclude, we expect that the impact of the pandemic on other responsibilities of caregivers may have influenced the time spent on caregiving and the perceived burden of caregivers.

Help from others

How the care needs of the care recipient are fulfilled, depends, among other things, on the social network of the care recipient (Broese van Groenou & De Boer, 2016). The availability of a social network is thus of importance for spreading the burden amongst caregivers, resulting in lower burden. Furthermore, the number of potential caregivers may have changed because of the pandemic (Rodrigues et al., 2021), which could have resulted in changes in burden and quality of life.

Data and methods

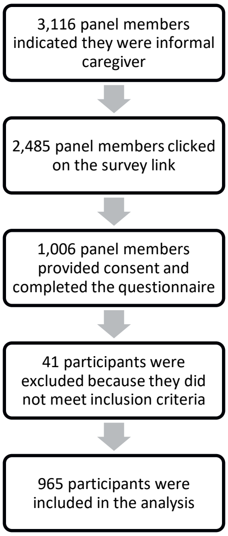
Data sample

We collected data through a questionnaire which we developed based on validated measures (Hoefman et al., 2013). The questionnaire was administered online by a commercial agency with a large panel in The Netherlands. The agency asked members of their panel aged 18 years and older whether they were informal caregiver for someone of 18 years and older for at least three months (although we only included caregivers providing care for more than a month before the start of the pandemic). In this message to panel members, informal care was described as giving help or providing care to someone, for example their partner, a family member or friend, because of a physical, mental or cognitive limitation or the consequences of ageing.

A total of 3,116 members of were invited by the agency to participate in this study. Of them, 2,485 (79,7%) clicked on the link to the survey that was provided in the invitation. After reading the information about the survey, the inclusion criteria, and the informed consent form, 1,006 members of the panel agreed to participate in the survey. After inspection of the data, 41 participants were excluded because they did not meet the inclusion criteria after all; they reported to provide care to a person younger than 18 years or were caregivers for less than four months, meaning they could not assess the situation before the pandemic. This resulted in a final sample for analysis of 965 participants.

Participants were instructed to keep in mind the person they provided care to while filling out the questionnaire. If they provided care to more than one care recipient, they were asked to keep in mind the one for whom the caregiving was most straining. This was done for reasons of feasibility in regards to questions about the socio-demographic characteristics, health and care needs of the care recipient and their relationship. 68.9% of the respondents indicated that they provided care to only one person, 23.3% to two persons and 7.8% to three or more persons. Respondents were not allowed to skip questions in the online questionnaire, therefore, there were no missing data points. Data and STATA code are available upon request.

Figure 1. Participant identification and response



Ethics

Participants were informed about the topic and aims of the study and the data collection and provided informed consent before filling out the questionnaire.

Timing of the survey

The questionnaire was administered between June 2nd and 16th, 2020. At that point, a lockdown to prevent further spread of COVID-19 in the Netherlands had been in place for almost 3 months. People were urged to keep 1.5 meters distance from people that were not in their household, stay at home as much as possible and minimize unnecessary travelling (Dutch Government, 2020). Many formal care providers scaled down their usual care to essential care. Day care facilities were closed and home care was regularly suspended, amongst other things (Dutch Ministry of Health, 2020). In addition, many people declined formal care due to concerns regarding COVID-19 infection and personnel shortage for more urgent care. The Oxford stringency index (Hale et al., 2021), which indices the response of government to the pandemic, had been around 79 throughout April and May, and was 63 during the period of data collection because in the aftermath of the first wave of infections, some measures had been relaxed (Dutch Government, 2020). For example, children under the age of 12 started to be able to go to school or day care again for a few days per week, where before the schools were fully closed. Also, care organizations in regions that did not have many confirmed COVID-19 cases returned to care as usual. In some nursing homes, one designated family member was allowed to visit their family member again, although still under very restricted circumstances.

Outcome variables

We report three main outcome variables: the changes in (1) objective burden and (2) subjective burden between the time of the survey and the situation prior to the COVID-19 measures, and (3) the care-related quality of life of informal caregivers at the time of the survey. Care-related quality of life was not measured retrospectively, because of concerns about the length and complexity of the CarerQol questionnaire. An overview of how all variables were measured and constructed is included in appendix 1.

The objective burden of care was measured as the sum of hours spent on household tasks, personal care, practical support and emotional support in the past week, and during a regular week before the start of the pandemic. The difference between these two values was used in this study.

The subjective burden of care was measured using a self-rated burden scale (Van Exel et al., 2004). That is, participants were presented with a visual analogue scale ranging from 0 to 10 (0 = not straining at all, 10 = much too straining) and asked to indicate how burdensome the caregiving situation was in the past week, and how burdensome it was during a regular week before the start of the pandemic. The difference between the two values was used in this study.

The CarerQol (Brouwer et al., 2006) consists of seven items addressing the potential impacts of caregiving on the quality of life of caregivers, of which two concern positive and five concern negative impacts, with three answering categories each. Using utility weights developed by Hoefman et al. (2014), a care-related quality of life score was computed that ranges from 0 to 100, with 100 defined as the highest possible care-related quality of life and 0 as the worst possible care-related quality of life.

Independent variables

We included characteristics that may be related to changes in objective or subjective burden and to care-related quality of life during the pandemic based on the literature discussed in section 2.2.

The care recipient's health was assessed by the caregiver on scales from 1-10, with worse health indicating a higher need for care. The change in physical and mental health was used to assess whether increasing health problems during the pandemic affected the need. The physical and mental health before the pandemic were used to assess the nature of the pre-existing health condition.

We included the caregiver's dispositional or restrictive characteristics gender, age, highest attained education, financial status (i.e., ability to make ends meet) and physical and mental health (measured in the same way as for the care recipient). In addition, we asked about other responsibilities of the caregiver, including work status, time spent in paid work during and before the pandemic, and childcare responsibilities. Aspects of the caregiving situation included the type of their relationship, the duration of caregiving, whether they shared a household and, if not, the living situation of the care recipient and the travel distance (in minutes) to where the care recipient lives.

The variable "social network" assessed the network of the care recipient, as a resource for sharing or (temporarily) taking over the care and as a source of emotional support. In the survey, we asked the informal caregiver to estimate how many other people the care recipient could ask for help, if needed. We also collected data on formal care use by the care recipient, which may be a substitute for informal care. We do, however, not use these data because most informal caregivers indicated not to know enough about how much and which formal care the care recipient received.

Methods

For objective and subjective burden, we regress the change in these variables between the time of the survey and the situation prior to the pandemic on the care need of the care recipient, the characteristics of the caregiver, and the social network. We do the same for the level of care-related quality-of-life during the pandemic. We use ordinary least squares regressions with standard errors clustered at individual level. To show the possible mediator effects of objective burden and subjective burden, Table 1 in Appendix 2 provides additional analyses. Also, to show the heterogeneity underneath the mean effect of variables on the change in objective and subjective burden, a multinomial logistic regression was performed. These analyses are included in Appendix 2, Table 2 and 3. Results of these analyses are discussed and compared to the analyses in the results in the Appendix. We do not interpret the coefficients as causal effects. Instead, we are interested in the magnitudes and direction of the associations because this helps to understand how the burden and the care-related quality of life changed for caregivers with different characteristics in the first phase of the pandemic.

Results

Descriptive statistics

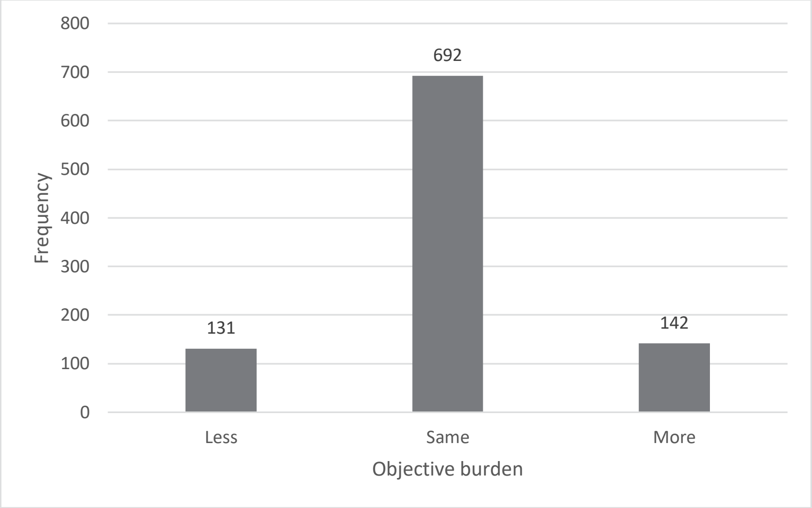
Table 1 presents the descriptive statistics of the three outcome variables and the main characteristics of the sample, which consisted of 965 caregivers.

Table 1: Descriptive statistics

	Before COVID-19 (t=0)		During COVID-19 (t=1)		Change	
	% or Mean	(SD)	% or Mean	(SD)	% or Mean	(SD)
Objective burden						
Number of hours of care	24.79	(27.79)	24.74	(27.53)	0.05	(5.84)
Subjective burden						
Perceived burden of the situation	4.75	(2.45)	5.04	(2.55)	0.30	(1.37)
Care-related quality of life						
CarerQol			76.27	(18.40)		
Care recipient care need						
Psychological health	7.46	(1.97)	6.93	(2.11)	-0.52	(1.41)
Physical health	6.70	(1.84)	6.40	(1.91)	-0.31	(1.30)
Caregiver characteristics						
Woman (=1)			55			
Age			52.20	(15.97)		
Level of education						
Low			18			
Middle			44			
High			38			
Ability to make ends meet						
Very difficult			8			
Somewhat difficult			37			
Somewhat easy			42			
Very easy			13			
Psychological health	7.56	(1.70)	7.35	(1.83)	-0.22	(1.24)
Physical health	7.20	(1.62)	7.03	(1.67)	-0.16	(0.95)
Employment status						
Working			57			
Not working			20			
Retired			24			
Hours employment	18.46	(17.38)	17.19	(17.10)	-1.27	(6.22)
Childcare responsibilities			23			
Relationship to respondent						
Partner			23			
Parent			39			
Other family member			22			
Friends and other			16			
Duration of care			7.27	(7.69)		
Living situation						
With respondent			28			
Other private home			54			
Nursing or care home			18			
Travel distance			19.92	(36.79)		
Social network			2.52	(1.46)		

The mean time spent on caregiving was 24.79 hours per week before the pandemic and 24.74 hours per week during the pandemic. However, the distribution was heavily skewed: the median was 15 hours per week, both before and during the pandemic. The study sample consisted of caregivers who provide rather intensive informal care, compared to of informal caregivers in general. The time spent on care by informal caregivers in a large Dutch sample was 7.4 hours per week, with a median of 3 hours per week (de Boer et al., 2020). 692 out of 965 informal caregivers indicated they experienced no change, and continued to provide the same amount of care despite of the pandemic (figure 2). However, the standard deviation in the changes was 5.84 hours, pointing to considerable heterogeneity.

Figure 2: The hours spent on caregiving during the pandemic, compared to before the pandemic.



The subjective burden was around 4.75 on a scale from 0-10 before the pandemic, and 5.04 during the pandemic. There was a statistically significant ($p<0.05$) increase of 0.30 points in subjective burden. Again, the standard deviation of 1.37 reveals considerable heterogeneity in the changes. In a large sample from the Netherlands, 9.1% of caregivers were heavily burdened (de Boer et al., 2020). If scores of 8 and higher are considered as being heavily burdened, 12.0% of caregivers felt heavily burdened before the pandemic in our sample. During the pandemic, that percentage increased to 17.5%. 601 out of 965 informal caregivers did not experience any change (figure 3).

Figure 3: The subjective burden experienced during the pandemic, compared to before the pandemic.

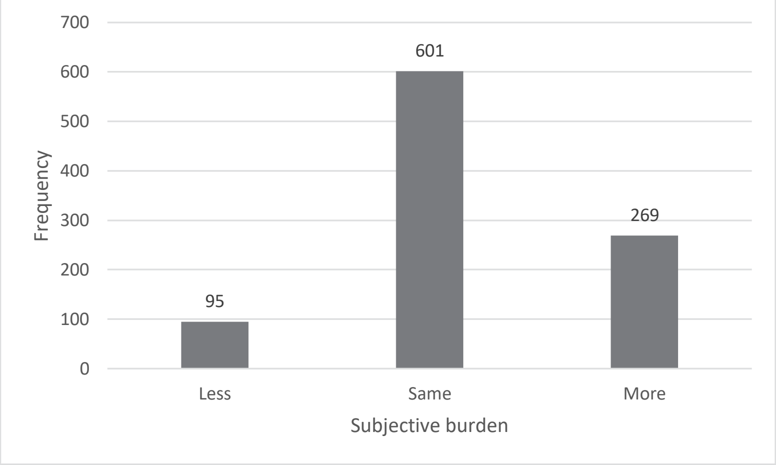
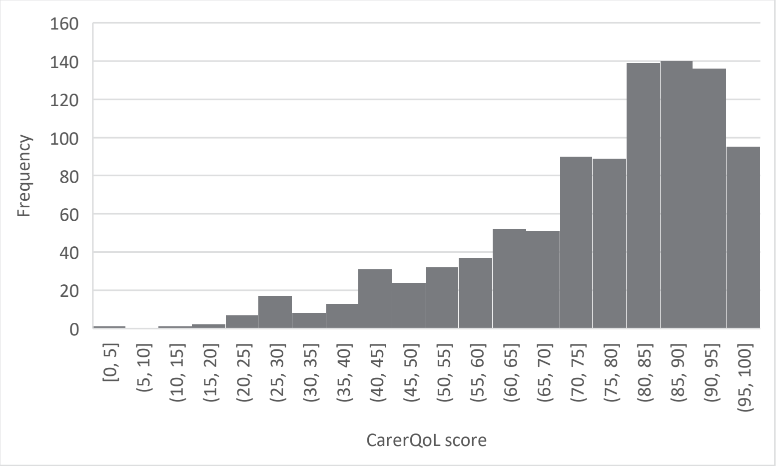


Figure 4: The frequency of CarerQol values during the pandemic. Lowest possible score is 0 and maximum score is 100.



The mean quality of life during the pandemic was 76.27 on a scale from 0-100. However, there is considerable heterogeneity in the group (figure 4).

The changes in objective and subjective burden of care were positively but weakly correlated (0.08). The changes in objective and subjective burden of care were both weakly negatively correlated with CarerQol scores (-0.02 and -0.08). These measures apparently seem to capture different aspects of the impact of informal caregiving.

Regression analyses

In table 2, we report our analyses of the three outcome variables by three groups of characteristics: the care need of the care recipient, dispositional and restrictive characteristics of the caregiver and social network.

Change in objective burden

In terms of care need of the care recipient, a 1-point better mental health of the care recipient before the pandemic was associated with an 18-minute larger increase in caregiving (0.295 hours). Furthermore, the variable living situation was significantly related to changes in objective burden. Caregivers who provided care to someone who lives in an institution reported a larger decrease (-3.108 hours) in the objective burden than the reference category caring for someone living in the same household.

Change in subjective burden

A decrease in physical or mental health of the care recipient during the pandemic was associated with increased subjective burden. Furthermore, caregivers who had difficulty making ends meet reported a larger increase in subjective burden than the reference group, as did women, people with childcare responsibilities and caregivers who were in better physical health before the pandemic. In all cases, the magnitude of the coefficient was small compared to the standard deviation in subjective burden. Furthermore, for caregivers who provided care to someone living in an institution, the change in objective burden was not accompanied by a change in subjective burden. These caregivers did not report a significantly different on quality of life score than caregivers providing care for someone living in the same household. However, the duration of care was positively related to an increase in caregiver burden, even though we controlled for the physical and mental health of the care recipient.

Table 2: The outcomes regressed on the characteristics.

	△ Objective burden		△ Subjective burden		Care-related quality of life (t=1)	
	β	(SE)	β	(SE)	β	(SE)
Care recipient care need						
Psychological health of recipient (t=0)	0.295**	(0.117)	-0.002	(0.027)	0.907***	(0.308)
Δ Psychological health of recipient	0.001	(0.152)	-0.107***	(0.035)	-0.027	(0.401)
Physical health of recipient (t=0)	0.086	(0.126)	-0.016	(0.029)	-0.463	(0.332)
Δ Physical health of recipient	-0.145	(0.166)	-0.178***	(0.038)	-0.316	(0.439)
Caregiver characteristics						
Woman (=1)	0.289	(0.423)	0.319***	(0.096)	-1.482	(1.117)
Age caregiver	-0.012	(0.018)	0.005	(0.004)	0.147***	(0.047)
Education (ref=low)						
Middle	0.182	(0.536)	-0.045	(0.122)	2.941**	(1.414)
High	0.390	(0.575)	0.022	(0.131)	-0.007	(1.518)
Ability to make ends meet (ref=fairly easily)						
With great difficulty	-0.500	(0.790)	0.107	(0.180)	-12.407***	(2.086)
With some difficulty	-0.690	(0.436)	0.232**	(0.099)	-3.226***	(1.151)
Easily	-0.360	(0.596)	0.167	(0.136)	1.427	(1.574)
Psychological health of caregiver (t=0)	-0.000	(0.159)	-0.058	(0.036)	2.435***	(0.420)
Δ Psychological health of caregiver	0.042	(0.178)	-0.136***	(0.040)	1.842***	(0.469)
Physical health of caregiver (t=0)	0.007	(0.160)	0.103***	(0.037)	1.400***	(0.424)
Δ Physical health of caregiver	0.178	(0.227)	0.059	(0.052)	1.887***	(0.598)
Work status (ref=working)						
Not working	-0.890	(0.868)	0.048	(0.198)	-3.218	(2.291)
Retired	-0.920	(0.909)	-0.026	(0.207)	-3.785	(2.401)
Hours employment (t=0)	-0.012	(0.025)	0.002	(0.006)	-0.108*	(0.065)
Δ Hours employment	-0.051	(0.037)	-0.013	(0.009)	-0.100	(0.099)
Childcare responsibilities (t=1)	-0.254	(0.516)	0.211*	(0.118)	-6.298***	(1.362)
Relationship (ref=partner)						
Parent	0.072	(0.725)	-0.038	(0.165)	2.277	(1.915)
Other family member	0.601	(0.751)	-0.094	(0.171)	1.398	(1.982)

Friends and other	0.785	(0.833)	-0.095	(0.190)	3.481	(2.199)
Duration of care	0.038	(0.026)	0.014**	(0.006)	-0.143**	(0.069)
Living situation (ref=in same home)						
Other private home	-1.095	(0.675)	0.189	(0.154)	1.996	(1.782)
An institution	-3.108***	(0.747)	0.153	(0.170)	-1.005	(1.974)
Travel distance	0.001	(0.005)	-0.001	(0.001)	-0.043***	(0.014)
Social network of recipient	-0.060	(0.135)	0.033	(0.031)	1.636***	(0.356)
Constant	-0.666	(1.815)	-0.544	(0.414)	36.994***	(4.793)
Observations	965		965		965	
R-squared	0.055		0.111		0.336	

Quality of life

Care-related quality of life was positively associated with age. A one-year increase in age was associated with 0.15 points increase on care-related quality of life on a scale from 0 to 100. Having a middle level of education also had a positive relationship to quality of life compared to having a low level of education. Furthermore, psychological and physical health state before the pandemic and changes therein were positively related to the quality of life. Finally, respondents reporting some or great difficulty making ends meet indicated a 3.2-point and 12.4-point lower care-related quality of life, respectively, as compared to those who answered "fairly easily". Childcare responsibilities and being retired were related to 6.3-point and 3.8-point lower care-related quality of life, respectively. Furthermore, duration of care and travel distance were negatively associated with care-related quality of life. The mental health of the care recipient before the pandemic was significantly positively associated with the care-related quality of life. Also, for every extra person in the social network of the recipient, the quality of life of the caregiver was 1.6 points higher. Additional analyses (see Appendix 2) furthermore showed that the changes in objective and subjective burden are negatively associated with care-related quality of life

Discussion

In this paper we highlight which groups of caregivers – and indirectly, care recipients – were particularly vulnerable to a public health crisis such as the COVID-19 pandemic and quantified the differences between these groups. Our research contributes to understanding how the changes in circumstances related to changes in informal care burden and quality of life. This information helps tailoring policy to support caregivers to those who need it the most. It also highlights which informal caregivers may be vulnerable for personal crises, which occur on a much smaller scale but a more regular basis. After all, disruptions in the caregiving process, such as changing responsibilities or loss of income, are not unique to the pandemic.

Main findings

We report three main findings. First, on average the time spent on caregiving did not change, while the subjective burden increased slightly. This finding suggests that (1) the subjective burden is also related to other aspects than the time spent on caregiving and that (2) the pandemic was associated with an increase in the subjective burden which cannot be directly linked to an increase in caregiving hours. The change in the subjective burden, however, is rather small. This is in line with findings from Austria that there was no change in the objective burden (Rodrigues et al., 2021), and with studies from Australia, Portugal, the U.S., Argentina, Canada, India, Italy, Japan, Taiwan, Germany, and the U.K. that report an increase of subjective burden (de Sousa et al., 2022; Hofstaetter et al., 2022; Lorenz-Dant & Comas-Herrera, 2021; Truskinovsky et al., 2022). Caregivers experienced not only negative effects, but also positive effects of the pandemic, such as the slower pace (Lightfoot et al., 2021). This could contribute to explaining why the subjective burden changed only slightly during the COVID-19 pandemic.

Secondly, there were considerable differences between subgroups of informal caregivers in the changes in objective and subjective burden and care-related quality of life during the pandemic. The ability to continue providing care during the pandemic depended on the living situation of the care recipient, with larger declines in objective burden among caregivers providing care to someone living in a nursing home. Also, a better mental health of the care recipient before the pandemic was positively related to the change in hours of care provided. In terms of subjective burden, the following caregivers experienced an increase: caregivers having difficulty to make ends meet, women, those with childcare responsibilities, those with better physical health before the pandemic, those who had been caring for a longer period and caregivers who provided care for someone with declining mental and physical health. Similarly, Lorenz-Dant and Comas-Herrera (2021) reported that in countries such as Italy, the UK and Australia the risk of increased burden was greater amongst women, younger caregivers and caregivers with financial difficulties. Additional analyses (see Appendix 2) showed that an increase in objective and subjective burden were related to lower care-related quality of life.

Thirdly, the characteristics related to a change in objective burden were not necessarily the same as for changes in subjective burden or care-related quality of life. Groups of caregivers who increased caregiving during the pandemic did not all report increased subjective burden or a lower quality of life, vice versa. For example, a larger social network does not seem to be related to changes in objective and subjective burden, but is related to higher care-related quality of life. Also, while men and women did not differ on changes in time spent on caregiving, women experienced a larger increase in subjective burden and a lower care-related quality of life. In general, women experienced more negative well-being consequences from the pandemic (Rodrigues et al., 2021), although other research shows that the gender gap in well-being of caregivers may be decreasing (Raiber & Verbakel, 2021). Our results could thus partly be due to a more general negative effect of the pandemic on women. Mechanisms behind this should be studied in future research. Policy aimed at supporting caregivers should account for the different drivers of objective and subjective burden and quality of life between caregivers.

Changes in objective burden, subjective burden and quality of life are thus explained by characteristics of the caregiver, care recipient and their relationship that are also featured in former work (Chappell & Reid, 2002; Pearlin et al., 1990; Yates et al., 1999). In this study, we found that particular characteristics were associated with a change in burden, which could be related to the pandemic (such as the policy of nursing homes, where caregivers were not allowed to provide care as usual), but we cannot confirm this based on our cross-sectional data. In return, increased objective and subjective burden was related to lower care-related quality of life. We do not expect the normal progress of disease over a few months to be the main reason for these findings (Oldenkamp et al., 2016).

Limitations

Because the pandemic was unexpected, no data could be gathered before the pandemic. Therefore, participants were asked to recall their caregiving situation before the start of the pandemic. It is well possible that respondents may not remember all characteristics of this past caregiving situation completely accurately. However, because of the relatively short recall period and a topic that is familiar, relevant and probably central to the lives of respondents, we anticipate that the recall bias is limited. In addition, the effect of this bias is also likely to be random (McPhail and Haines, 2010). Furthermore, the way the questionnaire was administered may have resulted in potential sample selection bias. A comparison of the characteristics of our sample to respondents of the 2019 Informal Care survey of the National Institute of Social Research (de Boer et al., 2020) shows that our sample had similar characteristics with two exceptions: caregivers in our sample have been providing care for more years (7.2 compared to 5.4) and were more likely to provide care to their partner. Lastly, the questionnaire was experienced as long and at some points difficult, which may have led to selective attrition. Future research should take this into account.

Implications

Our findings have implications for policymakers aiming to target caregivers in times of crises and researchers aiming to evaluate the impact of a crisis or policies affecting caregivers. Our study indicates that informal caregivers are not a homogenous group and may experience different consequences from societal or personal crisis situations. Whether caregivers were affected and in what way depended on their gender, income, education, health, childcare responsibilities, duration of caregiving, travel distance to care recipient, needs of the care recipient and the social network of the care recipient. Although our study focuses on a rather extreme crisis situation, namely the COVID-19 pandemic, there are many – and much more frequent – smaller crises over the course of the caregiving process, including those caused by influenza or norovirus outbreaks at nursing homes, unexpected events in competing roles of childcare and work or changes in health and social care provision.

Conclusion

In this paper we found that the objective burden of informal caregivers on average did not change during the COVID-19 pandemic. Caregivers are essential workers and generally sustained their practices. There was only a small increase in subjective burden. However, further analyses showed that there were considerable differences between informal caregivers, and that informal caregivers who changed the amount of time spent on caregiving were not necessarily the same as those who experienced changes in perceived strain. Therefore, the burden of informal caregiving is not unidimensional, and policymakers should tailor support policies to the different needs of caregivers. Finally, some of the disruptions due to the pandemic are also exemplary for smaller personal crises that may occur in the caregiving process. Future studies should look into the implications of such crises, their effects on caregivers, and best policies to support them in maintaining their valuable role.

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Appendix

Appendix 1: Explanation of variables[1]

Variable	Question in survey	Answer categories	Adjusted for use in this paper
Outcome variables			
Objective burden	How many hours did you spend on household tasks in the last week? These are tasks that you do extra because the person to whom you give help cannot do this due to health problems. In the past week, did you provide more or fewer hours of help with household tasks than before the start of the corona crisis? We asked the same questions for 'nursing', 'practical support', and 'emotional support'.	___ number of hours per week ○ I gave about the same amount of hours ○ I gave ___ hours more than before ○ I gave ___ hours less than before	Hours per sub domain were maximized at 18 hours a day, 7 days a week (126 hours). Then, these hours were summed up for during the pandemic (t=1). The change was directly asked. Furthermore, the change was subtracted from or summed up with that amount to calculate the objective burden before the pandemic (t=0). Again, the total was capped at 126 hours. If participants filled out the question so that the hours before the pandemic were less than zero, the value was set to 0.
Subjective burden	How burdensome do you find informal care for the person to whom you are currently providing help? How burdensome did you find the informal care for the person you are providing help to in the month before the start of the corona crisis?	Answers were asked on a scale from 0-10, with 0 being "not burdensome at all" and 10 being "most burdensome imaginable".	The change was calculated by subtracting the score on the first question from the second question.

Care-related quality of life (CarerQol (Brouwer et al., 2006))	I have ___ satisfaction in performing my care duties I have ___ relationship problems with her / him (e.g. she/he is very demanding, has started to behave differently, we have communication problems) I have ___ problems with my own mental health (e.g. stress, anxiety, sadness, worry about the future) I have ___ problems combining my daily activities with my care tasks (e.g. work, study, housekeeping, family and leisure activities) I have ___ financial problems with my care duties I have ___ support (from family/friends/neighbors/acquaintances) in performing my care duties, if necessary I have ___ problems with my own physical health (e.g. more often sick, fatigue, physical overload)	All sub-questions have the same three answer categories: no/somewhat/a lot	Weights provided by Hoefman et al. (2014) were used for the items.
Caregiver characteristics			
Woman	What is your gender?	Man, woman	NA
Age	What is your age?	___ years old	NA
Level of education	What is your highest attained education?	○ LO (lagere school, LAVO, VGLO)[2] ○ LBO (LBO, LTS, ITO, LEAO, Huishoudschool, LLO)[2] ○ MAO (MAVO, IVO, MULO, ULO, 3jr HBS, 3jr VWO, 3jr VHMO)[2] ○ MBO (MTS, UTS, MEAO)[2] ○ HAO (HAVO, VWO, Atheneum, Gymnasium, NMS, HBS, Lyceum)[2] ○ HBO (HTS, HEAO, Wetensch. kand., Univers. onderwijs kand.)[2]	We aggregated education level into three categories. Low: primary education or practical secondary education (the first three categories) Middle: other secondary education or practical

		○ WO (Universitair onderwijs, Doctoraalopleiding, TH)[2]	tertiary education (the third and fourth category) High: other levels of tertiary and further education (the last two categories)
Ability to make ends meet	When you think of your household's total income per month, how well can your household currently make ends meet?	Answer categories: very easy, somewhat easy, somewhat difficult, very difficult.	NA
Psychological health[3]	Indicate on the scale below what your psychological well-being is at the moment. A 0 stands for the worst imaginable psychological well-being and 10 for the best imaginable psychological well-being. Please indicate on the scale below what your psychological well-being was like before the start of the corona crisis. A 0 stands for the worst imaginable psychological well-being and 10 for the best imaginable psychological well-being.	Both from 0-10	The change was calculated by subtracting the score on the first question from the second question.
Physical health[3]	Rate your health at this point. The '0' stands for the worst health you can imagine, the '10' for the best health you can imagine. Before the start of the corona crisis, rate your health. The '0' stands for the worst health you can imagine, the '10' for the best health you can imagine.	Both from 0-10	The change was calculated by subtracting the score on the first question from the second question.
Work status	What is your current work situation? If several options apply (for example, if you are working and studying part-time), select the activity that takes up the most time.	○ Full-time or part-time ○ Retired ○ Unable to work, incapacitated for work ○ Student, high school student ○ Not working, looking for a job ○ Housewife/houseman	Answers were aggregated into three categories. Working: the first answer category Retired: the second answer category

			Not working: all other answer categories
Hours employment	How many hours per week do you currently work? Only count the hours for which you are paid. How many hours per week did you work in a paid job before the start of the corona crisis? Only count the hours for which you were paid.	___ hours	The change was calculated by subtracting the score on the first question from the second question.
Childcare responsibilities	Heeft u thuiswonende kinderen?	○ No Yes, my youngest child's age is ____ years old	Answers were transformed in two categories, where people whose youngest child at home was 18 years or older were counted as 'no childcare repsonsibilities'.
Relationship with care recipient			
Relationship	What is the relationship of the person you are helping with you? She or he is my ...	○ Partner ○ Mother or father ○ Mother-in-law or father-in-law ○ Daughter or son ○ Sister or brother ○ Other family member ○ Friend or acquaintance ○ Neighbor or neighbor ○ Someone else, namely ___	We aggregated relationship in four categories. Partner Parent: including in-law Other family member: all other family members Friends and other: all other categories
Duration of care	How long have you been providing this help? If less than one year, enter 0 for years.	___ years and ___ months	Transformed to years
Living situation	Does the person to whom you provide assistance live in a care or nursing home, an institution for the mentally handicapped or another care institution?	○ No, she/he lives with me ○ No, she/he lives independently (alone or with others) ○ Yes, she/he lives in a care or nursing home	Answers were aggregated into three categories. Same home: only the first answer category

		○ Yes, she/he lives in an institution for the mentally handicapped or another care institution ○ Yes, she/he lives in another healthcare institution ○ Other, namely ___	Other home: only the second answer category Institution: the third up to the fifth answer category 11 participants filled out "other" and were placed in categories based on their answer in the following open question.
Travel distance	How many minutes on average does it take you to get to the person you are helping? Please provide the average time for a one-way trip from your home to her / his home	___ minutes	NA
Care recipient characteristics			
Social network of recipient	If the person you are giving help to needs someone, how many people could she/he ask for? Please do not include yourself	___ people	NA

[1] Translated here from Dutch to English.

[2] Due to the specific Dutch situation, these questions/answers remain untranslated.

[3] These questions were also asked about the care recipient.

Appendix 2: Additional analyses

Additional analyses: extra control variables

We conducted the extra analyses that Referee 1 requested and report these below. In these extra analyses, we include changes in objective burden as a predictor for changes in subjective burden, and levels and changes of objective and subjective burden as predictor for care-related quality of life during COVID-19. For the change in subjective burden, we find a small positive relation between a change in objective burden and a change in subjective burden, while the other coefficients in the model remain largely the same (see table 1 below). For care-related quality of life, the coefficients the sign does not change and the magnitude is very similar compared to the main analysis. In the version with additional control variables, four coefficients are significantly different from zero that were not significant before. Furthermore, we found that the newly added predictors (levels of and changes in objective and subjective burden) are strongly associated with the outcome.

Table 1: OLS regressions with extra control variables

	Analysis with additional controls		Main analysis		Analysis with additional controls		Main analysis	
	(1) Δ Subjective burden		(2) Δ Subjective burden		(3) Care-related quality of life (t=1)		(4) Care-related quality of life (t=1)	
	β	(SE)	β	(SE)	β	(SE)	β	(SE)
Care recipient care need								
Psychological health of recipient (t=0)	-0.007	(0.027)	-0.002	(0.027)	0.358	(0.282)	0.907***	(0.308)
Δ Psychological health of recipient	-0.108***	(0.035)	-0.107***	(0.035)	-0.315	(0.364)	-0.027	(0.401)
Physical health of recipient (t=0)	-0.017	(0.029)	-0.016	(0.029)	-0.665**	(0.300)	-0.463	(0.332)
Δ Physical health of recipient	-0.176***	(0.038)	-0.178***	(0.038)	-0.454	(0.400)	-0.316	(0.439)

Caregiver characteristics								
Woman (=1)	0.314***	(0.096)	0.319***	(0.096)	-0.475	(1.018)	-1.482	(1.117)
Age caregiver	0.005	(0.004)	0.005	(0.004)	0.118***	(0.043)	0.147***	(0.047)
Education (ref=low)								
Middle	-0.049	(0.122)	-0.045	(0.122)	1.593	(1.277)	2.941**	(1.414)
High	0.015	(0.131)	0.022	(0.131)	-0.604	(1.370)	-0.007	(1.518)
Ability to make ends meet (ref=fairly easily)								
With great difficulty	0.116	(0.180)	0.107	(0.180)	-8.393***	(1.909)	-12.407***	(2.086)
With some difficulty	0.244**	(0.099)	0.232**	(0.099)	-1.491	(1.050)	-3.226***	(1.151)
Easily	0.173	(0.136)	0.167	(0.136)	0.271	(1.421)	1.427	(1.574)
Psychological health of caregiver (t=0)	-0.058	(0.036)	-0.058	(0.036)	1.735***	(0.381)	2.435***	(0.420)
Δ Psychological health of caregiver	-0.137***	(0.040)	-0.136***	(0.040)	1.563***	(0.425)	1.842***	(0.469)
Physical health of caregiver (t=0)	0.103***	(0.036)	0.103***	(0.037)	1.541***	(0.383)	1.400***	(0.424)
Δ Physical health of caregiver	0.056	(0.052)	0.059	(0.052)	1.343**	(0.541)	1.887***	(0.598)
Work status (ref=working)								
Not working	0.063	(0.198)	0.048	(0.198)	-3.029	(2.073)	-3.218	(2.291)
Retired	-0.010	(0.207)	-0.026	(0.207)	-1.979	(2.181)	-3.785	(2.401)
Hours employment (t=0)	0.002	(0.006)	0.002	(0.006)	-0.039	(0.059)	-0.108*	(0.065)
Δ Hours employment	-0.012	(0.008)	-0.013	(0.009)	-0.082	(0.089)	-0.100	(0.099)
Childcare responsibilities (t=1)	0.215*	(0.117)	0.211*	(0.118)	-3.831***	(1.240)	-6.298***	(1.362)
Relationship (ref=partner)								
Parent	-0.039	(0.165)	-0.038	(0.165)	1.420	(1.744)	2.277	(1.915)

Other family member	-0.104	(0.171)	-0.094	(0.171)	1.264	(1.794)	1.398	(1.982)
Friends and other	-0.109	(0.190)	-0.095	(0.190)	1.395	(1.995)	3.481	(2.199)
Duration of care	0.013**	(0.006)	0.014**	(0.006)	-0.085	(0.063)	-0.143**	(0.069)
Living situation (ref=in same home)								
Other private home	0.207	(0.154)	0.189	(0.154)	-0.720	(1.640)	1.996	(1.782)
An institution	0.207	(0.172)	0.153	(0.170)	-2.580	(1.817)	-1.005	(1.974)
Travel distance	-0.001	(0.001)	-0.001	(0.001)	-0.030**	(0.013)	-0.043***	(0.014)
Social network of recipient	0.034	(0.031)	0.033	(0.031)	1.455***	(0.322)	1.636***	(0.356)
Extra mediator variables								
Objective burden (t=0)					-0.054***	(0.019)		
Δ Objective burden	0.017**	(0.007)			-0.138*	(0.080)		
Subjective burden (t=0)					-2.846***	(0.208)		
Δ Subjective burden					-2.008***	(0.352)		
Constant	-0.532	(0.413)	-0.544	(0.414)	63.728***	(4.729)	36.994***	(4.793)
Observations	965		965		965		965	
R-squared	0.116		0.111		0.464		0.336	

Additional analyses: multinomial logistic regressions

In the paper we use an ordinary least squares regression. Alternatively, a multinomial logistic regression could be performed for the outcomes of objective and subjective burden. This means that the continuous outcomes were divided into three categories: a negative change in (either objective or subjective) burden, a positive change in (either objective or subjective burden), and no change. The latter category was used as a reference group. For all independent variables the relative risk ratio (RRR) is presented. The RRR represents the predicted risk of falling in this category relative to the risk of falling in the reference category (here: no change in burden) for each one unit increase of the independent variable (see tables 2 and 3 below). A RRR of close to 1 implies no increased risk for one group over the other to experience an increase or a decrease in burden compared to experiencing no change in burden. A RRR of lower than 1 means a reduced risk, a RRR of higher than 1 means an increased risk. These analyses show the heterogeneity behind the average effects of a variable but this comes at the cost of not being able to account for variation in the intensity of the change. For example, the main analysis (column 3 of Table 2) shows that there was no statistically significant difference between women and men in whether they experienced a change in objective burden. The additional analyses (columns 1 and 2 of Table 2) show that women were more likely to experience change in objective burden, while men were more likely to experience no change in objective burden.

Table 2: Multinomial logistic regression with outcome categories less objective burden, more objective burden and same objective burden as before the pandemic. The latter is the reference group.

	Multinomial logit				Main analysis	
	(1) Less objective burden		(2) More objective burden		(3) △ Objective burden	
	RRR	(SE)	RRR	(SE)	β	(SE)
Care recipient care need						
Psychological health of recipient (t=0)	0.820***	(0.053)	1.022	(0.065)	0.295**	(0.117)
Δ Psychological health of recipient	0.703***	(0.060)	0.735***	(0.059)	0.001	(0.152)
Physical health of recipient (t=0)	0.948	(0.066)	1.002	(0.066)	0.086	(0.126)
Δ Physical health of recipient	0.937	(0.085)	0.899	(0.075)	-0.145	(0.166)
Caregiver characteristics						
Woman (=1)	1.602**	(0.383)	1.567**	(0.354)	0.289	(0.423)
Age caregiver	1.014	(0.010)	1.009	(0.010)	-0.012	(0.018)
Education (ref=low)						
Middle	0.982	(0.298)	1.132	(0.332)	0.182	(0.536)
High	1.113	(0.358)	1.524	(0.467)	0.390	(0.575)
Ability to make ends meet (ref=fairly easily)						
With great difficulty	0.637	(0.306)	1.100	(0.429)	-0.500	(0.790)
With some difficulty	0.967	(0.231)	0.853	(0.196)	-0.690	(0.436)
Easily	0.834	(0.287)	0.999	(0.313)	-0.360	(0.596)
Psychological health of caregiver (t=0)	1.022	(0.088)	0.899	(0.073)	-0.000	(0.159)

Δ Psychological health of caregiver	0.907	(0.093)	0.852*	(0.074)	0.042	(0.178)
Physical health of caregiver (t=0)	0.929	(0.081)	0.990	(0.081)	0.007	(0.160)
Δ Physical health of caregiver	0.910	(0.116)	0.885	(0.099)	0.178	(0.227)
Work status (ref=working)						
Not working	1.192	(0.584)	0.858	(0.375)	-0.890	(0.868)
Retired	1.020	(0.520)	0.831	(0.387)	-0.920	(0.909)
Hours employment (t=0)	0.999	(0.014)	0.989	(0.013)	-0.012	(0.025)
Δ Hours employment	0.998	(0.022)	0.961**	(0.017)	-0.051	(0.037)
Childcare responsibilities (t=1)	1.617*	(0.461)	1.276	(0.344)	-0.254	(0.516)
Relationship (ref=partner)						
Parent	1.135	(0.499)	1.039	(0.398)	0.072	(0.725)
Other family member	0.696	(0.320)	0.770	(0.303)	0.601	(0.751)
Friends and other	0.727	(0.353)	0.462*	(0.213)	0.785	(0.833)
Duration of care	1.025*	(0.015)	1.028**	(0.013)	0.038	(0.026)
Living situation (ref=in same home)						
Other private home	2.742**	(1.227)	1.849*	(0.661)	-1.095	(0.675)
An institution	9.328***	(4.210)	2.164*	(0.881)	-3.108***	(0.747)
Travel distance	0.999	(0.003)	0.993	(0.004)	0.001	(0.005)
Social network of recipient	1.021	(0.076)	1.036	(0.073)	-0.060	(0.135)
Constant	0.186	(0.194)	0.131**	(0.126)	-0.666	(1.815)
Observations	965		965		965	

Table 3: Multinomial logistic regression with outcome categories less subjective burden, more subjective burden and same subjective burden as before the pandemic. The latter is the reference group.

	Multinomial logit				Main analysis	
	(1) Less subjective burden		(2) More subjective burden		(3) Δ Subjective burden	
	RRR	(SE)	RRR	(SE)	β	(SE)
Care recipient care need						
Psychological health of recipient (t=0)	1.003	(0.077)	0.990	(0.050)	-0.002	(0.027)
Δ Psychological health of recipient	0.943	(0.087)	0.823***	(0.054)	-0.107***	(0.035)
Physical health of recipient (t=0)	0.994	(0.081)	0.964	(0.052)	-0.016	(0.029)
Δ Physical health of recipient	0.996	(0.101)	0.811***	(0.057)	-0.178***	(0.038)
Caregiver characteristics						
Woman (=1)	0.630*	(0.165)	1.413*	(0.258)	0.319***	(0.096)
Age caregiver	0.969***	(0.010)	0.991	(0.007)	0.005	(0.004)
Education (ref=low)						
Middle	0.903	(0.338)	0.821	(0.192)	-0.045	(0.122)
High	1.537	(0.591)	1.463	(0.356)	0.022	(0.131)
Ability to make ends meet (ref=fairly easily)						
With great difficulty	1.034	(0.494)	1.827*	(0.592)	0.107	(0.180)
With some difficulty	0.788	(0.220)	1.331	(0.247)	0.232**	(0.099)
Easily	1.384	(0.510)	1.238	(0.324)	0.167	(0.136)

Psychological health of caregiver (t=0)	0.885	(0.086)	0.834***	(0.056)	-0.058	(0.036)
Δ Psychological health of caregiver	0.964	(0.105)	0.802***	(0.060)	-0.136***	(0.040)
Physical health of caregiver (t=0)	0.962	(0.097)	1.153**	(0.080)	0.103***	(0.037)
Δ Physical health of caregiver	0.875	(0.113)	1.020	(0.098)	0.059	(0.052)
Work status (ref=working)						
Not working	1.248	(0.674)	1.676	(0.600)	0.048	(0.198)
Retired	0.708	(0.434)	0.976	(0.381)	-0.026	(0.207)
Hours employment (t=0)	0.986	(0.015)	1.009	(0.010)	0.002	(0.006)
Δ Hours employment	1.001	(0.022)	1.006	(0.015)	-0.013	(0.009)
Childcare responsibilities (t=1)	1.874**	(0.536)	1.584**	(0.331)	0.211*	(0.118)
Relationship (ref=partner)						
Parent	1.011	(0.461)	1.030	(0.319)	-0.038	(0.165)
Other family member	1.409	(0.667)	1.186	(0.379)	-0.094	(0.171)
Friends and other	0.902	(0.478)	1.014	(0.363)	-0.095	(0.190)
Duration of care	0.951**	(0.022)	1.003	(0.011)	0.014**	(0.006)
Living situation (ref=in same home)						
Other private home	0.813	(0.333)	1.060	(0.302)	0.189	(0.154)
An institution	1.989	(0.862)	1.917**	(0.599)	0.153	(0.170)
Travel distance	1.004	(0.003)	1.001	(0.002)	-0.001	(0.001)
Social network of recipient	0.974	(0.085)	1.065	(0.061)	0.033	(0.031)
Constant	2.346	(2.514)	0.438	(0.339)	-0.544	(0.414)
Observations	965		965		965	

CHAPTER

3

The relationship between municipal support and burden of informal care provision: evidence from The Netherlands

Abstract

Municipalities in the Netherlands have been assigned with the task to stimulate and support informal caregiving to keep long-term care provision sustainable. So far, there is a lack of insight in whether and how informal care support of governments is related informal care outcomes. Therefore, this aim of study was to investigate how informal care support is related to the intensity of informal care provision and the perceived burden of informal care. We use cross-sectional data from 8649 caregivers to regress informal care intensity and perceived burden on whether they receive support and several characteristics of informal caregivers and their situation to study the association between support and outcomes. We highlight two main findings. First, informal care support was related to providing more hours of informal care and a higher caregiver burden, even when controlled for the need of the care recipient, but not to being heavily burdened. Second, we find that objective burden, subjective burden and being heavily burdened is related to characteristics of the caregiver, the needs of the recipient and the caregiving context, which is in line with the literature. Thus, support services are mostly used by caregivers who provide more hours of care and experience a higher burden, but not necessarily the subgroup that are overburdened. Our findings may help policy makers to target the available resources for support to the subgroups of caregivers who need it most.

Introduction

Municipalities in the Netherlands have been assigned with the task to stimulate and support informal caregiving to keep long-term care provision sustainable. Informal care is the unpaid care provided by those with a pre-existing relationship to the care recipient and is an important source of care for many people in need of long-term care (Genet, Boerma, Kroneman, Hutchinson, & Saltman, 2013). Since 2009, municipalities have become increasingly involved in supporting informal caregivers, and after the last wave of decentralization of social care in 2015, municipalities have become responsible for stimulating informal caregiving to reduce the use of formal health and social care services. Municipalities can support informal caregivers by offering services that aim to reduce the negative impact of providing care (e.g., peer support groups, information and advice, and respite care) and can try to stimulate informal caregiving by being more restrictive or selective in providing formal care services that could also be provided by people close to the person who needs these services.

Following the last wave of decentralization of social care, policies to support and stimulate informal caregiving have started to diverge between municipalities (Marangos, Waverijn, de Klerk, Iedema, & Groenewegen, 2018). So far, it is unknown how these differences have affected informal care provision and the outcomes for informal caregivers across municipalities. More specifically, there is a lack of insight in how and whether informal care support of governments affect informal caregivers (Courtin, Jemiai, & Mossialos, 2014). Therefore, in this paper, we use data from the Informal Care Monitor of The Netherlands Institute for Social Research (SCP) to investigate how informal care support provided by municipalities relate to the provision of informal care and impact on the perceived burden of informal caregivers.

Municipalities want to learn how they can adapt their informal care policies to the characteristics of their population (Vermeij et al., 2021) and better support informal caregivers within their municipality (e.g. Smith & Vlemmings, 2018). Demographic developments differ considerably between regions in the Netherlands, resulting in different gaps between demand and supply of informal care (De Jong & Kooiker, 2018). This calls for different policies across municipalities, tailored to the specific characteristics, needs and possibilities of their population. Therefore, in this study, we take into account the individual characteristics of informal caregivers to identify which informal caregivers are more heavily burdened and control for these characteristics when exploring how municipal support is related to the burden of local informal caregivers. By looking at the characteristics of both caregivers and support policies between municipalities we gain more insight into the potential origins of differences in outcomes for informal caregivers.

Although municipalities have become pivotal in support and stimulation policies for informal care, the effects of decentralization in this context are understudied. Prior studies focusing on the role of municipalities show that they do not seem to be effective in stimulating informal care (Marangos et al., 2018; Waverijn, Groenewegen, & de Klerk, 2017). Marangos et al. (2018) studied whether recipients of formal care by municipalities received more or less informal care depending on the local policy focus on informal care. They found that an emphasis on increasing the share of informal care in local policy did not lead to more informal care provision. Furthermore, although research shows that there are local differences in the use of social services (Pommer, Boelhouwer, Eggink, Marangos, & Ooms, 2018), the availability of services that support caregivers does not seem to be related to increased involvement of the community in providing care (Waverijn et al., 2017). The ‘social capital’ (Putnam, 2000) of a municipality, operationalized as contact between neighbours, is expected to increase informal care practices. However, this social capital is not higher in municipalities that offer more respite care, individual services and support for those in need and collective service and amenities. Waverijn et al. (2017) also measured collective efficacy, operationalized as the responsibility one feels for the liveability of their neighbourhood, blood donation, charity and voter turnout. They found that only in rural municipalities the interaction between social capital and collective efficacy is related to more informal care support services.

These studies mainly focused on whether informal care is received or provided, but not on how much care is provided and the impact of providing informal care on caregivers. Therefore, this aim of study was to investigate how informal care support is related to the intensity of informal care provision and the perceived burden of informal care. Insight into such effects is important because municipal support may have a role in mitigating the negative effects of caregiving.

Known determinants of informal care intensity

Several factors have been shown to influence informal care provision and the perceived burden of caregiving (Broese van Groenou & De Boer, 2016; Pearlin, Mullan, Semple, & Skaff, 1990).

We first discuss factors related to the intensity of informal care provision. Whether and to what extent someone takes up the role of informal caregiver seems to depend on four factors: the demand for care, the norms and ideas about who should care, the willingness to provide care and the ability to provide care (Broese van Groenou & De Boer, 2016).

First, the demand for care determines how many hours of care informal caregivers provide (Broese van Groenou & de Boer, 2016). Here, demand is determined by the need, stemming from a health-related issue. In return, the availability of formal care (van Exel, de Graaf, & Brouwer, 2008) and other informal caregivers (Keating, Otfinowski, Wenger, Fast, & Derksen, 2003) can decrease the intensity of caregiving because of substitution effects (Bonsang, 2009; Pickard, 2012).

Second, norms about who should care may influence to what extent someone takes on the role of caregiver. For example, people may become caregiver because they feel it is the responsibility of the family of those in need of care to do so (De Klerk, de Boer & Plaisier, 2021), because they feel needed (Oudijk, Woittiez & De Boer, 2011) or obliged (De Boer, Plaisier & De Klerk, 2019; Del-Pino-Casado, Frías-Osuna, & Palomino-Moral, 2011) to provide care, or because they derive utility from providing care (Brouwer et al., 2005; Al-Janabi et al., 2010). Municipalities can set norms for informal care provision, increasing the pressure on citizens to provide care (Verbakel, 2014). Such norms have been shown to differ across municipalities because of differences in political and religious affiliation and socio-cultural backgrounds (Diederich, Helmut, & Christian, 2022; Verbakel, Tamlagsrønning, Winstone, Fjær, & Eikemo, 2017; Wittenberg, de Boer, de Klerk, Verhoeff, & Kwekkeboom, 2021).

Third, the willingness to provide care influences informal care intensity. Attitudes towards caregiving, affection towards the care recipient, and perceived abilities make up the willingness to care (Broese van Groenou & De Boer, 2016). Willingness to care can be modelled as a function of demographic and socioeconomic characteristics, such as age, gender, education and income (Bertogg & Strauss, 2020; Cook, Snellings, & Cohen, 2018; De Klerk, De Boer, & Plaisier, 2021). Furthermore, when someone is providing care, the relationship to the care recipient and the living situation of the care recipient are important factors in determining the intensity of care (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Bom, Bakx, Schut, & van Doorslaer, 2019; De Boer, Plaisier, & De Klerk, 2019; de Klerk et al., 2021). Informal care support, like offering training, may influence the willingness to care by increasing the feeling of competence of caregivers.

Lastly, the ability to provide care needs to be considered. The health of potential informal caregivers themselves can make providing care more difficult or even impossible (Cook et al., 2018; Kooiker & De Klerk, 2015). Furthermore, working more hours (Bom & Stöckel, 2021; de Klerk et al., 2021; Oldenkamp et al., 2018), having children (de Klerk et al., 2021), living at a distance (Kooiker & De Klerk, 2015; Tolkacheva, Van Groenou & Van Tilburg, 2010) or other time constraints decrease the ability to provide care. In addition, there may be financial or practical constraints, such as having no transportation. Although some of these constraints are difficult to alleviate by municipalities, for example because they are in the domain of the employers of caregivers, policies such as free public transport or parking and relaxing rules around social benefits could possibly help ease some of the constraints (e.g. Bos & Elshout, 2023).

Known determinants of informal care burden

The perceived impact of informal caregiving is related to the intensity of the caregiving task, but also to other characteristics (Pearlin et al., 1990). Although characteristics largely overlap with the determinants of intensity of care (e.g., gender, age, health), their relationships to informal care burden tend to differ (Gräler, Bremmers, Bakx, Van Exel & Van Bochove, 2022). These characteristics may also require different interventions by the municipality to mitigate informal care burden, for example based on the characteristics of the caregiver and the caregiving context (Pinquart & Sörensen, 2003; De Boer, Plaisier & De Klerk, 2019; Adelman et al., 2014). Characteristics often mentioned include demographic and socioeconomic characteristics of caregivers, the relationship and history with the care recipient, or the time that the caregiver has been providing care. This background than feeds into how the provision of care is perceived. Second, the dependencies and difficulties that are posed by the frailty of the care recipient influence perceived burden (De Klerk, De Boer, Plaisier, & Schyns, 2017). For example, people who care for someone with dementia, psychological problems or a terminal illness are more heavily burdened than others (De Klerk et al., 2017). Third, conflicting other roles (e.g., childcare responsibilities) can cause additional stress (Bom & Stöckel, 2021; De Boer, Plaisier & De Klerk, 2019; Kohler et al., 2022; Adelman et al., 2014). Lastly, the perceived burden of informal caregiving can be mitigated by coping and social support (Pearlin et al., 1990). Municipalities can thus have an important role by providing training, information, advice and (peer) support to informal caregivers, either in generic form for all informal caregivers or targeted specifically at specific groups experiencing significant burden. Also, research shows that knowing there are resources available may already help informal caregivers feel supported (Wagner & Brandt, 2018).

Data and methods

Data collection

For this study we used the SCP Informal Care Monitor that includes 27,153 respondents, of which 612 were excluded here because they were younger than 18 years. The data set consisted of cross-sectional data from 2014, 2016 and 2019. Informal caregivers were identified by the following question:

> *The following questions are about providing help to acquaintances with health problems. Think of your partner, family member, friend or neighbour who needs help because of physical, psychological, intellectual disabilities or old age. Examples are doing housework, washing and dressing, keeping company, transport or chores. Help in the context of your profession or voluntary work does not count.*
> *Have you given this kind of help in the past 12 months?*

Based on this question, 9,569 participants self-identified as informal caregivers. Of them, 68 participants were excluded because they provided care for less than one month, provided less than 1 hour of care per week, answered ‘don’t know’ on questions such as for whom they provided care, were helping someone in a professional capacity, or helped someone with problems not related to their health (e.g., language problems). 852 participants were excluded because they had missing values for one or more variables included in the analysis. We checked, and the results remained largely robust when we excluded these participants. This left us with a final sample of 8649 informal caregivers for the analysis. Weights to make the sample representative for the general population of the Netherlands are provided by Statistics Netherlands, because women, people who are married, 55-64 year-olds, people with high income and people in rural areas are overrepresented in the sample. Data was gathered and handled according to the guidelines of the Dutch Data Protection Authority.

Outcome variables

For a comprehensive overview of the impact of informal caregiving, we use three outcome variables (Hoefman, Van Exel & Brouwer, 2013; Van Exel et al., 2004): (1) number of hours of care provided per week (i.e., objective burden), (2) burden experienced from caregiving (i.e., subjective burden), and (3) being heavily burdened (i.e., significant burden). The intensity of caregiving was measured by asking participants to report the number of hours spent on providing care per week. For 526 informal caregivers we imputed the number of hours spent on providing care by using means of subsamples. The total number of hours was cut-off at 112 hours per week, which corresponds to 16 hours a day on average, assuming that caregivers also need to time to sleep, shower and eat (Hoefman, Van Exel & Brouwer, 2013). Second, the perceived burden was calculated by using a measure of experienced informal care pressure, an adapted version of the EDIZ-plus (De Boer et al., 2012) that is based on the validated EDIZ-plus questionnaire. The adapted version consists of 10 questions (see Appendix 1) that aim to capture the subjective burden of caregiving through multiple dimensions. The scores on this scale run from 0 to 10, where 0 corresponds to no burden and 10 to a very high burden. Third, we constructed a binary outcome variable for significant burden by classifying participants reporting a score between 6 and 10 on the adapted EDIZ-plus as being heavily burdened (De Klerk et al., 2017). Table 1 shows the descriptive statistics of the outcome variables.

Table 1: descriptive statistics of the outcome variables

	N	**Mean**	**SD**	**Median**	**Min.**	**Max.**
Objective burden (hours of care per week)	8649	7.03	12.97	3.00	1	112
Subjective burden (EDIZ) on scale 0-10	8649	1.85	2.24	1.00	0	10
Heavily burdened (yes=1)	8649	0.09				

Variable of interest

We are interested in the extent to which municipal support is related to caregiving outcomes. The support variable was constructed based on a question that asks which forms of informal care support caregivers received. The options were: information and advice, training, support groups, material help (e.g. free parking), financial help, help with requesting arrangements, other. As percentages of specific types of support were very low (see Appendix 2), we clustered these options and created a binary variable to indicate whether or not someone receives support.

For 132 caregivers that did not answer this question, we imputed the values following a logistic multiple imputations method. After imputing the missing values, an estimated proportion of 22.7% of the informal caregivers in our sample received some form of informal care support.

Individual determinants

To account for the individual determinants of informal care outcomes, we used several independent variables included in the survey. Table 2 shows the descriptive statistics for these variables.

First, we included the following variables representing the characteristics of informal caregivers: gender[1], age in categories, having a non-western migration background, level of education (low, mid, high), income (in quartiles), hours spent in paid work (0, 1-11, 12-31 and 32+ hours per week), having problems with activities of daily living (no, some or strong) and household composition in three categories (living alone, with other people, with a child). Furthermore, we included 3 binary variables about norms and background: going to church monthly, norms about family care, working or worked in the past in the care sector. For the variable about family care norms, we constructed a binary variable, where 1 represents those people answering affirmative (agree or strongly agree) to the statement: Family members should provide care for those with health problems.

Second, for the caregiving situation, we included variables about the care relationship and the care recipient. To account for the needs of the care recipient we included four aspects: need for surveillance, aggression by care recipient, care recipient asks a lot of attention, and to what extent is the care recipient incontinent. Also, we included the type of condition of the care recipient. Furthermore, we included variables about other care that was received by care recipients: does a client also receive care from other informal caregivers, from publicly arranged formal care or from privately paid caregivers. If the client lived in a nursing home, we coded this as ‘No’ automatically because these questions were not asked. Lastly, we included the relationship to the care recipient (in 6 categories), the living situation of the care recipient (in a care home or not) and travel time to the care recipient in minutes.

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[1] We are aware that gender is not binary. However, in this questionnaire only the options “man” or “woman” were provided. Because informal caregiving is a gendered experience, we did include this variable even though it does not fully capture all identities and sexes.

Table 2: Unweighted summary statistics of the independent variables

		Informal caregivers (N=9,501)
CHARACTERISTICS PARTICIPANT		
Gender	*Woman*	5,026 (58.1%)
Age	*18- 34*	1227 (14.2%)
	35- 44	1038 (12.0%)
	45- 54	2025 (23.4%)
	55- 64	2167 (25.1%)
	65- 74	1525 (17.6%)
	>74	667 (7.7%)
Non-western background	*Yes*	656 (7.6%)
Education	*Low*	2432 (28.1%)
	Middle	2961 (34.2%)
	High	3256 (37.6%)
Net household income	*1st quartile*	1817 (21.0%)
	2nd quartile	2110 (24.4%)
	3rd quartile	2241 (25.9%)
	4th quartile	2481 (28.7%)
Hours in paid work	*0*	2874 (33.2%)
	1-11	573 (6.6%)
	12-31	2039 (23.6%)

		Informal caregivers (N=9,501)
	>31	3163 (36.6%)
Problems with ADL	*Non*	6401 (74.0%)
	Somewhat	1488 (17.2%)
	A lot	760 (8.8%)
Household composition	*Living alone*	1315 (15.2%)
	Living with partner, without children<18	5080 (58.7%)
	Living with partner, with children<18	2254 (26.1%)
NORMS AND ATTITUDES PARTICIPANT		
Monthly church visitor	*Yes*	1635 (18.9%)
Norm that family should provide care	*Yes*	5511 (63.7%)
Work(ed) in care sector	*Yes*	2720 (31.4%)
CARE NEEDS RECIPIENT		
Care recipient is unable to be alone	*Yes*	1457 (16.8%)
Care recipient is incontinent	*Yes*	1518 (17.6%)
Care recipient asks a lot of attention	*Yes*	2696 (31.2%)
Care recipient is aggressive	*Yes*	1211 (14.0%)
Type of condition of care recipient	*Somatic*	4378 (50.6%)
	Terminal	548 (6.3%)
	Dementia	1199 (13.9%)
	Psychological/social	1512 (17.5%)

		Informal caregivers (N=9,501)
	Intellectual disability	317 (3.7%)
	Old age/other	695 (8.0%)
SHARING CARE WITH…		
Other informal caregivers	*Yes*	65.8%*
Privately paid formal care	*Yes*	13.0%*
Publicly paid formal home care	*Yes*	24.4%*
CARE CONTEXT		
Relationship to caregiver	*Partner*	1277 (14.8%)
	Parent	3790 (43.8%)
	Child	1099 (12.7%)
	Other family	935 (10.8%)
	Other	1548 (17.9%)
Care recipient lives in care home	*Yes*	1332 (15.4%)
Travel distance in minutes	*0-15*	4248 (49.1%)
	16-30	1399 (16.2%)
	>30	1224 (14.2%)
	Same home as care recipient	1778 (20.6%)
Intensity of care in hours per week	*1-8*	7028 (81.3%)
	9-16	863 (10.0%)
	17-24	281 (3.2%)

		Informal caregivers (N=9,501)
	25-112	477 (5.5%)
CONTROL VARIABLE		
Year	*2014*	2455 (28.4%)
	2016	2292 (26.5%)
	2019	3902 (45.1%)

*The multiple imputation method provides estimated proportions. The standard errors of the proportion that shares care with other informal caregivers, privately paid formal care and publicly paid formal home care are respectively: 0.5, 0.4 and 0.5.

We controlled in all models for the year in which the survey was held to account for time specific effects. Furthermore, we controlled for the total number of informal care provision per week in 4 categories (1-8 hours, 9-16 hours, 17-24 hours, 25-112 hours) in the models with the outcomes subjective burden and being heavily burdened.

For some variables we missed data for some participants. For the variables about whether there are other informal caregivers, publicly paid care, or privately paid care, the question was not asked in 2014 to informal caregivers living in the same home as the caregiver. Furthermore, there were 8 informal caregivers providing care for someone living independently who also did not fill out these questions. We imputed values for these 474 missing observations in the same way we imputed values for the support variable. The estimations were robust, because if we excluded these missing observations or the variables, they remained largely the same.

Analyses

We used ordinary least-squares regression models to assess the relationship between received municipal support and the three caregiving outcomes: the number of hours spent on informal care, the subjective burden from caregiving and whether the informal caregiver was heavily burdened. In all models, the above discussed variables are included, and sample weights are used.

Results

Table 3 shows the results of the regression analyses.

We find that several characteristics are related to the three caregiving outcomes, and that these relations generally differ between the outcomes. Receiving informal care support was significantly and positively related to two of the caregiving outcomes: caregivers who received support provided more hours of care and experienced higher burden of caregiving.

Various characteristics were significantly related to objective burden. Intensity of care was related to the following characteristics of the informal care provider: gender, age, net household income, hours in paid work and household composition. Moreover, intensity of care was related to going to church, the relationship to the care recipient, the recipient being terminally ill and to the amount of received public formal care, but not to other forms of additional care.

Furthermore, caregivers who received support spent, on average, almost one and a half hours more on caregiving per week than caregivers who did not receive municipal support.

For subjective burden, controlling for the number of hours of care provided, we found that, characteristics such as being a woman or having experience with working in care significantly related to the perceived burden. Moreover, the needs of the care recipient, whether there are other informal and formal caregivers involved and several aspects of the context of the caregiving situation were related to perceived burden. Lastly, caregivers who received municipal support experienced almost 0.3 points higher subjective burden (on a scale from 1 to 10).

Lastly, whether an informal caregiver felt heavily burdened was related to characteristics of the caregiver, the need of the care recipient, whether other informal caregivers were involved and several aspects of the caregiving situation. Being heavily burdened was not statistically significantly related to receiving municipal support.

Table 3: The regression results of the relationship between characteristics of the participant, norms, care needs, sharing care, care context, informal care support and outcomes.

		Objective burden*	**Subjective burden***	**Heavily burdened***
CHARACTERISTICS PARTICIPANT				
Gender	*Woman*	0.864**	0.470***	0.041***
Age (ref=18-34)	*35-44*	0.853	0.280**	0.037**
	45-54	1.443***	0.050	0.003
	55-64	1.704***	-0.034	0.005
	65-74	1.355*	-0.131	-0.006
	75+	3.191**	-0.119	-0.012
Non-western background	*Yes*	0.907	0.297*	0.014
Education (ref=Low)	*Middle*	0.025	0.139*	0.012
	High	-0.179	0.185**	0.025**
Net household income (ref=<18889)	*2nd quartile*	-0.592	-0.088	-0.025**
	3rd quartile	-1.169**	-0.060	-0.005
	4th quartile	-1.302**	-0.079	-0.007
Hours in paid work (ref=0)	*1-11*	-2.160***	-0.007	0.016
	12-31	-2.232***	0.140	0.009
	32+	-2.420***	0.183*	0.022

		Objective burden*	Subjective burden*	Heavily burdened*
Problems with ADL (ref=none)	*Some*	-0.488	0.384***	0.039***
	A lot	0.087	0.888***	0.100***
Household composition (ref=Alone)	*Multiple without a child<18*	-1.488***	-0.030	-0.004
	Multiple with a child<18	-1.444***	0.076	0.007
NORMS AND ATTITUDES PARTICIPANT				
Monthly church visitor	*Yes*	-0.742*	-0.037	-0.011
Norm that family should provide care	*Yes*	-0.003	-0.003	-0.002
Work(ed) in care	*Yes*	0.111	-0.085	-0.009
CARE NEEDS RECIPIENT				
Care recipient is unable to be alone	*Yes*	4.986***	0.236**	0.017
Care recipient is incontinent	*Yes*	0.646	0.232**	-0.001
Care recipient asks a lot of attention	*Yes*	2.723***	1.094***	0.095***
Care recipient is aggressive	*Yes*	0.778	0.681***	0.089***
Type of condition (ref=Somatic)	*Terminal*	2.030***	0.538***	0.024
	Dementia	-0.034	0.252***	0.029**
	Psychological/social	0.091	0.671***	0.058***
	Intellectual disability	0.667	-0.384**	-0.062**
	Old age/other	-0.292	-0.105	0.002
SHARING CARE WITH…				
Other informal caregivers	*Yes*	0.000	-0.271***	-0.031**

		Objective burden*	Subjective burden*	Heavily burdened*
Privately paid formal care	*Yes*	-0.295	0.058	0.011
Publicly paid formal home care	*Yes*	0.671	0.183**	0.010
CARE CONTEXT				
Relationship to caregiver (ref=Partner)	*Parent*	-3.748***	-0.409**	-0.011
	Child	-3.351**	-0.109	0.018
	Other family	-4.298***	-1.064***	-0.051*
	Other	-5.418***	-1.159***	-0.058**
Care recipient lives in care home	*Yes*	-1.905**	-0.341***	-0.037*
Travel distance in minutes (ref=0-15)	*16-30*	-0.406	0.058	-0.006
	>30	-0.405	0.127	-0.006
	Same home as care recipient	8.586***	0.159	0.016
Hours of care provided per week (ref=1-8)	*9-16*		1.230***	0.116***
	17-24		1.242***	0.132***
	25-112		1.507***	0.176***
MUNICIPAL SUPPORT				
Caregiver received municipal support	*Yes*	1.462***	0.271***	0.017
Constant		8.331***	1.031***	-0.002
N		8649	8649	8649

*Models are weighted and controlled for year of observation (2014, 2016 and 2019)

Discussion

Main findings

This study investigated how informal care support related to the provision and impact of informal care. We highlight two different outcomes.

First, informal care support seems related to providing more hours of informal care and a higher caregiver burden, but not to being heavily burdened. Almost 25% of the informal caregivers in our sample received some form of support. This group is most likely not random, as the receipt of support probably is related to the intensity and burden of care. The finding that caregivers who receive informal care support are not more likely to be heavily burdened (or vice versa) could be due to the definition used, the low proportion of this group of caregivers, or municipalities targeting informal caregivers that are providing more care and are more burdened but not necessarily reaching those experiencing significant burden. In any case, this finding is in line with earlier research that finds that municipalities aim to provide easily accessible support for all caregivers, but do not reach informal caregivers in an earlier stage (Van der Ham et al., 2018). Informal caregivers may only be seeking help when facing a high care load or high burden. The association of higher objective and subjective burden with receiving support could be due to factors that are not controlled for (enough) in the current analysis, such as a more continuous measure of several aspects of care need of the care recipient (Lindt, Van Berkel & Mulder, 2020) or wear-and-tear effects (Townsend et al., 1989).

Second, we find that objective burden, subjective burden and being heavily burdened is related to characteristics of the caregiver, the needs of the recipient (as taken up in this study) and the caregiving context, which is in line with the literature (e.g. Pearlin et al., 1990; Broese-Van Groenou & De Boer, 2015). However, the different outcomes are related to different characteristics, which was also reported in other studies (e.g. Gräler et al., 2022; Brouwer et al., 2004). Furthermore, in line with literature that shows that religiosity is related to providing care (e.g. Verbakel et al., 2017; De Klerk et al., 2021), we found that going was related to the number of hours providing care. Although literature shows that the norm that family should care are relatively strong in the Netherlands (Wittenberg, De Boer, De Klerk, Verhoeff, & Kwekkeboom, 2021), we did not find this norm to be related to any of the outcomes. Sharing care with other informal caregivers was related to a lower subjective burden and being heavily burdened, but not to objective burden. This confirms that social support affects the mental well-being of informal caregivers (De Maria et al., 2020). Lastly, sharing care with formal caregivers was positively related to objective and subjective burden, which is in line with the literature (e.g., Bonsang, 2009; Pickard, 2012).

Limitations

We highlight two limitations that could have affected the outcomes of this research. First, we did not distinguish between types of support arrangements that were used by informal caregivers because percentages of users for each arrangement were fairly low. Future research should take a more intricate look into specific support services to gain a better understanding of how municipalities support informal caregivers, who they support and whether it helps alleviating the burden of caregiving. Second, we did not investigate causal relationships. This means that we could not determine whether making use of support services led to higher burden or whether caregivers with higher burden more often made use of support services. Although the latter mechanism seems more obvious, there are also signs that coordinating and collaborating with formal care providers may be a source of burden in itself (Heerings et al., 2022). A causal design would provide more insight in the direction of the studied relationship.

Implications

The findings of this study can help policy makers to think about the effects of support and target the available resources better. Informal care support is more often received by caregivers who report a high subjective burden and provide more care. Informal care support includes arrangements such as free parking, discounts on municipal services, or help with requesting entitlements to such arrangements. These arrangements are arguably also useful for caregivers that are not heavily burdened and may alleviate some of their burden of caregiving as well.

Conclusion

We find that support services are mostly used by caregivers who provide more hours of care and experience a higher burden, but not necessarily the subgroup experiencing significant burden. Our findings may help policy makers to target the available resources for support to the subgroups of caregivers who need it most.

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Appendix

Appendix 1: Adjusted EDIZ questionnaire

Now, some statements about how you experience/have experienced providing care will follow. Can you indicate for each statement to what extent you agree or disagree?

1. Because of the help I give/gave, I have do/did my work or other activities less carefully than I am used to.
2. It takes/took me more effort than usual to manage my household.
3. Because of the help I give/gave, I am/was too tired to do anything in my spare time.
4. I became sick or overworked because I give/gave help.
5. I feel/felt very pressured overall by the help I give/gave.
6. The help for the one I take/took care of, falls/fell too much on my shoulders.
7. I have/had felt that I always have/had to be there for the one I help/helped.
8. My involvement with the person I care/cared for, causes/caused conflict at home or at work.
9. The situation of the one I help/helped, never lets me go.
10. Giving help has made my health worse.

Answer categories to all questions are: totally agree, agree, not agree nor disagree, disagree, totally disagree, and don’t know.

Appendix 2: Frequencies of types of informal care support that is received by informal caregivers (without imputations)

	N	%
Information and advice	1,231	14.45
Courses and training	129	1.51
Support groups	253	2.97
Material help	197	2.31
Financial help	237	2.78
Help with procedures and application for help	291	3.42
Other	106	1.23

CHAPTER

4

The micropolitics of (re)negotiating professional and informal care in the changing welfare state

This chapter was published as:

Gräler, L., Van de Bovenkamp, H., Felder, M. (forthcoming). Micropolitics at the intersection of formal and informal care. In T. Klenk, M. Noordegraaf, E. Notarnicola, K. Vrangbaek (Eds.), The societal value of welfare politics, policies and services. Palgrave Macmillan.

Abstract

There is an increasing reliance on informal caregivers in the organization and provision of care services for older people. The convoys of care model, that assumes that networks around care recipients are dynamic and negotiated, offers a way to study the interactions between professional and informal caregivers when they are both involved. However, little attention is given to how they actually negotiate their roles, the institutional challenges they face when redistributing responsibilities, and the consequences of these negotiations and challenges for the care provided. To capture this, we ask the question: *how can we understand the micropolitics between professionals and informal caregivers in their shared attempts to organize care?* Based on qualitative research in four organizations, we highlight different aspects of negotiations between informal caregivers and professionals. We also show the consequences of this, namely that individual healthcare trajectories are becoming more situated and negotiated accomplishments. There seems to be scant critical reflection on this. This reflection is needed to prevent inequality and support professionals in these negotiations. This requires organizations and policymakers to broaden their understanding of inclusion of informal care from merely instrumental to political and effortful, and take serious how it interacts with various processes and societal outcomes.

Introduction

Sustainable care for older people is high on the policy agenda in many countries dealing with aging populations (Pavolini & Ranci, 2008). Informal caregivers are increasingly expected to play an important role in this context by providing care and support (Newman & Tonkens, 2011). With informal care we refer to care (usually unpaid) provided by someone who has a pre-existing relationship with the care recipient.

The rationale behind emphasizing informal care is twofold. First, it cuts costs and mitigates workforce shortages because informal caregivers take over tasks from professionals (e.g., Pickard, 2012; Bonsang, 2009). Second, involving family members can contribute to personalized care (McCormack & McCance, 2016). The literature, however, also points out that informal care is not a magic bullet. Informal caregivers can become overburdened (Lindt, Van Berkel & Mulder, 2020), combining formal and informal care can lead to fragmentation (Kemp et al., 2018; van Wieringen et al., 2015) and informal caregivers' priorities may clash with those of professionals or policymakers (Burgess et al., 2022; Hunter, Ward & Puurveen, 2023; Wittenberg et al., 2018).

The literature pays only scant attention to the effort required to make the relationship between informal and professional care work in everyday healthcare provision. Kemp et al. (2013) argue that this is because professional and informal care are often mistakenly treated as separate domains, seen in terms of substituting and complementing, rather than as overlapping spheres. The overlapping properties become clear when, for example, informal caregivers take over professional work (Ward-Griffin & Marshall, 2003; Chase et al., 2020). Kemp and co-authors further question the dominant framing of professional and informal care and their respective roles as static and predetermined. Instead, they developed the "convoys of care model," which emphasizes the interdependent, networked character of personal relationships that are everchanging and influenced by their institutional context. This means that as care trajectories proceed, and circumstances and relationships change, care must be constantly (re)organized and (re)coordinated to fit in. Care is thus a constant (re)negotiation between actors about their roles, tasks and responsibilities, with consequences for the distribution of resources and burden of care. To uncover the mechanisms underpinning distribution, we conceptualize the negotiations in convoys of care in terms of micropolitics.

Micropolitics in this context refers to the day-to-day interactions between (in this case) professionals and informal carers that determine who does what, when, how and for whom. We argue that these interactions are political because they are about negotiating care and carer roles and bridging differences and, importantly, because they can lead to different outcomes. Previous studies have, for instance, indicated that certain patients and patient groups are better able to mobilize economic and social networks of support while others are more vulnerable to failing networks of support and consequently exposed to neglect (Espina & Narruhn, 2021; Gengler, 2014; Butler, 2004, 2015) or overburdening (Gräler et al., 2022). This perspective reveals new interdependencies between these actors that may well help some but not others to continue securing timely access to good quality care.

To foreground the mechanisms through which professionals and organizations allocate care in their everyday practices and through which the burden of care is distributed between informal caregivers and professionals, we examine the following question: *how can we understand the micropolitics between professionals and informal caregivers in their (shared) attempts to organize care?* Our aim is to advance the debate about the growing reliance on informal caregivers and the consequences this has for professionals, informal caregivers and clients in terms of the division of the burden of care and the outcomes of care trajectories.

In this chapter, we first show how the convoys of care model can help us understand relationships between actors. We then look at the negotiations between actors through the lens of micropolitics. In the method section, we examine the context of our research and the interviews we conducted. The results section considers how convoys of care are mobilized, i.e. how they flesh out and reify care, by focusing on the everyday practices of informal caregivers, professionals and managers in the context of existing policies and norms. Finally, we discuss the implications of our results for policy and practice.

Micropolitics in convoys of care

To understand the micropolitics between professionals and informal caregivers, we need to understand how they are related. Caring for the same care recipient makes professionals and informal caregivers part of the same care network (Kemp et al., 2013). The members of this network can change over time as relationships within them change or fade (e.g. Keating & Eales, 2017), and as professionals enter or leave the network based on formal arrangements. Maintaining continuity in care therefore requires the actors involved to work on (re)build (new) relationships (e.g. Duggleby et al., 2022; Keating & Eales, 2017), pass on information to other actors or adjust care processes and communication when the network changes. To account for this, and to emphasize the labor the networks involve to produce care, we use the convoys of care model, which underscores the way networks move throughout time, with actors negotiating their way of being in the network (Kemp et al., 2013).

The convoys of care model builds on work of Kahn and Antonucci (1980) regarding social relationships. Their basic idea is that people are members of networks of close relationships that move and change throughout time. Within these networks, coined "convoys," individuals provide and receive help. Kemp et al. (2013) extend this convoy model to include professional caregivers, in other words relationships that are not necessarily personal and close. They define convoys of care as "the evolving collection of individuals who may or may not have close personal connections to the recipient or to one another, but who provide care, including help with activities of daily living (ADLs) and instrumental activities of daily living (IADLs), socio-emotional care, skilled health care, monitoring, and advocacy" (Kemp et al., 2013, p. 18). Within convoys, actors put in effort to coordinate and align care. The convoys of care model thus portrays the collective, evolving and conveying character of the social networks to which caregivers and care recipients belong.

Within convoys of care, the roles of and relationship between professionals and informal caregivers are negotiated rather than predetermined, because formal care and informal care are interrelated and interdependent. These negotiations are ongoing and part of everyday practices (Kemp et al., 2022). This means that the care provided is a product of relationships and interactions within the convoy. For example, how convoy members work together, or against one another, has consequences for the care recipient's ability to age in place (Kemp et al., 2018), and for the values adhered to (Burgess et al., 2022). The work put into the relationship between the actors, such as professionals and informal caregivers, partly determines who gets what care.

Scarce resources such as time and effort are clearly distributed within convoys of care along with burdens, but few researchers have addressed the "how" question. The political dimensions of such negotiations have been particularly neglected but merit a closer look, since – as noted by Burgess et al. (2022, p. 608): "[w]hen priorities failed to align, power relations were inherent in the process of 'negotiating priorities' and among the most influential factors determining how priorities were worked out, including in quality dilemmas." It is also important to highlight this political dimension because new mechanisms of exclusion and inequality have remained invisible, along with the effort and skills required to distribute resources and burdens and resist demands (Gengler, 2014; Gilliom, 2001).

We turn to micropolitics for a deeper understanding of the negotiations in convoys of care. Such negotiations are attempts by formal and informal healthcare actors to organize the "best" care possible while negotiating what such care should entail and their own roles in this process. Micropolitics in this sense refers to the dynamics through which healthcare and support are established and points to strategies through which roles are determined in relation to one another and care trajectories become organized (Bévort & Suddaby, 2016; Gilliom, 2001). It is important to consider this because it can have consequences for the quality of and access to care (Gengler, 2014; Butler & Spivak, 2007; Butler, 2004).

The role of micropolitics in the organization and provision of care in the welfare state has been shown to be pivotal. How resources are distributed in the workplace has been the subject of growing interest (e.g., Georges, 2008; Cloyes, 2010; Espina & Narruhn, 2021). Bhatia (2020), for example, shows that street-level bureaucrats used their discretion to refuse refugees appropriate medical care to which they were legally entitled because of widespread distrust in their motives for seeking care. Sue et al. (2007) show that when certain patients gain access to services, professionals engage in microaggressions to discriminate against them. At the same time, scholars have largely neglected the work of professionals in creating workarounds to deal with inappropriate rules and allocate care that they deem appropriate (Hope, 2003). Micropolitics is also apparent in resistance (e.g., Scott, 1985; Gilliom, 2001). Gilliom (2001) shows how poor disenfranchised women offer microresistance to rules governing their social benefits by covertly babysitting for extra income.

All this shows that, alongside professionals and street-level bureaucrats, clients and informal caregivers also actively practice micropolitics. For example, clients engage in impression management to gain access to services (Oldenhof & Linthorst, 2022), and build good relationships with professionals to manage their vulnerability and dependency (Sutton et al., 2023). Some are better able to do so than others. Gengler (2014) shows that this could be due to structural inequalities in capital. She finds that some parents of children with complex conditions were able to gain microadvantages by capitalizing on their cultural and social capital. It is along these lines that power distributions become apparent, showing that the system serves those who have larger networks and greater knowledge and authority, or even those who are generally more likeable or less demanding (Gengler, 2014; Oldenhof & Linthorst, 2022; Sutton et al., 2023).

Even so, the literature on the organization of care networks has yet to pay explicit attention to the politics of organizing care. The convoys model appears to offer a productive metaphor showing that care is negotiated and requires relational work, but the politics involved remain unpacked. We combine these strands to deepen our understanding of the political dimension in convoys of care. We focus on those areas where micropolitics becomes visible in order to gain a clearer understanding of the interdependencies and relationality in care provision and of the consequences not just for clients (as commonly covered in the studies mentioned above) but also for informal caregivers and professionals. We show how micropolitics serves as a vehicle for negotiating work and responsibilities and for creating advantages and disadvantages in everyday practices. We provide the language needed to study the dynamics at play and the consequences for all actors involved.

Context of our study case: Nursing homes in the Netherlands

We use the context of nursing homes in the Netherlands to study the micropolitics in the relationship between informal caregivers and professionals. We briefly explain this context and the role of informal caregivers in Dutch nursing homes below.

The emphasis on informal care has been increasing in the Netherlands since the 1970s (van der Lyke, 2000) and has been accompanied by a shift from intramural to home care. Today, nursing homes are largely available only for people who need 24-hour care (Verbeek-Oudijk et al., 2014). Nursing home care is paid by the national government, with residents charged an income-dependent (but still relatively low) co-payment. Unlike many southern European countries (Casanova et al., 2017), it is rare in the Netherlands for paid informal caregivers to brought in from abroad.

Although the focus on informal caregivers traditionally comes from the home care sector, where informal care helps prevent nursing home admissions and reduce the number of visits by home care professionals, it has also gained traction in the nursing home sector (van Groenou, 2010). This used to be called “family participation” and was aimed at maintaining the client’s network for quality-of-life reasons. Increasingly, however, informal caregivers are regarded as a means of mitigating shortages caused by stringent budgets and the declining workforce potential (Wetenschappelijke Raad voor Regeringsbeleid, 2021).

Methods

For this study, we conducted 48 interviews in five organizations operating multiple nursing homes, chosen for their geographically dispersed locations. We also analyzed documents describing each organization's informal care policy (in the making) (n=10) and took observational notes in one of these organizations (7 hours). We interviewed three managers/staff (all from the same organization), three clients, 22 informal caregivers (a client's close family members or a partner) and 20 professionals (mostly nurses and nursing aides involved in direct client care). All participants gave their informed consent and the study was approved by the ethical board of Erasmus School of Health Policy & Management (reference: 21-028).

The interviews were conducted in 2020 and 2021, the same period in which the organizations provided us with their informal care policy. The observations were conducted in 2022. At the time of the interviews and observations, the COVID pandemic had impacted processes in care organizations and research practices and this had several implications for our research. First, some interviews were conducted by phone or online and some in-person. Second, the pandemic was also discussed during the interviews. Boundaries between informal caregivers and professionals became more explicit during the pandemic, for example because rules variably did or did not allow family members to visit their loved one in a nursing home.

We asked the organizations involved to send us their informal care policy. The various documents they submitted showed that these policies were in varying stages of development. Other documents they submitted were an infographic, talk forms, a flyer and an evaluation of the COVID pandemic. We focused mainly on informal care policies: how the documents positioned informal caregivers in the organization and how they treated seemingly disparate values, such as unburdening the informal caregiver while also wanting them to take on a larger role.

We coded the data for our analysis abductively, moving back and forth between policy documents and interviews as well as between the literature and the data. Informed by the literature on care convoys and micropolitics, we were particularly interested in dissecting the practices and processes through which roles were determined in relation to one another and care trajectories became organized, zooming in specifically on divisions of labor/responsibilities, negotiated priorities, and the institutional context that informed such negotiations and was simultaneously (re)constituted through them.

Some of the interview excerpts and notes in the results section have been lightly edited for readability. Some details of no direct relevance to our analysis have also been changed to ensure the respondent's privacy.

Results

We found micropolitics becoming manifest in three ways: (1) in mobilizing actors in the convoy, (2) in weighing values of caregiving, and (3) in following, bending or ignoring organizational rules and regulations. These manifestations had consequences for how care trajectories were established and reestablished and for the roles and responsibilities of the formal and informal caregivers involved. Moreover, they had consequences for the values adhered to, for who had a say, but also for who was burdened. In the following we elaborate on the three manifestations of care convoys.

Mobilizing the convoy

Although the literature does not elaborate on how convoys of care become a vehicle of care, we find that in practice, this already requires effort on the part of actors. In care provided by both professionals and informal caregivers, the actors in the care convoys were actively involved in (1) including others while (2) negotiating boundaries. Below, we delve more deeply into these actions.

Including others

Contrary to policy assumptions, we saw that including informal caregivers did not always unburden professionals. On the contrary, mobilizing and dealing with informal caregivers and other professionals sometimes took a lot of effort on their part. This becomes clear in our interview with Esther, who saw that some informal caregivers had trouble attending appointments because they could only be scheduled on days when the physician was present and during office hours, thus discounting the fact that informal caregivers often also worked then. Esther therefore proposed accommodating informal caregivers by scheduling meetings with them outside her working hours.

> *Esther: "But of course, a lot of informal caregivers work, so the question has also been a few times, can you not plan it in the evening? But that's almost impossible for us right now. Because, for example, as a care coordinator I only work during the day and the doctors only work during the day. ...So yeah, that's just not possible right now. ...So, I've raised the issue on behalf of informal caregivers…who can't be there during the day. [We could then offer an alternative:] 'If you want, I can schedule a meeting in the evening, but not with all disciplines involved.'"*

In Esther's case, mobilizing actors meant her sometimes working overtime to accommodate informal caregivers. This shows that including informal caregivers changed the work of professionals and required adjustments in routines. And it was not just professionals who included others. Informal caregiver Jeanette, whose husband has a muscular degenerative condition, arranged a whole system of volunteers to help feed her husband.

> *Jeanette: "And then sometimes there's an argument [between others in the common living room], or something, and then it's not easy to eat there, because he chokes more easily. So now we have a few volunteers who feed him every week on Thursday evening. In his own room, a hot meal. So that makes a big difference to him. …They're actually all friends who do that. So not volunteers, because they're all friends."*

Both informal caregivers and professionals can therefore arrange to include others in the convoy, but this depends largely on certain individuals' actions. Although including others may well divide the burden over more people, and consequently reduce the burden for some, the act of inclusion can itself be an extra burden.

Negotiating boundaries

The actors in the convoy negotiated tasks and responsibilities. This often went almost unnoticed: for a professional to ask an informal caregiver to buy a new bottle of shampoo felt quite natural, according to informal caregivers. However, such agreement did not always come naturally. Informal caregivers and professionals also made an effort to erect boundaries defining their involvement and how they wanted the other to be involved. For example, although informal caregivers were often invited to get involved in all kinds of capacities, they often did not want to take on activities such as showering, dressing or taking someone to the toilet. As Lorna, a professional, explained:

> *"And I also always say to them: if you're used to helping your relative with this or that, with getting dressed or something, with showering or something, be my guest. You know, do it! We'd even be happy. But you notice in the first instance, it's often 'no thank you.' And then it's like: 'well, it's going really well, now you've taken over. Let me just drink that cup of coffee, I'll make sure the room is in order, I'll take care of the clothes and I'll take my family member out somewhere, it's fine like that.'"*

This shows that informal caregivers erect boundaries defining their involvement when their loved one moves to a nursing home. Interestingly, we saw that their efforts to set boundaries were not always successful. Informal caregivers were sometimes unwillingly included in certain aspects of care, such as clipping nails. One family complained that their close involvement meant they were taking on tasks that the professionals did for other clients. Whether informal caregivers were able to resist the demands placed upon them differed from one situation and relationship to another.

Professionals also negotiated the informal caregivers' boundaries. They restricted their role for various reasons, such as conflicting views, quality-of-care concerns or to unburden them. For example, Alexandra, a long-time nurse in a small dementia facility, said that she had an informal caregiver on her ward who was there almost all the time to take care of his wife. However, he also meddled with other clients.

> *Alexandra: "He was taking over a lot; he thought, at a certain point – we had quite a number of fairly young staff members here – and he thought he had to protect them from a resident who could be quite aggressive. And [the staff and I] thought that staff didn't actually get the opportunity to build their own relationship with that man, the [aggressive] client ...and be able to change it, because this [other] man always jumped in. So I talked to him and it was kind of awkward because he actually had good intentions, to protect us, but as professionals, we felt we could handle it."*

As exemplified here, professionals tried to protect their role and reestablish boundaries within their relationship with informal caregivers. In Alexandra's case, she and her colleagues referred to their professionalism in putting up boundaries for an informal caregiver. Negotiation of boundaries was omnipresent in the interviews and policy documents. One organization even talked about a fundamental shift in their policy, which flipped the boundaries and roles completely: *"In the future, the family will not participate in care, but care workers will participate in the customer's social network."*

Informal caregivers also actively took over tasks from professionals because they felt the latter's work fell short of their own quality standards or because of the professionals' time constraints. Joanne, for example, still put her mother to bed every night. She mentioned still wanting to do something for her mother, but also the professionals' time pressure.

> *Joanne: "Well first of all, I always put my mom to bed every night. So, I take plenty of time for that, because those girls…have to put ten residents to bed in the evening and yes, you know that's quite time-consuming and I can just put my mother to bed there myself taking my time. She's a woman who loves beautiful things so her face needs to be cleaned nicely with face milk and a night cream needs to be applied and she often suffers from itching, so then I moisturize her whole body. And those girls don't always have time for that and I don't blame them and that's why I'm glad I get to do it."*

In this example, the professionals did not contest the newly negotiated roles, but this was not always the case. We saw some informal caregivers sidelining professionals by going directly to the manager in a conflict. One negotiating strategy was thus to circumvent some actors and actively include others. For example, Amy, an informal caregiver for her mother, who had diabetes and other conditions, did not agree with the diet the nurse specialist had put her mother on. She went over the head of the nurse specialist and requested a geriatrician, who agreed with her. By going to the geriatrician, Amy excluded the nurse specialist from having a say in her mother's diet. As she put it:

> *"Yes, they're really good, [they] look at everything she eats to see if she's eating well and swallows well… But of course, that wasn't what we as a family, along with my mother-in-law, put first."*

As Amy's case illustrates, just as professionals fell back on their professionalism, informal caregivers referred to their know-how and protected boundaries to delineate their expert status.

Informal caregivers thus played an active role in dividing tasks and responsibilities, even when this entailed taking tasks and responsibilities away from someone and negotiating boundaries.

Interestingly, the negotiation of boundaries of involvement went beyond that of informal caregivers and professionals. Both actors also negotiated boundaries for the client's involvement, for example because of the latter's reduced abilities. Such negotiations can therefore have consequences for the involvement and potential burdens of all actors.

Weighing values

Negotiations between informal caregivers and professionals concerning inclusion or exclusion and boundaries reveal tensions regarding what quality of care entails, what priorities should be set and how quality comes about. Differing ideas about quality of care, priorities in care, and the underlying values caused friction and were at the heart of the negotiations in the convoy. Informal caregivers and professionals had to figure out together what good care constituted for a specific care recipient: what is beneficial and what is important? How are scarce resources such as time and attention divided between people and tasks? We found that these questions became more prominent when informal caregivers were included because while the two sides did not always see eye-to-eye, they were increasingly dependent on each other. This is complex terrain for professionals and informal caregivers to navigate. Below we describe two ways in which values were weighed and negotiated: (1) negotiating the definition of care when actors have differing ideas about it, and (2) surveilling the other.

Defining what the object of care should be

Informal caregivers might define care differently than professionals. They often referred to living conditions and treatment of belongings as critical aspects of care and attempted to negotiate with professionals about them. Sandra, for example, found that the medical focus, which involved using ointment, interfered with an aspect she also found important, namely the cleanliness of her husband's clothing.

> *Sandra: "Then they dress him, he has ointment on his leg from the wound treatment, and wearing the same glove they smear it all over everything, and then they grab and tidy his closet, and then there are stains, …Then I think: would you do the same at home? I find that all very strange. And that's what I say in such a conversation. And then it goes well for a while, and then it creeps back in again."*

After a short period of adjustment, new practices often slowly regressed to former practices. It appeared that the professionals only enacted the understanding of care advanced by informal caregivers locally and temporarily, and sometimes only symbolically, sticking largely to their own priorities. Informal caregivers thus felt they had to constantly renegotiate through complaints and conversations. Sometimes professionals experienced the informal caregivers' frustrations as burdensome, as nitpicking. Professionals also referred to their time constraints. We found that they tried to enact as many values as possible but were simply not able to do everything as agreed. Petra, a professional, explicitly referred to this when negotiating with informal caregivers.

> *Petra: "And I also sometimes have to tackle certain appointments differently, for example because there's absenteeism at that time. If two call in sick in the morning, my schedule changes. And I try to explain that and nine times out of ten people understand. I'll do what we agreed, only it will be a little later or a little earlier. And if it really doesn't work out, nine times out of ten people understand."*

Sometimes, however, informal caregivers did not understand. In rare cases, this led to professionals fearing informal caregivers and potential outbursts. Professionals adhered to the wishes of these informal caregivers for the most part, although it was sometimes mere window dressing. As Gwyneth, a professional, explained:

> *"Then you saw him cycling in and everyone flew into action. [They checked] that her hair was straight, that she was wearing an apron... I just think that's going too far. With everyone was running around before he came in."*

This type of negotiation, or rather avoiding negotiation, was in evidence not just among professionals. Clients and informal caregivers also feared saying anything to professionals, or actively did or avoided things to preserve a good relationship, such as being strategic in their criticisms. In return, a good relationship could also lead to advantages, such as extra practical or emotional support.

These cases reveal a high level of interdependence between the actors. We found that actors had different strategies for dealing with this in negotiating the definition of care, and that these strategies had different outcomes and depended largely on the situation.

Surveilling the other

Beside pushing for a different definition of care, professionals and informal caregivers also surveilled the other party to defend their own definition. We saw informal caregivers checking the work of professionals, for example by counting the number of underpants in the laundry basket. They also surveilled them more overtly. Sandra, for example, saw that professionals did not adhere to new protocols around urinals. Sandra confronted the professionals with her findings and demanded a change in their routines.

> *"First you had glass or plastic urinals, and [client] wears a bag, a urine drainage bag. It has to be emptied several times a day. Before, the urinal was emptied into the toilet, flushed, and simply reused. At a certain point, a new system with a grinder was introduced. ...There are cardboard urinals, and they are disposable and are deposited with pee and all into the grinder, which is diagonally opposite in such a room. In the beginning it went well, no problem, into the grinder. But then things started to slide. The urinal ends up in the bathtub, it's emptied into the toilet, and they put it on the laundry basket or on the radiator. ...So when you open that door, the smell hits you. That's what happens. ...It smells awful. So I had a conversation a few weeks back, I said, you have to change that. ...I find it downright filthy. You smell it as soon as you enter. ...You see issues everywhere. I replied: you've completely missed the point. Her mouth dropped open and she said: you're right."*

Here, the conflict is between routines and values. Sandra uses materialities, such as urinals, smells, laundry baskets and radiators, to surveil and oppose the routines of the care professionals.

Professionals explained how new mechanisms of transparency, and opportunities for surveillance, can also undermine the care process and the relationship with informal caregivers. For example, electronic patient files have become accessible to informal caregivers. Whereas before, these files were a means of communication between professionals and provided documentation for accountability processes, they have now also become a channel of communication with informal caregivers. These goals may not always be compatible, however.

Professional standards may require documenting an impactful argument with an informal caregiver, but that caregiver can also read the account. One professional explained that she did not write such things down anymore for that reason and tried to find workarounds instead.

Surveillance mechanisms therefore influenced the work of professionals and were very much part of the repertoire of negotiation strategies wielded by informal caregivers. However, while some were hypervigilant, others explained they trusted the professionals' judgment and how they prioritized tasks and attention.

Working the rules

The negotiations between professionals and informal caregivers took place in the very particular organizational context of the nursing home. In this highly institutionalized context, rules, protocols and informal norms influence practices. One informal norm can arise from the ideas about professionalism discussed earlier, but there were other contextual aspects that influenced the negotiations between professionals and informal caregivers in various ways. How actors dealt with the rules differed across situations and relationships. We saw that informal caregivers and professionals (1) worked around the rules, bent them or even defied them, while (2) also using the rules to claim legitimacy.

Working around, bending and defying rules

When the rules did not match the wishes of informal caregivers and their inclusion, they sometimes worked around, bent or defied them. The work this required was not always successful, however. For example, the rules set by his mother's nursing home limited the help Tom could provide.

> *Tom: "My mother's ward is pretty demanding and the residents need a lot of care. And there are a lot of people in wheelchairs who need to be taken to the toilet. But there's a doorsill between the bedroom and the bathroom that people pushing the wheelchair have to overcome. This is hard work for the staff. There should be a small threshold ramp. And I told them that and said I would order one and install a trial version. ...But they want to do it through the technical service, and it takes a long time... we've already emailed about it three times."*

The rules impeded the role Tom wanted to play in his mother's care. Although he was able to arrange a threshold ramp for his own mother, he wanted to do the same for other clients. To his regret, he was unsuccessful. This shows that some rules can burden professionals, informal caregivers, clients and organizations and can prevent informal caregivers from assuming the role that organizations would like them to have.

Nevertheless, Tom's case also shows that he was successful in installing a threshold ramp for his own mother. The rules were therefore broken situationally. Another example is the case of an informal caregiver who came every day to help out. He really helped the professionals, Esther said, because his wife was less restless. He would also take other clients for a walk. Although he always came around lunchtime, he was not allowed to eat with his wife because the budget was strictly for clients. Esther, however, encouraged her team to turn a blind eye, because she felt it was inane to refuse him a sandwich. But she did not always take this position.

> From notes: *"In the past, the organization's rule was that informal caregivers were not allowed to eat with clients. Now there is the unwritten rule that staff offers them food, because sometimes family members would immediately check the cupboards for leftovers if they forgot to have lunch... Esther does not think that is right. It costs residents more money, she says. There is a certain budget and orders have to be placed from it. For dinner, the food is always ordered in advance, so there is little leeway for family to join in. Ordering for family is not allowed."*

Actors negotiated how to apply rules. Because those rules were sometimes contradictory, professionals had to weigh them and the associated values. The choices made depended on the actors involved, their relationship and the situation. How rules were applied was thus somewhat arbitrary. On the one hand, this led to conflicts within teams of professionals and between professionals and informal caregivers. On the other, it enabled personalized care and facilitated the relationship between professionals and informal caregivers, because rules that hampered that relationship were defied.

Using the rules

While professionals and informal caregivers tried to circumvent the rules in some cases, in others they used the rules to legitimize action/inaction and boundaries, making them part of the negotiations. For example, Jolene, informal caregiver for her mother-in-law, was very active in the nursing home. For several years she had used the key to a fire escape door to gain easier access to her mother-in-law's apartment. One day, however, an intern saw her use it and became suspicious.

> *Jolene: "She came back with a head nurse and said: 'Ma'am , you can't use [that key] because you aren't allowed [to use that door].' I said, 'But I have a key for it. Why can't I use it if I've been given the key?' 'Well, because of the fire department rules.' Well, I said, 'You know, it's okay, I'm not going to argue then. You do what you do, you do your job.' ...Out of curiosity, my husband and I went to the corridor [from the other side] the next day, but there's a sign there saying 'No entry, for employees only.' That would mean we couldn't visit his mother, because it clearly says 'No entry.' Well, we said to each other, we'll just use that key. And no one has ever said anything about it."*

Here, the fire department rules are used to explain why this informal caregiver cannot use a particular door. Jolene felt like an unwanted visitor, and the professionals found her too demanding. She felt that the conversation was not just about the key but about her involvement in the nursing home in general, which the professionals were trying to limit. This shows that rules can be used to legitimize boundaries, and that an informal caregiver can also resist the demands placed on them and defy the rules. Informal caregivers can also use rules to legitimize their stance, however. Sandra, for example, referenced the "system" of new urinals to get the professionals to adhere to her values. She referred to the protocol and work routine governing the use of carboard urinals to substantiate her claim about the smell and legitimize her criticism.

Discussion

At first glance, including informal caregivers appears to align seamlessly with the values of participation and cost-efficiency. If we look more closely at practices, interactions and relationships, however, we see tensions between protecting the rights of clients and informal caregivers, the sustainability of care beyond that extended to a single client, and citizen involvement (Jørgensen & Bozeman, 2007). Welfare states are becoming more provisional places, and timely, person-centered, individual healthcare trajectories have developed into situated and negotiated accomplishments rather than *a priori* and bureaucratically established entitlements (Butler, 2015). Some actors are better able to get things done than others, which can give rise to inequalities (Gengler, 2014). Moreover, this inequality is invisible because those on the short end of the stick are usually those who do not have the network and resources needed to sway situations their way.

This prompts questions about what the consequences of forgoing these tensions will be. These are questions such as: how do we ensure that some clients, informal caregivers and professionals are not snowed under while others gain advantages at their expense? How do we balance the interests of all the actors in and beyond the network? And what policy framework and organizational culture does that require? That is why we need to view the discourse around including informal caregivers and the increasing relationality of care through a political lens. This study did so by examining the following question: *how can we understand the micropolitics between professionals and informal caregivers in their (shared) attempts to organize care and the consequences this has for professionals, informal caregivers and clients?*

We found that this micropolitics consisted of negotiations about who is involved, who gets to define care and how rules are applied. First of all, care was negotiated by mobilizing other actors in the convoy of care, which required effort on the part of both informal caregivers and professionals. The distribution of workload in terms of task content and distribution was highly situational. Moreover, informal and formal caregivers actively negotiated the boundaries of what was included in their role as expert and excluded from the role of the other, limiting opportunities for others to participate in the care process. As our empirical examples have shown, how professionals and informal caregivers negotiate inclusion, responsibilities and boundaries depends on their persistence, likeability, perceived usefulness, perceived constraints and other factors.

When workforce shortages force us to rely more on informal caregivers, the relational and process-driven dimensions of the care convoy become increasingly important. There are, for example, consequences for professionals because they must continuously renegotiate their professional status (Noordegraaf, 2020). What is exclusively a task for professionals or explicitly not part of their work is negotiated in everyday practices. At the same time, dealing professionally with informal caregivers is becoming a more important aspect of the nursing profession. The relational dimension of professionalism therefore merits more serious attention in nurses' and nurses aides' training (Noordegraaf, 2020).

Informal caregivers also must be skilled in dealing with professionals to effectively have a voice. Some found it easier and were better able than others to voice their concerns and needs. This corresponds with the characterizations of Gengler (2014), who saw some parents of sick children "care-captaining" (i.e., taking control) and others "care-entrusting" (i.e., trusting professionals to take control). She found that care-captaining parents were those who knew the system, had a relevant social network or could communicate effectively, allowing them to gain microadvantages in the care process. Our study, however, shows that the process of establishing negotiations between professionals and informal caregivers is fragile and requires ongoing work, as they often lead only to local, and sometimes temporary, adjustments.

A last point is that, although emphasizing the importance of including informal caregivers, organizational policies did not provide much support for care convoys to function well. In fact, professional and informal caregivers negotiations were influenced by organizational rules and demanded work by both sides. This shows how important it is for policymakers to create the right conditions, for example by considering possible value tensions arising from being more dependent on informal caregivers (e.g., treating multiple clients equally in terms of scheduling versus acknowledging specific needs and wishes to allow informal caregivers to participate on an equal footing). This is important because when these tensions remain unaddressed, professionals and informal caregivers are left overly responsible for weighing them in their everyday practices.

In conclusion, a critical approach to including informal care is warranted. While we show that including the voice of informal caregivers improves quality of care for some, it also brings about new complexities of opposing values, changing roles and clashes with existing policies. How these complexities are worked out, now remains in the realm of micropolitics in daily practices. There seems to be little guidance for professionals and informal caregivers to critically reflect on consequences of increasing interdependency. While it could help to provide tools to develop skills to deal with this, it especially requires organizations and policymakers to broaden their understanding of inclusion of informal care and take serious how it interacts with various processes and societal outcomes.

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CHAPTER

5

Objects at the intersection of formal and informal care

This chapter was published as:

Gräler, L., Felder, M., Van de Bovenkamp, H. (forthcoming). The role of objects in negotiations in convoys of care: addressing fundamental concerns of informal caregivers. Journal of Aging Studies, XX (XX)

Abstract

Due to an increased policy focus on informal care in many Western countries, professionals and informal caregivers increasingly grow interdependent. This has consequences for the type of care provided, and for whom and when this care is provided. This needs to be negotiated within care convoys, i.e. the dynamic networks of care recipient and caregivers. Because of these consequences, these negotiations are political in nature. Scant attention has been given to objects as part of these convoys and negotiations. Therefore, in this paper, we answer the question: *what is the role of objects in the negotiations between healthcare professionals and informal caregivers?* We use interview data from 48 participants (clients, professionals, and informal caregivers). In the results, we discuss how objects, in terms of their affordances and the values they embody, become important in the relationship between professionals and informal caregivers, and how they become part of negotiations on quality of care because of this. We find that seemingly mundane objects become topics of conversation to address more fundamental concerns in how healthcare is organized for and provided to individual clients. Our study helps in opening up the care convoys model to objects as important actors, and further understanding of the politics within care convoys.

Introduction

Due to an increased policy focus on informal care in many Western countries, professionals and informal caregivers increasingly grow interdependent (Wittenberg et al., 2018; Jacobs et al., 2014). Who does what, when, and how has to be worked out amongst actors within the network of the client, which includes both informal and professional caregivers. These client networks, coined as 'convoys of care' by Kemp, Ball and Perkins (2013), are dynamic, because actors come and go, but also because their relationships change. In these convoys of care, negotiations take place about the care to be provided. These negotiations are informed by changes in the condition and needs of clients, the living situation of the clients and organizational policies. These negotiations often have consequences for the way that resources are distributed, care processes are shaped and who has a say in the care that is provided (e.g., Burgess et al., 2022; Kemp et al., 2018; Lambotte et al., 2020) and have therefore been considered as political processes (Gräler, Van de Bovenkamp & Felder, forthcoming).

Recent studies have drawn attention to the political dimensions of care convoys; both in terms of how it is determined who does what and what is prioritized in quality of care; and in terms of actor dynamics such as boundary work to protect or shift responsibilities or policing actors enrolled in the network to monitor whether agreements are lived-up to (Gräler, Van de Bovenkamp & Felder, forthcoming; Burgess et al., 2022). The rather limited attention paid to the role of objects in this literature, and the literature on care convoys more generally, is striking. This can be considered a limitation because others have observed that objects are entangled within "the political economy of a caring apparatus" (p.311, Cozza, Bruzzone & Crevani, 2021), as our environments are repleted with objects ranging from advanced technologies such as cameras, to mundane objects such as clothing (Buse, Martin & Nettleton, 2018). It is therefore important to better understand how objects matter in shaping the growing interdependencies between formal and informal caregivers as well as their patients. In this paper, we do so by focusing on the role of objects in the shaping of and negotiations in care convoys. Doing so, we aim to add to the body of literature on the relationship between professionals and informal caregivers, and more specifically the role of objects in this relationship, and offer a broader understanding of care networks and its political dimensions.

Objects can influence the relationship between professionals and informal caregivers and the care process in different ways. First, objects provide (im)possibilities for action (Fox, 2016).

For example, cameras give the possibility for organizations to surveil care recipients in a more centralized and covert way, which raises privacy concerns (Cozza, Bruzzone & Crevani, 2021). Therefore, the physical properties of the camera allow for certain actions, while prohibiting others. Second, objects have meaning inscribed in them, and actors attach values to these objects (Fox, 2016). For example, Mol (2010) shows that pleasurable food plays a significant role for care recipients in care homes.

Especially mundane objects, objects that become intertwined in our daily lives, but are not necessarily “highly technological”, have an important role in daily interactions. Research shows they provide a possibility to maintain one’s own identity (Twigg & Buse, 2013), upholding one’s sense of autonomy when getting help (Brownlie & Spandler, 2018), and negotiate values such as private and public (Buse & Twigg, 2014; Pink, 2005). We argue that to understand the interactions, including their political nature, in convoys of care better, we should specifically focus our attention on the mundane objects that shape and are shaped by human relations and actions (Buse, Martin & Nettleton, 2018a). We therefore answer the following question: *what is the role of objects in the negotiations between healthcare professionals and informal caregivers?*

This paper proceeds as follows. First, we will explain how we conceptualize objects within the literature on convoys of care. In the method section, we will elaborate on the study design. In the results, we will show how objects play a role in the negotiations between professionals and informal caregivers and how they provide a start and a beginning in talking about good care from the perspective of informal caregivers. Lastly, we will discuss how opening up to objects in practice, policy and research can help to understand care convoys and the negotiations within them better. Furthermore, we will go further into the political dimension of the role of objects in negotiations and what the consequences of neglecting objects are.

Objects in the negotiation of care between professionals and informal caregivers

In the literature, the establishment of constructive relationships between professionals and informal caregivers is deemed important for good care (Tronto, 1993). Relationships are important for ethical considerations in care (Heerings, 2022), but they also influence several healthcare outcomes, such as involvement in and satisfaction with care of informal caregivers (Twigg & Atkin, 1994; Berglund, 2007), work satisfaction of professionals (Hertzberg, Ekman & Axelsson, 2003; Kemp et al., 2009), and the care recipient’s ability to age at home (Burgess, Kemp & Bender, 2022). However, this relationship is also notoriously complicated because different views on care and needs exist and need to be negotiated (e.g., Wittenberg et al., 2018; Burgess, Kemp & Bender, 2022). Therefore, much effort and coordination are required to make care work when both formal and informal caregivers are involved, as they are both part of the network of the care recipient (Gräler, Van de Bovenkamp & Felder, forthcoming).

The network of the care recipient is theorized by Kemp, Ball and Perkins (2013) in the convoys of care model. This model is an expansion of the model of convoys of social relationships (Kahn & Antonucci, 1980), which theorizes that individuals are embedded in dynamic networks of close relationships. Within these networks, which are referred to with the metaphor of "convoys", help is exchanged. These convoys evolve and change over time and within different contexts. Kemp et al. (2013) add professional caregivers to the model. By doing so, they not merely focus on people with an existing close relationship to the care recipient as the original model does, but also on professionals. Importantly, the model includes both informal and professional caregivers without a hierarchical connotation or a preferred type of care. The approach means that care needs to be negotiated between the actors involved in the convoy. These negotiations are not necessarily explicit or verbal, but rather a way of working out care together over time. The negotiations are influenced by norms, ideas about good care, the way the other and the relationship are perceived and the setting where care takes place. Thus, professional and informal caregivers have to negotiate their role and values, and they have to do so iteratively throughout the care process because of changing relationships, circumstances and situations. These negotiations contribute to the division of resources and are part of how care trajectories become organized (Gräler, Van de Bovenkamp & Felder, forthcoming). Therefore, they constitute a political economy, underscoring the relational dimension of care, which has consequences for who is involved, who has a say and how rules are applied (e.g. Gengler, 2014; Oldenhof & Linthorst, 2022).

Besides professionals, clients and informal caregivers, objects also give shape to care processes (Buse et al., 2018a; Mol, 2002; Cozza, Bruzzone & Crevani, 2021). Particularly so in the context of nursing homes or care provided at home, mundane objects are part of the often unnoticed and daily ways of negotiating and structuring care practices (Buse et al., 2018a), as they make tangible the tensions between homely and medical values. For example, Buse, Twigg, Nettleton and Martin (2018b) found that laundry gives rhythm to care practices, organizing care routines and the architecture of the care home. Clothes in the laundry need a certain treatment with several steps that require specific timing (Pink, 2012; Pink, 2005). They need to be gathered, carried to the place of cleaning, washed at a certain temperature, folded and organized in a closet. Therefore, their physical properties influence the routines of professional caregivers and laundry workers (Buse et al., 2018b). However, laundry practices as well as the workers doing the laundry, have a marginalized role. The laundry, as a neglected object of daily life, is also neglected as work. At the same time, informal caregivers and care recipients attach great importance to how the care recipients are dressed, for instance, because clothes help in sustaining the identity of persons with dementia (Twigg & Buse, 2013). The example of the laundry shows that objects are part of an interacting network of, for instance, bodies, ideas, social organizations, and other objects (Fox, 2016). Relating back to the convoys of care, objects such as clothes, washing machines, washing powder, water, and enzymes should therefore be considered part of the convoy of the care recipient.

There are different ways through which objects could be part of negotiations in care convoys. First, the objects provide (im)possibilities for actions (Fox, 2016). For example, in the sense that they steer people through their physical properties (Buse et al., 2018b; Shaw & Meehan, 2013), or their 'affordances' (i.e. the frame they give for potential actions; Gibson, 1979; Hutchby, 2001). For instance, if the laundry is not put on a drying rack in time, it will dry in the washing machine and start to smell. Therefore, the "doing of the laundry" is steered by the properties of the object of the laundry that manifest within the process. This also shows that it is always in relation to other objects, people and processes that properties of objects manifest themselves and have a sway over the situation (Shaw & Meehan, 2013). Thus, the properties that are manifested in relation to care recipients, informal caregivers and professionals can structure their relationships.

Second, objects have a role in convoys of care because they are value laden and provided with meaning by actors (Fox, 2016). For example, Buse and Twigg (2014) found that the care recipient wearing dirty clothes was seen as a sign of neglect and deterioration by family members. This may be the case because clothes are a way of representing yourself and showing your identity, as well as your socioeconomic class (Twigg, 2013). However, this meaning is not always shared between professionals and informal caregivers. Studies show that what professionals and managers call the "little things", are actually very important to clients and their representatives in terms of quality of care (Ryan & Mckenna, 2015; Schillemans, Van de Bovenkamp, & Trappenburg, 2016). This has implications for what is perceived as quality of care for informal caregivers. However, this may clash with what professionals find good quality of care.

Drawing on the literature on care convoys, material gerontology and science and technology studies described above we set out to analyze the different roles objects play in the establishment of and coordination within convoys of care. We are particularly interested in the ways through which they shape informal and professional relations and negotiations and give meaning to the care provided.

Methods

Context

We zoom in on care homes for older people in the Netherlands. Care homes are the homes care recipients move to, to have easier and more access to care. In our study, they include both homes where people with somatic and psychogeriatric illnesses live. Some may live more independently than others, as living arrangements can differ across and within care homes. For example, some live in small-scale living arrangements, sharing a living room with other clients, with professionals walking around all day. Others may live in what looks more like assisted-living apartments with professionals close by. What they have in common is that they are places where professional care is more or less the default. The spaces are arranged in such a way that they accommodate professional care and the things that are needed to overcome the growing disabilities of clients. Hallways are wide, bathrooms spacious and specialized facilities are in the near vicinity. Involvement of informal caregivers is increasingly deemed important and organizations are actively trying to involve informal caregivers more.

Including informal caregivers in such an institutionalized context brings about changes for the care convoys, with consequences for what care looks like. Furthermore, the micropolitical realm of the interactions between professionals and informal caregivers is important for how care is given shape (Gräler, Van de Bovenkamp & Felder, forthcoming). So are objects and the politics of objects (Buse et al., 2018a). Therefore, in this paper, we will further go into the role of these objects in negotiations between professional and informal caregivers.

Data collection

In the context of a project about the relationship between formal and informal caregivers, we conducted 48 interviews in five care home organizations. Informal caregivers, health care professionals, and additionally clients and personnel in managerial functions were interviewed. For this study, we mainly focused on the 22 interviews with informal caregivers, as they referred to objects much more then professionals did. The interviews of others, such as professionals and clients, were therefore used as a contrasting point (see for example Nijhoff, 1995). The contrast sensitized us to the use of objects by informal caregivers. This means that the analysis mainly contains data from the interviews with informal caregivers, but is grounded in a broader range of perspectives. This study was approved by the ethical board of Erasmus School of Health Policy & Management of Erasmus University Rotterdam (reference: 21-028). All participants gave informed consent for the interview.

Timing

At the time of the interviews, the organizations were working towards an organization-wide policy about how to work with informal caregivers. Some organizations were further in this process than others. Whereas one organization only had a section in another policy on personalized care that talked about informal care inclusion, another had a policy of tens of pages exclusively focused on informal care.

The COVID-19 pandemic had been a fact for six months at the time employees were interviewed, and a year at the time informal caregivers were interviewed. This has had several implications for this study. First, the context is different than it would have been and maybe will be in the future, such that for example informal caregivers were not as free to enter nursing homes in the first months of the pandemic. Also, some care was scaled down at the peak of the it. That means that the interviews also touched upon the pandemic, partially explicit but also implicit. Although the situation was in some senses unique, we found the crisis also put “normal” under a magnifying glass. Exploratory interviews showed that details of the relationship between formal and informal care became especially visible, as well as discussions about different values. One manager explained how after informal caregivers were not welcome for two months, they felt they could say out loud that informal caregivers can also burden the clients and health care professionals, where they first could not. Second, at the time of the interviews physical measures were in place. Especially social distancing, keeping at 1,5 meters distance from each other, and being careful with older people and other vulnerable groups, meant we opted for online interviews mostly. We did physical interviews when this was preferred by respondents and possible. In case of physical interviews, social distance measures were adhered to and options for locations were provided and discussed with the participant. In general, most employees were interviewed on location, while most informal caregivers were interviewed online or by telephone.

Analysis

We analyzed the data iteratively, going back and forth between the data and theory. We coded objects that were used in stories about the relationship between professionals and informal caregivers that could be seen as mundane. We focused on physical objects, such as doormats, doorsills, cleaning supplies, clothing and so on. While coding, we theorized what role they played between professionals and informal caregivers, using literature on material gerontology and the politics of objects. Objects became a sensitizing concept, due to their omnipresence in stories of informal caregivers. We coded objects that were part of stories of participants about their relationship to other actors in the care process. More specifically, we coded what the function of these objects was, and how the objects were talked about. That resulted in codes such as: transferring information, indicating neglect, facilitating the (shared) process, caring for objects, representing values, and negotiating boundaries.

Findings

Below, we will go into our findings. As a prelude, we will introduce an exemplary vignette, the case of Anne, to provide a picture of why it is important to look at objects and how they influence relationships in fundamental ways.

The vignette of Anne

Anne was one of the informal caregivers that regularly came to the care home to visit her mother who lived on a dementia ward. During the COVID-19 pandemic, informal caregivers were not allowed into care homes for periods of time. Therefore, Anne stood in front of her mother's window that faced the parking lot. The professionals would crack open the window, and in that way, she could talk to her mother. However, she also observed how her mother, who was not always able to communicate how she was doing due to her condition, was doing during these moments. Anne explained that she saw that her mother increasingly not doing well, which saddened her greatly. She came to this judgement, looking through the window, seeing her mother wearing a visibly dirty dress for days on end. The dress was full of brown stains. Furthermore, her nails were dirty. This was not the first time Anne had observed this. The dress and nails turned out to be dirty with feces.

At one point, when she came to pick up the laundry, she was told there was no laundry. There she stood: baffled, in front of the door of the care home which she was not allowed to enter, but behind which her mother walked around in her own feces. She asked: "why is there no laundry? This is the third time she is wearing that filthy dress!" The professional's response was that she would go, take off the dress right away and hand it over through the window.

> *"[The professional caregiver] then opened [my mother's] window and gave the bag. She took of the dress of my mother right there and then. However, [I saw that] there were also feces on her underdress. How can it be that you put something like that on!"*

Anne contacted the care professionals about her observations. She could not believe that the team of professionals responded surprised. How could they have missed this, or seen it and done nothing about it? It could also not have been a lack of dresses; Anne had arranged a closet full for her mother. Anne could understand the professionals were strained and worked very hard during lockdowns, but was it that bad that they could not even wash the hands of a woman with feces on her hands? Or put on a clean dress in the morning?

Anne's story is in a lot of ways exemplary of how objects represent values, reveal otherwise hidden information and have the ability to structure the relationship and negotiations between professionals and informal caregivers. It shows a negotiation between professionals and informal caregivers about what is important, who can address issues, and in what way. The dirty dress had a vital role in organizing Anne's relationship with the professionals: it enabled her to surveil the care process. The dress connected the world within the care home with the due to COVID-19 strained professionals with multiple clients, and the outside with the informal caregivers of a loved one with a personal history who had moved to a care home. Furthermore, the dress represented values, such as dignity, hygiene and identity, that were not met. Therefore, Anne used it to start a conversation about quality of care with the staff and (re)negotiate these values with professionals. However, even though care improved after Anne went to the client council and the head of the team of professionals, Anne felt that she was perceived as difficult for voicing her concerns. The whole situation impacted her a great deal, as she was deeply sad about the treatment her mother received and the trust she had lost in the care home.

Mundane objects were omnipresent in many of the stories of informal caregivers and professionals. Especially informal caregivers told stories where objects played a significant role: they talked about doorsills, doormats, clothing, laundry, urinals and so on. But they did so in different ways, at different times and for different reasons. It prompted us to further dissect what role objects play in the convoys of care. Based on our analysis we will further unpack below how (1) objects provided (im)possibilities, (2) how objects were valued, and (3) how these two aspects were consequently used in negotiations between professionals and informal caregivers.

Objects providing (im)possibilities

Objects play an important role in our daily lives through the ways in which they provide possibilities for action and routines, the ways in which they structure social relationships and the ways in which we give meaning to them, care for them and grow attached to them (Fox, 2016; Twigg, 2013). Yet, even though they are fundamental in shaping our reality and relationships, we often do not pay much attention to them and their affordances – that is the ways in which they facilitate or steer social action – only become apparent when objects break down, are malfunctioning, missing, or out of their usual context (Harman, 2004). Studying the role of objects in care convoys we found that especially objects that were missing in the perception of informal caregivers, or those that seemed to be misaligned with preferred practices stood out. However, some mundane objects also provided possibilities for personalized care through their specific affordances and the creative ways in which these were harnessed by informal and formal care providers. We will go into these three ways that affordances manifested in care practices.

First, some objects were experienced as missing by informal care providers. One reason for this sense of missing, was that informal caregivers missed certain functionalities these objects had. For example, an informal caregiver talked about missing toothbrush holders:

> *"So, with a lot of [other caregivers], five or six, we succeeded and we also have, what is that called? Received a tray on which you can place a toothbrush near the sink, but none of that was there and we were not allowed to put it in ourselves because then there*

> *would have to be a hole in the wall and that was a mortal sin; a hole in the wall. We were not allowed to hang towel racks, well then you just have to stick something [sigh] and so it went on, there were no grab rails, well, there wasn't much that should have been there for someone who cannot stand independently. So, I thought that was a real shame."*

The tray provided a way to store a toothbrush in a manner that is recognizable to how it is done 'at home'. The bathroom, in this case, was a space that was designed to be clinical and efficient, lacking the affordance to place a toothbrush or to hang a towel. Yet, not having a place to put your toothbrush is far from convenient and does not fit in with the way people live their lives when living independently. Therefore, the missing tray – and the lack of a place to put your toothbrush or hang your towel – manifested itself politically in its absence as a rupture between the idea of home and living in a care home.

Second, some objects and their physical properties were misaligned with the healthcare practices which they were part of – and taking part in. This is what Franny, an informal caregiver, experienced whilst providing care for her husband, Gerard. He needed to use urinals because of his condition. The care home in which Gerard was living had however just switched from using glass urinals towards using cardboard urinals.

> *"They switched to a system a few years ago. At first you had a glass or plastic urinal, and Gerard has such a bag hanging from him, a urine bag. So, it has to be emptied several times throughout the day. Then the [glass or plastic] urinal was emptied in the toilet, rinsed out, and was simply used again. However, at some point a new system with a grinder was introduced. Then you have cardboard urinals, I don't know if you've ever heard or seen them? ...Then you have those cardboard urinals, which are disposable, and they then go, pee and all, into the grinder that is diagonally opposite in such a room. At first it went well, no problem, in the grinder. But what has crept in? They use a urinal, and then they put it in the bathtub, or they empty it in the toilet and put it on the laundry basket or on the radiator. ...So, when you opened that door: the smell! Yes, you understand, if the cardboard of those urinals gets soaked and it than tears... and Gerard has a suprapub, so there is a tendency for bladder infections and bacteria. That smells terrible."*

The urinals were made of cardboard, but the professionals were still treating them as if they were made of glass. In their routine approach to emptying urinals, the professionals would leave them somewhere to dry. Such ways of going about the cardboard urinals did not work as the cardboard would soak-up much of the urine and thereafter, through evaporation, release it back into the air, creating a penetrable smell for anyone not used to it entering the room. In that way the dress with which we opened the results section, but also the cardboard urinals and the missing trays above the sink became sources of unsettlement for informal caregivers. It prompted caregivers to open-up conversations about the provision of care in terms of quality and priorities.

Quality of care could also be improved through the possibilities that objects provided, as these possibilities could, for instance, facilitate personalized care. The affordances of objects sometimes had very positive effects when recognized, supporting and improving care and practices. For example, Lucy's father Fred really appreciated his autonomy in terms of being able to have an alcoholic drink on his own terms. Therefore, it was agreed to put the gin bottle next to his chair, together with a tall glass. However, that posed a problem, because Fred would poor a full glass and the bottle would be empty very fast. Therefore, the professionals and Lucy discussed they would change the glass next to the chair to a smaller one. As Lucy explained:

> *"I think he either drinks [all the gin from the tall glass] or the professionals think: oh, that's water that has been sitting there all day, we'll throw it away. Then it is going fast, of course. But even if there is a tea cup or whatever. If he wants a drink and he doesn't have a little glass, he will put it in there. So now they make sure that his little glass is always with him. And that's going really well."*

The little glass had a significant different affordance than that of the tall glass: it held less liquor. Therefore, the little glass had a very constructive effect on the amount of liquor that Fred drank. Thus, the affordance that the glass was only able to hold little liquid, supported and improved care in terms that Fred was able to sustain his autonomy. After all, he was still able to operate the bottle and glass as he preferred but a balance was struck with preventing excessive drinking.

Concluding, the affordances of objects matter for care and practices. They provide (im)possibilities for those involved, such as a way to feel more at home (or less in the absence of the object), or the need to adjust certain routines and practices. Mundane objects made homely routines, such as putting your toothbrush away, possible. They provided a possibility to retain a level of autonomy. However, they also sometimes forced to change routines, as exemplified by the cardboard urinal. On the other hand, we saw that the object could also help in constructing practices together. In the next two subsection, we further delve into the conversations both in terms of the different values that informed these conversations and in terms of the negations that subsequently took place to settle a new way of working in the care convoys.

Valuation of objects

Objects are not just influential for the fact that their presence or absence provide (im)possibilities for action. They are also political because they are perceived and valued differently by actors who are part of the care convoys. Already from the previously mentioned examples, it becomes clear that objects can have different meanings to different actors (e.g., Schillemans et al., 2016). Objects represent certain values such as feeling at home, autonomy, and dignity. The tray above the sink stood for homely routines for informal caregivers, whilst for the nurses or the facility staff it was just another object that progressed the deterioration of the building because of the holes in the wall.

Informal caregivers perceived objects to be a sign of bigger issues, such as quality of care, neglect, and red tape. First, not attaching the same values to objects, indicated to informal caregivers that quality of care, as defined by informal caregivers, was not up to par. For example, not being dressed concisely, meant for some informal caregivers that the care was not up to standard. Second, objects gave insight in aspects of the care process they would otherwise have no access to, as was seen in the case of Anne, where the dress became a sign of neglect. She had insight in the practices in the care home, through the feces on her mother's dress. Third, objects could also mark institutional boundaries, i.e. the red tape, that informal caregivers encountered. One informal caregiver wanted to have a doormat at the front door to prevent the floor from getting wet if it rained outside. However, she was told this was not possible because residents could slip and fall on the doormat. When the informal caregiver asked for the doormat to be recessed, to circumvent the slipping of the doormat, she was told this was not allowed because of the building regulations. Values clashed: habits and cleanliness as experienced in one's own home versus values of safety, adhering to the rules, and maintaining a building in good condition clashed. The rules became tangible for the informal caregivers through the doormat.

Furthermore, objects were not only tools to be used (properly) based on their affordances but also needed to be cared for in their own right. Informal caregivers value the care for objects, as part of care for the care recipient. Therefore, informal caregivers committed to making sure objects were taken care of. For example, one informal caregiver complained about how professionals were uncareful with clothes. Therefore, she surveilled the clothes and tried to repair them before it was too late:

> *"[...] for example, they pull his shirt out of his pants, and almost all the shirts are torn at the side along the seam. Then something has ripped here, his pants are torn, the loops are off... so there is always something to be repaired. And that's why you keep control, so you can repair it before it tears off completely."*

This shows that the care for objects themselves was also deemed important. In the eyes of informal caregivers, objects were a part of and substantiating the care recipient's identity and dignity. Therefore, part of care was, according to informal caregivers, also care for the objects. Which was something informal caregivers largely took upon themselves. In their eyes, the objects were sometimes mistreated by professionals: the pants became part of an institutional routine, rather than a part of decorum. In the example above, the caregiver repaired clothes to maintain a standard for the condition of the clothing, while she found that professionals did not have the same standards. This was perceived by the informal caregiver as a lack of quality of care. In other examples we saw that badly handling objects was also seen as an indicator for the quality of care, as can be seen in the vignette of Anne.

In the next section, we will show how both the affordances of objects and the valuing of objects are part of the negotiations between professionals and informal caregivers that organize care within care convoys.

Negotiation through objects

Objects play an important part in care as they influence involvement, quality of care and care processes, as can be seen in the examples above. We highlighted two ways in which they do so: through their affordances and through the values that are attached to them. We now move to connect these two faculties to the negotiations that constitute convoys of care. We dissect two ways through which objects spark and are part of negotiations: they prompt conversations about quality of care and are leveraged to negotiate values and care.

First, affordances of objects were used by informal caregivers as openers in conversations through being missing, misaligned or constructive in care practices. The way in which objects – or their absence – manifested themselves in everyday healthcare practice were often reason for informal caregivers to open up conversations with professionals about the way in which care should be organized and provided. Through the affordances of objects, conversations started about quality of care, priorities and the care process. For example, in the case of Fred and the gin bottle the use of objects (glasses and bottles) was negotiated extensively. The absence of the bottle and size of the glass were used to open up conversation about autonomy. Therefore, they became part of a strategy to talk about care in a tangible way: e.g., what size glass could balance all values?

Second, because mundane objects contained values and represented institutional structures, they were used in negotiations. They subsequently structured relationships in care convoys, through different strategies that were used. For example, one informal caregiver chose to not explicitly negotiate aspects of care, as a tactic to not be prohibited to do something. Therefore, she undermined the rules of the organization that did not adhere to her values.

> *"They are not allowed to use a lot of cleaning products and when I am there myself, I use green soap [...] and the girls say "nice and fresh again", you know. Then I clean, just clean the handles, just clean the seat. Or fine, I just add a little bleach to the toilet, fine. But now I notice when I come on Thursday, it is cleaner, the smell is gone. I don't ask [why I'm allowed to use these products and they are not], because otherwise I'm afraid they'll say I am not allowed to use it."*

Here, for the informal caregiver, the solution to different Ideas of what is clean and what the room should look and smell like, is to take on this task herself instead of making the care home staff try to adjust to what she sees fit. However, there were also other strategies. For example, in negotiating the care of objects themselves. Because informal caregivers saw them as part of care, objects became part of the negotiations of what care should entail. Strategies included referring to past wishes of care recipients to substantiate this idea of good care. For example, one informal caregiver referred to the store with expensive clothing his wife had for years. He found clothing and the appearance of his wife very important, as well as the treatment of the clothes and accessories that constituted this appearance:

> *"Her beautiful watch is broken. On one side I find the watch and on the other side I find [other mysterious parts]. ...upon closer inspection the glass [of the watch] was off, and then I found the glass and fittings. ...I don't think that watch will ever work again. She now has another watch, which looks 90% like her old watch, for 60 euros. Who pays for that?"*

Another strategy also becomes visible in this example. Namely, this informal caregiver holds the professionals responsible for the broken watch, as becomes clear from his last statement: who pays for that? He became very angry, and was appointed a special someone to complain to with whom he had regular meetings to negotiate aspects of care. His demeaner thus yielded some result. Nevertheless, professionals experienced the complaints about objects to be burdensome at times, as they felt it could be about negligible things, and nothing would ever be right.

In conclusion, both the affordances and values of objects were entry into and topic of negotiations about care for the recipient. However, the objects themselves were also negotiated for their role as part of the care recipient, and therefore part of care. In the discussion we will go further into this.

Discussion

The aim of this paper is to better understand the role(s) that objects play in convoys of care (Kemp, Ball & Perkins, 2013). In what follows, we recapitulate on three distinct roles that (mundane) objects played in the care convoys and discuss their implications. We argue that better awareness of these role(s) is pivotal for our understanding of how healthcare is organized – and resources are distributed – now that healthcare organizations increasingly rely on the contributions of informal caregivers to deal with scarcity and adhere to values of personalized care. Below, we first present the different roles and thereafter discuss their implications.

The first role that objects played in healthcare convoys related to their ability to act as a source of unsettlement for informal caregivers. Objects for instance manifested themselves as ‘missing’ in the care provided to clients (e.g. a tray above the sink to place personal itinerary), or because they malfunctioned in the way in which care was being provided to clients (e.g. [re]using increasingly sobby cardboard urinals). Not only did objects present themselves as political entities in healthcare convoys – in the ways in which they provided (im)possibilities for actions (Fox, 2016) – but their political manifestations as missing or malfunctioning also gave informal caregivers cause to voice their concerns about the way in which care was being organized (Shaw & Meehan, 2013; Gräler, Van de Bovenkamp & Felder, forthcoming). This could be very constructive, and in that sense the objects could help to improve care, as was seen in the case of the gin glass and bottle. However, that this is not always the case can be seen in examples such as that of the soiled dress, or the carboard urinals.

Second, objects played an important role in the care convoys because they represented values deemed important by informal caregivers. By consequence, objects offered informal caregivers a way, because of their tangibility, to discuss more abstract healthcare values (such as dignity and autonomy) and helped to articulate which values were or should be prioritized in certain situations. Even more so, objects gave insight in the health care process in general. Objects bridged the world of informal caregivers and the world their loved ones lived in, as informal caregivers inferred the quality of care, or even neglect, through objects. For example, the dress in the vignette of Anne was a clear bridge between her world and that inside the care home: it gave some visibility of what was going on in the care home, when it was impossible for Anne to go in herself. Through the dress, she was able to address the neglect of her mother. Lastly, objects made tangible which values were institutionalized through rules and regulations, and were used to negotiate these. This means that some values attached to objects were supported by the organization while others were not, making it difficult for informal caregivers to bring in their own values to the table in these cases. Therefore, organizational procedures were sometimes challenged, because they did not accommodate practices of informal caregivers.

Third, part of the values attached to objects by informal caregivers was the care for the object itself. This is often neglected, while it is these exact objects that accommodate and constitute the environments and practices of care, and are therefore a vital part of care (Puig de la Bellacasa, 2011). Examples of such care for the object were: repairing clothes, washing specific clothes with special care, repairing the floor after construction, and cleaning the room. Discussing and caring for objects therefore sometimes also meant an important reorientation in the scope of tasks and responsibilities of those involved in the care convoys. Professionals for instance needed to pay more attention to how they handled objects, such as clothes according to informal caregivers. Informal caregivers in turn picked up tasks such as cleaning in a way that fitted their standards of what is clean. The values that were attached to taking care of objects thus gave way for new practices, sometimes covert (as was seen in the case of the bleach that was not allowed), and became part of negotiations about what care should entail.

There are two important implications of our findings for the literature on care convoys. First, this study shows that objects were part of the micropolitics that constitute care practices between professionals and informal caregivers (Gengler, 2014; Gräler, Van de Bovenkamp & Felder, forthcoming). Thus, objects are political and should be studied accordingly when intending to capture how the dynamics in care convoys unfolds and with what kind of consequences in terms of how care becomes organized through relationships – also those with non-human objects. We find that objects should be studied in terms of both their affordances and values, as both these faculties have a role in how care is negotiated between professionals and informal caregivers.

The importance of objects for constructing care and vice versa has solid grounds in other bodies of literature, such as material gerontology (Latimer, 2018) and science and technology studies (e.g. Mol, 2002). Providing an insight in the political role of objects in the convoys of care framework, helps to think of the convoys in a broader way than being a network of human entities only. Furthermore, there needs to be more attention for this in the literature on nurses and professionalism, as mundane objects play an important role in the way informal caregivers bring things up. Objects can therefore be an important component of joint reflections and experimenting to improve quality of care. Certainly, seemingly mundane objects become topics of conversation to address more fundamental concerns in the ways in which healthcare is organized for and provided to individual clients.

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CHAPTER

6

General discussion

The text of the discussion has been reviewed and edited with the assistance of Grammarly's AI-powered writing assistant.

Introduction

"The closest people in our lives are irreplaceable to us, and it is in that sense that we care for them, but our care does not stem from our private interests, from their 'gain' for us, but from the common world that we share with them, and that we wish to preserve beyond our personal stay on earth."

Timofei Gerber[2]

In the introduction, I shared a personal anecdote to illustrate the intricacies and ambiguities of providing informal care. These complexities include the potential for caregiving to be both rewarding and demanding, as well as simultaneously private and public. Furthermore, the declining health of a loved one can have ripple effects beyond the individual in need of care: it is never just the person who needs care that is affected.

Subsequently, I zoomed out to discuss the wider context of informal care. I highlighted how informal caregivers were affected during the COVID-19 pandemic, and how support arrangements relate to informal caregiver outcomes. I also showed that collaboration between professionals in care organizations and informal caregivers becomes increasingly important. However, exactly how these policies and changing care practices affect informal caregivers, requires further investigation.

Therefore, the primary objective of this thesis was to provide insight into the current policies and practices surrounding informal care. The main research question was: *What can we learn from current informal care policies and care practices in the Netherlands for future endeavors to better involve informal caregivers in care?* To answer this research question, I have looked in two specific directions, which are articulated in two sub-research questions:

1. *How are national and local government policies related to informal care outcomes?*
2. *What does the involvement of informal caregivers mean for how care is negotiated between professionals and informal caregivers in practice?*

Below, I will answer these research questions.

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[2] Gerber refers to the work of Hannah Arendt in his piece "Hannah Arendt: Culture as Care and Resistance" in Epoché Magazine (March, 2023).

Key findings

Sub-question 1: Governmental policy and informal care outcomes

In the first part of this thesis, I studied two cases where national and municipal policies influence informal caregiver outcomes. The first case, presented in Chapter 2, focuses on the COVID-19 pandemic, where the fear of the virus and the policies to prevent the spread of the virus influenced the involvement of informal caregivers. The second case, presented in Chapter 3, is the case of municipal support arrangements that aim to alleviate the burden of informal caregivers to help them persevere in their role. Together, these cases answer the sub-question: *How are national and local government policies related to informal care outcomes?*

First, I found that national circumstances, such as the COVID-19 pandemic and the corresponding policies, are related to changes in the burden for informal caregivers. During COVID-19, both the threat of getting infected and the policies that were installed to prevent the spread of the virus (e.g., social distancing, PPE distribution, denying informal caregivers entry to nursing homes) impacted the involvement of informal caregivers. For example, informal caregivers for someone living in the same home isolated themselves to reduce the risk of giving the virus to their loved one (Lightfoot et al., 2021). Furthermore, several countries, including the Netherlands, denied informal caregivers (and others) access to nursing homes at various points in time during the pandemic (e.g., Dolberg, Lev, & Even-zahav, 2023; Verbeek et al., 2020; Kemp, 2020), while informal caregivers for those who lived at home saw a decrease of formal care (Verbakel et al., 2022).

My study showed that, on average, the subjective burden of informal caregivers increased slightly, while the average time spent on caregiving did not change. This is similar to results from other countries (Rodrigues et al., 2021; de Sousa et al., 2022; Hofstaetter et al., 2022; Lorenz-Dant & Comas-Herrera, 2020; Truskinovsky et al., 2022). However, looking beyond the average, I find that some informal caregivers were affected more, and differently than others. Thus, the impact of the COVID-19 pandemic on informal caregivers was not homogeneous. While some caregivers increased the number of hours they provided care compared to others (such as caregivers living in the same home as the care recipient), others experienced an increase in the perceived burden of care without providing more hours of care (such as women and people with young children facing home schooling). I identified which groups were vulnerable, and what changes in burden they experienced. These findings add to the knowledge of how the COVID-19 pandemic affected informal caregivers in different ways. Thus, my study shows that informal caregivers are a diverse group, and that they are not affected in the same way by policies or circumstances. Therefore, in future occasions, tailored policies and support arrangements should be put in place to address the unique needs of different groups.

However, my study also showed that providing support arrangements proved difficult. Local policymakers seem to struggle to reach informal caregivers with their policies. Informal caregivers who received support often experienced a greater burden as compared to those who did not receive such assistance, indicating that informal caregivers are likely only reached in a late stadium, despite efforts by municipalities to reach out to informal caregivers early to prevent overburdening (Van der Ham et al., 2018). This indicates that municipalities seem to run into the same trouble as has been outlined in the literature about the underutilization of services: inadequacy in meeting the needs of informal caregivers (e.g. Henoch et al., 2020), lack of awareness about available support services (Van Exel, De Graaf & Brouwer, 2008), and difficulty in identifying informal caregivers at an early stage (De Boer, De Klerk, Verbeek-Oudijk, & Plaisier, 2020; De Boer, Plaisier & De Klerk, 2018).

Chapter 3 thus showed that the customized support arrangements proposed in Chapter 2 must account for the difficulty in proactively engaging informal caregivers and the uncertainty surrounding the effectiveness of existing support arrangements. A better understanding of the distinct needs of different groups of informal caregivers and a tailored approach to their engagement may be beneficial, as Chapter 2 demonstrates that the informal caregiver population is highly heterogeneous. I elaborate on this in the implications section.

Sub-question 2: Negotiating care between professionals and informal

In the second part of this thesis, I zoomed in on the care practices of informal caregivers and professionals and specifically on how they negotiate these care practices together. In the introduction, I noted that the collaboration between professionals and informal caregivers is complex: responsibilities can be unclear, informal caregivers feel like their perspective and contribution is not valued equally or sufficiently, and professionals can experience dealing with informal caregivers on top of care recipients as burdensome (Wittenberg et al., 2018; Hertzberg, Ekman & Aksselson, 2003). Moreover, in care homes, the cooperation between informal caregivers and professionals is governed by a host of rules and regulations, for example on quality and safety. Such structures have a bearing on the degree of involvement of informal caregivers, and also on the ability of professionals to actively engage them in the care process (e.g., Van Wieringen, Broese-Van Groenou & Van Groenewegen, 2015).

Therefore, the involvement of informal caregivers is constantly and situationally negotiated between professionals, informal caregivers and care recipients. Scholars have coined the dynamic network around care recipients in which these negotiations take place as "convoys of care" (Kemp, Ball & Perkins, 2013). The convoys of care model provides an entry into studying practices of care where both informal caregivers and professionals are involved. In the following, I will answer the second sub-question: *What does the increased recognition of informal care mean for how care is negotiated between professionals and informal caregivers in practice?* I answer this sub-question based on chapters 4 and 5.

I found that the negotiation between informal caregivers and professionals are political in nature. This insight adds to the existing literature, by highlighting the political dimension of the relationship between healthcare professionals and informal caregivers, which has remained largely unexplored, particularly in the context of the convoys of care literature (e.g., Kemp, Ball & Perkins, 2013). As the involvement of informal caregivers gains a more prominent place on the agenda in care organizations, what care looks like becomes more dependent on how care is worked out between professionals and informal caregivers. My study provided insight into the micro politics of these interactions.

First, although the involvement of informal caregivers appears to align with values such as participation and cost-efficiency, I found that in practice, involvement can also be at odds with other values such as protecting the rights of clients and informal caregivers or the sustainability of care beyond that extended to a single client. The weighting of these values, and the balancing act this requires in care practice, remains largely invisible in organizational policies.

Second, I found that organizational rules and regulations (e.g., financial policies, quality and safety policies) do not provide much guidance to professionals for dealing with tensions with informal caregivers. Moreover, policies often were also in tension with the wish to include informal caregivers. For example, when informal caregivers are not allowed to join the table for lunch or dinner, while they are there to help out with dinner for their loved one.

Finally, relying on informal care means that the relationship between professionals and informal care becomes important for how care is organized, which requires new skills from professionals and informal caregivers. Professionals have to renegotiate their role as trained caregivers, and they have to deal with informal caregivers professionally. Informal caregivers need to become skillful in voicing their concerns to acquire personalized care for their loved one in the way they see fit.

Regarding this, I observed that mundane objects played a significant role in voicing needs and negotiating care by informal caregivers. Through such objects, different ideas of quality became explicit and subject to discussion as part of the micropolitics between professionals and informal caregivers. For example, objects can be a source of unsettlement for informal caregivers, especially when certain objects were deemed ‘missing’ or not used appropriately. One informal caregiver talked about carboard urinals that were left out to dry on the radiator, resulting in a horrible smell. This greatly unsettled the caregiver, who initiated a conversation about this. In other words, the negotiation between the professional and the informal caregiver about the quality of care was prompted by the handling of this carboard urinal in care practice. Other authors have pointed out that the manifestation of particular physical properties makes objects political actors (Shaw & Meehan, 2013).

Also, objects made it possible to address certain values important to informal caregivers. Objects helped articulate the values that should be prioritized according to the informal caregiver and made visible which of those values were (not) adhered to in the care home. For example, treating clothes with dignity and making sure they are clean when dressing the care recipient was very important to some informal caregivers to sustain the personhood and dignity of the care recipient. However, informal caregivers sometimes found their loved ones being dressed in clothes dirty from ointment, or torn at the seams. During the COVID-19 pandemic, one informal caregiver observed, through the window and later through the laundry she received, that her mother wore a dress that was covered in feces. This shows that through objects such as clothes, informal caregivers can observe neglect in professional care, even when they are unable to visit the care home like during the COVID-19 pandemic.

Furthermore, objects required care in their own right according to informal caregivers. This meant that informal caregivers did repair and maintenance work to keep objects clean, functional, and dignified. They also wanted professionals to treat objects in the same way.

However, when they were able to establish a care practice as they saw fit, this was often very situational and required reiterated efforts from informal caregivers to be maintained.

Thus, involving informal caregivers means that the way knowledge is produced in care trajectories needs to be reorganized and that objects can play a fundamental role. Because fundamental concerns of informal caregivers were addressed through objects, they could help in joint reflections between professionals and informal caregivers and can be part of experimenting to improve the quality of care. Although I found objects are important for care, literature has mainly focused on human actors in care convoys. By showing that objects are part of the micropolitics within care convoys, I contributed to opening the convoys of care literature to objects, building on knowledge from STS and material gerontology (e.g., Hutchby, 2001; Pink, 2012; Buse & Twigg, 2014). My research shows that this direction may be fruitful in the democratization of knowledge and organization of care trajectories.

Strengths and limitations

Several strengths and limitations of this thesis are worth mentioning before I turn to the implications of my findings.

First, a strength of this thesis is that I use both qualitative and quantitative methods. Combining these methods provides a multifaceted picture of informal care. By using quantitative methods, I have been able to study large groups and deduct differences between informal caregivers systematically, as well as the relationship between receiving support and informal care outcomes. I have done so in part 1 of this thesis. To better understand the heterogeneity I found, as well as the difficulty to reach informal caregivers in an early stage, qualitative methods can be helpful. Using qualitative methods, I studied the mechanisms potentially underlying the differences in relationships between informal caregivers and their environment. This gave more insight into the mechanisms at play in practice and allowed opening up these mechanisms to a critical reading.

An important limitation of using both quantitative and qualitative methods, though, is that these methods are not always easy to combine (Liu, 2022). The methods I have used imply different scopes of measurements and techniques for analysis, a different relationship with the subject under study, and a different ontological and epistemological stance. For example, combining ethnography and regression analyses in one dissertation has consequences for the epistemological consistency throughout: moving from a more positivistic stance (we can observe the rather stable reality out there) to social constructivism (the reality is influenced by us looking and therefore not necessarily stable). Nonetheless, I have learned that in practice they (partially) can but that being pragmatic is key, as has been noted long before I came to this conclusion (e.g., Howe, 1988). Rather than one method devaluating the other, they can strengthen the research results by giving complementary insights (Foss & Ellefsen, 2002). Likewise, academia could benefit from researchers trained in both techniques and backgrounds to bridge the knowledge worlds that remain largely separate (Roberts, 2002). Future research should focus on what is needed to be able as a researcher, and more specifically as a PhD student, to combine quantitative and qualitative methods that are embedded in different literature and epistemological backgrounds effectively.

Second, most of the research presented in this thesis took place during the COVID-19 pandemic. This is considered a strength because it opened up the possibility of studying informal caregivers during these enduring times. Chapter 2, for example, was a direct result of the COVID-19 pandemic. Furthermore, Chapters 4 and 5 are based on interviews that were also largely done during the COVID-19 pandemic. As they focus on care homes, it was a challenge to ride the waves of COVID to find the right moment to do interviews and observations.

Nevertheless, as the topic was the involvement of informal caregivers, the pandemic also made more explicit what the role of informal caregivers exactly was (e.g., Kemp, 2020). In practice I saw that, while professionals in some care homes observed that the absence of informal caregivers made residents less agitated because there was less commotion in the living rooms, others saw that residents were lonelier, and declined in health and well-being more rapidly. Furthermore, the communication channels as well as what should be communicated needed to be rethought. Therefore, because COVID-19 denormalized the normal, it gave great insight into what was taken for granted and how relationships between professionals and informal caregivers are negotiated.

A limitation of doing this research during COVID-19 is that I was unable to do the planned desired number of observations in care homes. Therefore, I relied heavily on interviews in Chapters 4 and 5. This limited me to only speak about the verbalized aspects of the relationship between professionals and informal caregivers. The stories about this relationship are thus leading in the findings presented in these chapters. This means that there could be other aspects important for negotiations between professionals and informal caregivers as well, that may not be part of stories or difficult to put into words. An observational study is required to investigate whether this is the case. Furthermore, for the COVID-19 chapter, I was not able to do a pre-COVID measurement, as the pandemic was an unexpected event. This limited the possibilities for causal inference and we had to rely on the recollection of informal caregivers of the pre-COVID situation.

Implications

Given the strengths and limitations, what do the results of this thesis mean for policy and care practice?

First, there is a lot of variety when it comes to informal caregivers that must be considered by policymakers when developing and implementing support arrangements or policies to increase the involvement of informal care. Different groups of informal caregivers require different types of support to reduce the burden they experience and the negative consequences of providing care for a substantial number of hours, or different conditions to start providing informal care, or increase their role.

Therefore, there is a need for tailored policies. Such tailored policies will be particularly important for those informal caregivers who are the most vulnerable to societal and personal crises. My research helps identifying these most vulnerable groups and understanding their specific needs, which can be useful for developing more tailored policies and support arrangements to help them better cope with the challenges they face.

Furthermore, I observed that support arrangements generally do not reach informal caregivers at an early stage. If informal caregivers only become visible as such when they are already heavily burdened, it may be more difficult to help them persevere in their role. Therefore, it is important that municipalities try to better understand the needs of various groups of informal caregivers to be effective and reach them at an earlier stage with tailored policies. For example, providing culturally sensitive support may prove advantageous for informal caregivers from a migrant background who perceive cultural or social obstacles in making use of support (Spit et al., 2023). Therefore, involving target groups of informal caregivers in developing the support that is aimed at them could have great potential. Furthermore, research into the needs, preferences and conditions for support among groups who are vulnerable or currently underuse support arrangements is recommended.

Second, the political dimension of informal care involvement needs to become a more visible part of the debate. This means that the dependencies that arise when involving informal caregivers in care should be considered by policymakers, both in government and in care organizations. Not doing so, means that inequalities between care recipients may arise based on who has a social network that can negotiate personalized care, while it may also increase rather than decrease the workload of professionals. Furthermore, more emphasis on informal care puts extra strain on informal caregivers to make sure their loved one gets appropriate care. In general, the voice of informal caregivers is not included in care processes. This would require rules and regulations at the level of care organizations, and potentially also a change in attitude toward (quality of) care among actors in the formal care landscape.

Mundane objects can be a way through which informal caregivers voice what they value, and their needs and preferences become tangible. For example, negotiations between professionals and informal caregivers about dressing the care recipient show that informal caregivers define care as also caring for the objects of the care recipient. Future research should consider the participation of care recipients and informal caregivers also to open up the research process and knowledge production to include voices that have not been valued the same as the system- and professional perspectives.

Final thoughts

In conclusion, my dissertation shows that involvement of informal caregivers is easier said than done. First, because the "informal caregiver" as such remains elusive, as there is great heterogeneity amongst informal caregivers and the consequences of providing care they experience. Furthermore, support does not always reach informal caregivers in an early stage to help prevent an increase of burden so that they can persevere in their role. Third, involvement of informal caregivers may have consequences beyond those recognized in policies: the work of professionals changes, and how care is organized becomes more dependent on the relational skills of professionals and informal caregivers. Lastly, involving informal caregivers in care means also including their views and values. This poses a challenge to organizations and professionals, but more eye for interactions around mundane objects can provide a lot of information about what is important for informal caregivers in the care for their loved one. Policymakers, professionals, informal caregivers and care recipients can use the insights from this thesis for identifying and paving the paths for future endeavors to better involve informal caregivers in care processes.

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Summary

This dissertation studies policies and practices that affect informal caregivers. This is important because of the increasing attention for informal care as a solution to a plethora of problems in the healthcare sector. The range of consequences of more involvement of informal caregivers is still much debated in the literature. This dissertation aims to contribute to a better understanding of these consequences for informal caregivers and healthcare organizations. Using both qualitative and quantitative methods, the relationship between policies and practices of informal care is investigated. The main research question is:

What can we learn from current informal care policies and care practices in the Netherlands for future endeavors to better involve informal caregivers in care?

This dissertation shows that reliance on informal caregivers is consequential for those involved and policies should be better attuned to these consequences. First, these policies need to incorporate attention for differences, because the "informal caregiver" does not exist. There is much heterogeneity between informal caregivers and the experienced consequences of providing care. This conclusion can be drawn from **Chapter 2**, which studies informal caregivers and their burden of care during the COVID-19 pandemic. The main question was: how did the burden of informal caregivers change following the COVID- 19 crisis? And how was this burden related to characteristics of caregivers, care recipients and the caregiving situation? Self-reported data of 965 informal caregivers were used to study to what extent caregivers experienced a change in burden three months into the COVID-19 pandemic in the Netherlands. Three outcomes were used: (1) the change in time spent on informal caregiving, (2) the change in perceived burden and (3) the care-related quality of life. Chapter 2 finds that on average, the perceived burden of informal caregivers increased slightly, while the average time spent on caregiving did not change. However, looking beyond the average, the data shows that some informal caregivers were affected more, and differently than others. Some increased time spent on informal care, while others experienced an increase in perceived burden. This also did not necessarily relate to their relative quality of life. Thus, the impact of the COVID-19 pandemic on informal caregivers was not homogeneous. This notion has implications for current support arrangements for informal caregivers, which aim to alleviate caregivers through (temporary) substitution and decreasing perceived burden. Results from chapter 2 imply that policies and support arrangements should be tailored to address the needs of different groups.

Building on that, **Chapter 3** shows that support arrangements do not always reach informal caregivers timely to help preventing an increase of the burden to a level that they can no longer persevere in their role. The main question of chapter 3 was: how is informal care support related to the time spent on informal care and the perceived burden of informal care? For this study, data from 9,569 informal caregivers included in the Informal Care Monitor by the Netherlands Institute of Social Research were used. In this survey, informal caregivers reported on using the following support arrangements: information and advice, training, support groups, material help (e.g., free parking), financial help, help with requesting arrangements, other. As percentages of specific types of support were very low, we clustered these options and created a binary variable to indicate whether or not someone receives support. Ordinary least-squares regression models were applied to assess the relationship between received municipal support and the three caregiving outcomes: the number of hours spent on informal care, the subjective burden from caregiving and whether the informal caregiver was heavily burdened. Findings show that informal caregivers who received support often experienced a greater burden as compared to those who did not receive such assistance. One explanation could be that informal caregivers are only reached in a late stage, despite efforts by municipalities to reach out to informal caregivers early to prevent overburdening. This implies that, beyond tailoring support (chapter 2), support arrangements must account for the difficulty in proactively engaging informal caregivers and the uncertainty surrounding the effectiveness of existing support arrangements.

Besides looking at the burden of informal caregivers and how crises and support arrangements relate to that, this thesis also studies the practices of informal care involvement in nursing homes. This, to gain better insight into how professional care practices and organizational policies relate to informal care involvement. While the first half of this thesis used quantitative methods, the second half uses qualitative methods: mainly interviews. In these interviews, relationships between professional caregivers and informal caregivers are picked apart. The data is analyzed through a political lens: who gains what, when and how.

Chapter 4 starts from the notion that involving and substituting professional care with informal care more has consequences for both the practices of informal caregivers and professionals.

According to the convoys of care model, informal caregivers and professionals are interdependent and care has to be negotiated within these convoys. The negotiations between professionals and informal caregivers can therefore be considered a form of micropolitics. However, negotiations within the convoys of care have not explicitly been considered through a micropolitical lens in the literature. Therefore, in chapter 4 we pose the research question: how can we understand the micropolitics between professionals and informal caregivers in their (shared) attempts to organize care? For this study, 48 respondents were interviewed (including informal caregivers, professionals, care recipients and managers). The results show that both professionals and informal caregivers use different forms of micropolitics (e.g., (not) mobilizing the other, putting up boundaries, defining the object of care, surveillance, defying rules, and strategically applying rules). Micropolitics in the convoys of care give shape to care and what is perceived as quality of care. Some actors were better at having influence on care than others. This means that the interdependency between professionals and informal caregivers has consequences beyond those recognized in policies: (1) the work of professionals' changes as they have a role in the involvement of informal caregivers, and (2) how care is organized becomes more dependent on the relational skills of professionals and informal caregivers. Therefore, although involvement seems to align with values such as participation and cost-efficiency, in practice, involvement can also be at odds with other values such as protecting the rights of clients and informal caregivers or the sustainability of care beyond that extended to a single client. There is little guidance for professionals to deal with these tensions, and informal caregivers do not always have the skills to be successful in negotiating their values.

Chapter 5 focuses on the negotiation of values. Namely, involving informal caregivers in care means also including their views and values. This poses a challenge to organizations and professionals. The interviews from chapter 4 showed that interactions around mundane objects can provide a lot of information about what is important for informal caregivers in the care for their loved one. However, thus far, objects have not been considered as part of convoys of care. Therefore, Chapter 5 uses interview data from 22 informal caregivers to answer the research question: what is the role of objects in the negotiations between healthcare professionals and informal caregivers? The results show that objects, in terms of their affordances and the values they embody, become important in the relationship between professionals and informal caregivers, and that they become part of negotiations on quality of care because of this. Seemingly mundane objects become topics of conversation to address more fundamental concerns in how healthcare is organized for and provided to individual clients. To informal caregivers, objects can be a source of unsettlement, and a way to articulate concerns about care. Furthermore, objects require care in their own right, which was very important to informal caregivers. Chapter 5 helps in opening up the care convoys model to objects as important actors, and deepening our understanding of the politics within care convoys. This study implies that, as fundamental concerns of informal caregivers were addressed through objects, they could help in joint reflections between professionals and informal caregivers and can be part of experimenting to improve the quality of care.

In conclusion, this dissertation shows that shifting more responsibility. to informal caregivers is easier said than done. First, because the “informal caregiver” as such remains elusive, as there is great heterogeneity amongst informal caregivers and the consequences of providing care they experience. Furthermore, support does not always reach informal caregivers in an early stage to help prevent an increase of burden so that they can persevere in their role. Third, involvement of informal caregivers has consequences beyond those recognized in policies: the work of professionals changes, and how care is organized becomes more dependent on the relational skills of professionals and informal caregivers. Lastly, involving informal caregivers in care means also including their views and values. This poses a challenge to organizations and professionals. More attention for interactions around mundane objects can provide a lot of information about what is important for informal caregivers in the care for their loved one. Policymakers, professionals, informal caregivers and care recipients can use the above insights for identifying and paving the paths for future endeavors to better involve informal caregivers in care processes.

Samenvatting

Dit proefschrift bestudeert beleid en praktijken die mantelzorgers beïnvloeden. Dit is van belang vanwege de toenemende aandacht voor mantelzorg als oplossing voor tal van problemen in de zorgsector. Over de gevolgen van een grotere betrokkenheid van mantelzorgers wordt in de literatuur nog steeds veel gedebatteerd. Dit proefschrift heeft tot doel een bijdrage te leveren aan een beter begrip van de gevolgen voor mantelzorgers en zorgorganisaties. Met behulp van zowel kwalitatieve als kwantitatieve methoden wordt de relatie tussen beleid en praktijk van mantelzorg onderzocht. De belangrijkste onderzoeksvraag luidt:

Wat kunnen we leren van het huidige mantelzorgbeleid en de zorgpraktijk in Nederland voor toekomstige inspanningen om mantelzorgers beter bij de zorg te betrekken?

Dit proefschrift laat zien dat de afhankelijkheid van mantelzorgers gevolgen heeft voor zorgontvanger, professioneel zorgverlener en mantelzorger en dat het beleid beter op deze gevolgen moet worden afgestemd. In de eerste plaats moet in dit beleid aandacht zijn voor verschillen, omdat 'de mantelzorger' niet bestaat. Mantelzorgers vormen een bijzonder heterogene groep. Ook wordt het verlenen van mantelzorg zeer verschillend ervaren. Deze conclusie kan worden getrokken op basis van **hoofdstuk 2**, waarin de objectieve en ervaren zorglast van mantelzorgers tijdens de COVID-19-pandemie worden onderzocht. De belangrijkste vraag was: hoe is de belasting van mantelzorgers veranderd gedurende de COVID-19-crisis? En hoe was deze belasting gerelateerd aan kenmerken van mantelzorgers, zorgontvangers en de mantelzorgsituatie? Zelf-gerapporteerde gegevens van 965 mantelzorgers zijn gebruikt om te onderzoeken in hoeverre mantelzorgers drie maanden na de COVID-19-pandemie in Nederland een verandering in belasting ervoeren. Er zijn drie uitkomstmaten gebruikt: (1) de verandering in de tijd besteed aan informele zorg, (2) de verandering in ervaren lasten en (3) de zorg-gerelateerde kwaliteit van leven. Uit hoofdstuk 2 blijkt dat de ervaren belasting van mantelzorgers gemiddeld licht was toegenomen, terwijl de gemiddelde tijd die aan mantelzorg werd besteed niet veranderde. Als we echter verder kijken dan het gemiddelde, laten de gegevens zien dat sommige mantelzorgers meer en anders getroffen werden dan andere. Sommigen besteedden meer tijd aan het verlenen van zorg, terwijl anderen een toename van de ervaren belasting ervoeren. Dit had niet noodzakelijkerwijs betrekking op hun relatieve kwaliteit van leven. De impact van de COVID-19-pandemie op mantelzorgers verschilde derhalve van geval tot geval. Deze bevinding heeft implicaties voor ondersteuningsregelingen voor mantelzorgers, voor zover deze betrekking hebben op de vermindering van door hen ervaren belasting door bijvoorbeeld tijdelijke vervanging of het bieden van aanvullende zorg. De resultaten uit hoofdstuk 2 impliceren dat beleid en steunregelingen moeten worden afgestemd op de behoeften van verschillende groepen.

Hierop voortbouwend laat **hoofdstuk 3** zien dat mantelzorgers niet altijd tijdig worden bereikt met ondersteuning om te helpen voorkomen dat de belasting zodanig toeneemt dat zij hun rol niet langer kunnen volhouden. De hoofdvraag van hoofdstuk 3 was: hoe verhoudt mantelzorgondersteuning zich tot de tijd die aan mantelzorg wordt besteed en de ervaren belasting van mantelzorgers? Voor dit onderzoek is gebruik gemaakt van gegevens van 9.569 mantelzorgers die zijn opgenomen in de Monitor Mantelzorg van Maatschappelijk Onderzoek. In dit onderzoek rapporteerden mantelzorgers over het gebruik van de volgende ondersteuningsvormen: informatie en advies, training, steungroepen, materiële hulp (bijvoorbeeld gratis parkeren), financiële hulp, hulp bij het aanvragen van regelingen, overige. Omdat de percentages van specifieke vormen van ondersteuning erg laag waren, hebben we deze opties geclusterd en een binaire variabele gemaakt om aan te geven of iemand wel of niet ondersteuning krijgt. OLS-regressiemodellen werden toegepast om de relatie tussen de ontvangen gemeentelijke steun en de drie zorguitkomsten te beoordelen: (1) tijd besteed aan mantelzorg, (2) de ervaren belasting van mantelzorgers en (3) of de mantelzorger wel of niet zwaar belast werd. Uit de bevindingen blijkt dat mantelzorgers die ondersteuning kregen vaak een grotere belasting ervoeren dan degenen die deze hulp niet kregen. Een verklaring zou kunnen zijn dat mantelzorgers pas in een laat stadium worden bereikt, ondanks inspanningen van gemeenten om mantelzorgers vroegtijdig te bereiken om overbelasting te voorkomen. Dit impliceert dat, naast het op maat maken van de ondersteuning (hoofdstuk 2), er rekening moeten worden houden met de moeilijkheid om mantelzorgers preventief te betrekken en met de onzekerheid rond de effectiviteit van bestaande ondersteuningsvormen.

Naast de belasting van mantelzorgers, bestudeert dit proefschrift de praktijken van mantelzorgers in verpleeghuizen. Dit om beter inzicht te krijgen in hoe professionele zorgpraktijken en organisatiebeleid zich verhouden tot betrokkenheid van mantelzorgers. Terwijl in de eerste helft van dit proefschrift gebruik werd gemaakt van kwantitatieve methoden, maakt de tweede helft gebruik van kwalitatieve methoden. Door middel van interviews worden relaties tussen professionele zorgverleners en mantelzorgers bevraagd. Daarin worden twee dimensies uitgelicht: de politiek dimensie en die van de rol van objecten.

Hoofdstuk 4 vertrekt vanuit het idee dat het betrekken en vervangen van professionele zorg door mantelzorg consequenties heeft voor zowel de praktijk van mantelzorgers als professionals. Volgens het *Convoys of Care* model (CoC) zijn mantelzorgers en professionals onderling afhankelijk en moet er binnen de netwerken rondom zorgontvangers ("*convoys*") over de zorg worden onderhandeld. De onderhandelingen tussen professionals en mantelzorgers kunnen worden beschouwd als een vorm van micropolitiek. Onderhandelingen binnen de CoC worden in de literatuur echter niet expliciet door een micropolitieke lens bekeken. Daarom stellen we in hoofdstuk 4 de onderzoeksvraag: hoe kunnen we de micropolitiek tussen professionals en mantelzorgers begrijpen in hun (gedeelde) pogingen om de zorg te organiseren? Voor dit onderzoek zijn 48 respondenten geïnterviewd (waaronder mantelzorgers, professionals, zorgvragers en managers). De resultaten laten zien dat zowel professionals als mantelzorgers verschillende vormen van micropolitiek gebruiken (bijvoorbeeld het (niet) mobiliseren van de ander, het stellen van grenzen, het definiëren van het zorgobject, toezicht houden, het afwijken van regels en het strategisch toepassen van regels). Micropolitiek in de CoC geeft vorm aan de zorg en aan wat als kwaliteit van zorg wordt ervaren. Sommige actoren konden beter invloed uitoefenen op de zorg dan andere. Dit betekent dat de onderlinge afhankelijkheid tussen professionals en mantelzorgers gevolgen heeft die verder gaan dan die welke in het beleid worden erkend: (1) het werk van professionals verandert naarmate zij een rol spelen in de betrokkenheid van mantelzorgers, en (2) de manier waarop de zorg wordt georganiseerd wordt afhankelijker van de relationele vaardigheden van professionals en mantelzorgers. Hoewel betrokkenheid van mantelzorgers overeen lijkt te komen met waarden als participatie en kostenefficiëntie, kan betrokkenheid in de praktijk ook op gespannen voet staan met andere waarden, zoals het beschermen van de rechten van zorgontvangers en mantelzorgers en de houdbaarheid van de zorg die verder reikt dan alleen een enkele cliënt. Er zijn weinig richtlijnen voor professionals om met spanningen in de relatie met mantelzorgers om te gaan, en mantelzorgers beschikken niet altijd over de vaardigheden om succesvol te zijn in het onderhandelen van hun waarden.

Hoofdstuk 5 richt zich op het onderhandelen over waarden. Het betrekken van mantelzorgers bij de zorg betekent namelijk ook het betrekken van hun opvattingen en waarden. Dit vormt een uitdaging voor organisaties en professionals. Uit de interviews uit hoofdstuk 4 bleek dat interacties rond alledaagse voorwerpen veel informatie kunnen opleveren over wat belangrijk is voor mantelzorgers in de zorg voor hun naaste. Tot nu toe worden objecten echter niet beschouwd als onderdeel van CoC (i.e., de netwerken van zorgontvangers). Hoofdstuk 5 gebruikt daarom interviewgegevens van 22 mantelzorgers om de onderzoeksvraag te beantwoorden: wat is de rol van objecten in de onderhandelingen tussen zorgprofessionals en mantelzorgers? De resultaten laten zien dat objecten, in termen van hun mogelijkheden en de waarden die ze belichamen, belangrijk worden in de relatie tussen professionals en mantelzorgers, en dat ze hierdoor onderdeel worden van onderhandelingen over de kwaliteit van zorg. Ogenschijnlijk alledaagse objecten worden gespreksonderwerpen om meer fundamentele problemen aan te pakken in de manier waarop de gezondheidszorg wordt georganiseerd voor en wordt verleend aan individuele cliënten. Voor mantelzorgers kunnen voorwerpen een bron van onrust zijn en een manier om zorgen over de zorg te uiten. Bovendien hebben objecten op zichzelf zorg nodig, wat voor mantelzorgers erg belangrijk was. Hoofdstuk 5 helpt bij het openstellen van het CoC model voor objecten als belangrijke actoren, en bij het verdiepen van ons begrip van de politiek binnen CoC. Deze studie impliceert dat, aangezien fundamentele zorgen van mantelzorgers door middel van objecten worden aangepakt, ze kunnen helpen bij gezamenlijke reflecties tussen professionals en mantelzorgers en deel kunnen uitmaken van experimenten om de kwaliteit van de zorg te verbeteren.

Concluderend laat dit proefschrift zien dat zorg verder verschuiven naar mantelzorgers gemakkelijker gezegd is dan gedaan. Ten eerste omdat er grote verschillen bestaan tussen mantelzorgers en ten tweede omdat het bestuurlijk complex is om hen tijdig en adequaat te ondersteunen. Ten derde vereist de samenwerking van professionals met mantelzorgers nieuwe vaardigheden van beiden en zijn structuren en regels in zorgorganisaties onvoldoende ondersteunend aan de wens mantelzorgers beter te betrekken. Tenslotte dient geconstateerd te worden dat betrekking van mantelzorgers respect impliceert voor door hen belangrijke normen en waarden. Door de mantelzorger uitgelichte objecten kunnen een aanleiding vormen om hierover in gesprek te gaan. Beleidsmakers, professionals, mantelzorgers en zorgontvangers kunnen bovenstaande inzichten gebruiken voor het effenen van de weg voor toekomstige inspanningen om mantelzorgers beter te betrekken bij zorgprocessen.

Dankwoord

Hier staan wij dan, elkaar genadeloos terloops omhelzend.
Het is met hangen en wurgen maar we zijn er nog
en kunnen getroost huiswaarts naar onze tweezitsbank.

Victor Vroomkoning (Uit: Gebroken Wit, 2018)

Dit proefschrift staat niet op zichzelf en heeft alleen maar tot stand kunnen komen door een aantal belangrijke mensen in mijn leven. Ik ben ze daar stuk voor stuk ontzettend dankbaar voor. Ik heb me voor, tijdens en na mijn proefschrift gedragen gevoeld.

Ten eerste wil ik graag mijn promotieteam bedanken. Hester, Job en Pieter, jullie waren een heel fijn team om mee te werken. Jullie zijn drie hele verschillende mensen en onderzoekers, wat veel kleur heeft gegeven aan het onderzoek in dit proefschrift. Ondanks de verschillen vonden we altijd weer gemeenschappelijke taal gedurende de afgelopen jaren. Dankjewel voor jullie tijd en aandacht. Pieter, dankjewel voor je inhoudelijke gedrevenheid en je pragmatische kijk op het proces. Met jouw insteek waren dingen beter behapbaard. Job, bedankt voor de warme procesbegeleiding en betrokkenheid. Je stond altijd klaar om mee te denken. Hester, bedankt voor het invliegen halverwege. Jij bracht lol en souplesse in het proces en je bracht nieuwe invalshoeken met je mee. Ik heb jouw ontspannen houding als erg leerzaam ervaren. Tot slot wil ik Marianne van Bochove bedanken. Zij maakte deel uit van mijn promotieteam in de eerste twee jaar, maar kreeg daarna een andere baan. Dankjewel, Marianne, voor de gezamenlijke start. Als beginnende promovenda voelde ik me altijd erg op mijn gemak bij jou. Ik had je er graag bijgehad tot het eind!

Naast mijn supervisors, zijn er vele andere collega's die ik moet bedanken, omdat zij het proces leuk hebben gemaakt en omdat ze met hun invalshoeken mijn werk hebben verdiept. Dankjewel Chiara, Nada, Iris, Sabrina, Nienke, Mirjam, Renee, Margot, Hugo, Hanna, Robert, Marjolein, Jonathan, Amalia, Oemar, Relmbuss, Sydney, Koray, Jolien, Tessa, Syb, Gijs, Karin, Gigi, Marcello, Milan, Jans en nog velen! Ook werkte ik samen met een aantal collega's, die ik wil bedanken voor de interessante discussies en de fijne samenwerking. Bedankt Martijn, voor het enthousiasme dat je overbrengt en je conceptuele kundigheid. Verder wil ik Teyler, Judith en Leonie bedanken voor de samenwerking op verschillende papers. Tot slot, wil ik Mirjam de Klerk en Inger Plaisier van het SCP bedanken voor de prettige samenwerking voor hoofdstuk 3 van deze dissertatie.

Ook naast werk heb ik veel steun gehad aan mensen om mij heen. Mijn vrienden, met een aantal van wie ik in de laatste twee weken van mijn proefschrift contract nog een week op vakantie ging en die mij dus in alle staten kennen, wil ik bedanken voor hun vriendschap. Ook al zie ik sommige minder dan anderen, bij jullie allemaal heb ik het gevoel thuis te komen. Jullie zijn heel belangrijk voor me, zoals ik al vele malen in beschonken toestand heb georeerd. Ik zal proberen niet iedere zin te beginnen met 'ik vind' in de verdediging… Dankjewel Jik, Ali, Roos, Jan, Piertje, Fred, Vik, Od, Lies, Siem, Linds, Lianne, Floriaan en Michelle! *Furthermore, I made some new friends along the way who deserve a shout out for our good conversations about (women in) academia, endless nights of beers and stunning Eurovision outfits. Thank you Orsa, Emma, Andreas, Gorka, Nora, Nico, Wade, Kevin and Tara. Hopefully we'll have many more roadtrips and weekends away together!*

Wie ik ook wil bedanken met heel mijn hart is Douwe. Ik ben het pad wat ik nu bewandel grotendeels ingeslagen in de tijd dat ik bij jou en Joke werkte. Ik neem aan jullie graag een voorbeeld als het gaat om hoe met anderen om te gaan: met mededogen, vertrouwen en humor. Dit geldt ook voor Wim, Jelle, Lore, Jan-Willen en nog vele anderen in Winsum en omstreken. Helaas kan ik Joke niet meer bedanken voor alles wat ze voor me heeft betekend. Dat had ik graag gedaan. Ik denk aan haar op dit soort momenten.

Mijn familie heeft ook een belangrijke rol gespeeld. Dankjewel Egens, Sacha, Kees, Gijs en Celine. Jullie zorgen altijd voor welkome afleiding met alle bijzondere *life events* die er de afgelopen jaren zijn geweest. Ik ben trots op jullie en alles wat jullie doen! Ook bedankt aan Marjon en Pierre, mijn schoonouders. Door Mar kwam er altijd een eindeloze stroom schoenen en kleren mijn kant op en Pierre draaide eindeloos veel lampjes in in ons oude en huidige huis. Jullie onvoorwaardelijke steun en liefde aan Dyl en mij vanaf de eerste keer dat ik jullie ontmoette, vind ik heel bijzonder.

Het laatste dankwoord voor familie wil ik geven aan mijn ouders, die met grote trots het hele proces hebben meegeleefd en -gedacht. Pap, toen jij promoveerde, zaten de jongens en ik met Donald Duckjes in de zaal. Ik weet nog hoe leuk die dag was, maar ik weet ook nog het werk dat eraan voorafging. Kennelijk was dat toch niet afschrikwekkend genoeg om het niet zelf ook nog te proberen. Mam, ook jij was gedurende mijn promotietraject bezig met een groots project. Ik weet zeker dat we daar ook ooit een feestje voor gaan vieren. Pap en mam, ik hou van mijn fiets… en van jullie. En niet noodzakelijkerwijs in die volgorde! Bedankt voor jullie luisterend oor, trots en enthousiasme.

Lieve Dyl. Alweer 4 jaar geleden vierden we dat jij promoveerde. Helaas zonder feestje vanwege corona. Trots en gespannen zaten je ouders en ik op de bank voor de tv, in de airbnb om te hoek van het academiegebouw, terwijl jij peentjes zweette in die veel te lege zaal. Ik zat voor de tv zoals jij voor een spannende voetbalwedstrijd zit, schreeuwend: DIT WEET 'IE! Nu zijn de rollen omgedraaid en is het tijd om wat rekeningen te vereffenen als het gaat om *mental breakdowns* over lettertypes (in de volksmond: *"font gate"*)! Jouw steun en plezier in het doen van onderzoek hebben me altijd weer uit de put getrokken als het even te veel werd. Ik ben dol op jouw kijk op de wereld en het plezier dat we samen hebben. Jij ziet altijd wat belangrijk is in het leven. En in essentie is dat wat belangrijk is in het leven, ook wat het onderwerp van dit proefschrift omhelst: liefde en samen zijn. Dankjewel dat jij jij bent, ik kan me geen leukere pensioenpartner voorstellen dan jij. Ik kijk uit naar de volgende avonturen met jou en Pusan. #Hannah&Lutti4ever #44m2tijdenscorona.

Portfolio

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BKO courses
Groepsdynamiek
Lesobservatie
Basic didactics
Supervise your students

Contributions to conferences and symposia

Conferences
Transforming Care Conference (TCC) • 2023
European Health Economists Association (EuHEA) • 2022
European Association for the Study of Science and Technology (EASST) • 2022
European Group for Public Administration (EGPA) • 2022
Transforming Care Conference (TCC) • 2021
Vienna Institute of Demography (VID) – Best poster award • 2020

Symposia
Argos - samenwerken met mantelzorgers • 2023
Mantelzorgcafé - samenwerken met mantelzorgers • 2023

Teaching activities

Quality and safety – tutor – Master health care management • 2019 Comparative health policy – tutor – Master health economics, policy and law • 2020
Comparative health policy – tutor – Master health economics, policy and law • 2021
Thesis supervision (3 students) – Master health care management • 2021

Comparative health policy – tutor – Master health economics, policy and law • 2022
Thesis supervision (6 students) – Bachelor gezondheidswetenschappen • 2022
Advanced research methods – tutor – Master health economics, policy and law & health care management • 2023

Ancillary activities

PhD representative (external relations) – young ESHPM • 2021-2022
PhD representative – Erasmus Graduate School for Humanities • 2021-2022

About the author

Leonoor Gräler was born in 's-Hertogenbosch on the 28th of February 1993. She studied psychology at the University of Groningen. During her studies she provided care for someone with Parkinson's disease.

After her bachelor degree, she worked at the University Medical Hospital Groningen (UMCG), where she was part of several projects in a multitude of nursing homes. All these projects focused on the intersection between improving practices and academic knowledge accumulation. Leonoor was involved in projects on pain assessment, problematic behavior and psychotropic drug use, and developing an app and process to assess the problems and needs of people with dementia. During her work at the UMCG, Leonoor completed a pre-master in Health Care Management at the Erasmus University Rotterdam. Consequently, she moved to Rotterdam to finish her master degree in Health Economics, Policy and Law.

During her master program, Leonoor worked as a research assistant at the department of Health Systems, Management and Operations at the Erasmus School of Health Policy and Management (ESHPM). She was involved in a project on municipal support for people with multiple and complex problems. Furthermore, she gathered data on preferences for cataract surgeries in the Eye Hospital in Rotterdam. She finished her master degree with an economic dissertation on informal care: "The influence of macroeconomic shocks on informal care in regions".

In 2019, right after attaining her master degree, Leonoor started her PhD on informal care at the sections Health Care Governance and Health Economics at ESHPM. During her PhD, Leonoor's research focused on how informal care relates to formal care arrangements and governmental policies. She has developed herself into a multidisciplinary scholar, using several different quantitative and qualitative research methods. Furthermore, she was involved in projects with other colleagues, taught several courses in different bachelor and master programs, and did ancillary activities such as the PhD board of the Erasmus Graduate School for Humanities. Leonoor's goal in life is to have her own nursing home, where doors do not close and family and friends are central to the day-to-day lives of people residing in the nursing home.

This dissertation studies informal caregivers and their position within the Dutch healthcare system. In the past decades, governments and care organizations have paid attention to informal care as a solution to many problems in the healthcare sector. However, the range of consequences of reliance on informal care is still much debated in the literature. Using qualitative and quantitative methods, this dissertation aims to contribute to a better understanding of the consequences of providing informal care, and how policy and professional care affect informal caregivers.

The analysis of this dissertation shows that shifting responsibility to informal caregivers is complex, while substantial consequences for informal caregivers, professionals and care recipients remain unseen. The first part of this dissertation shows that the group of informal caregivers is very diverse, requiring more tailored policies, such as support arrangements aimed at specific groups of caregivers. At the same time, findings show that support arrangements are mostly used when the burden of care is already very high, while they are meant to prevent high burden. The second part of this dissertation studies the relationship between professionals and informal caregivers in nursing homes. Findings show that the increasing interdependency between professionals and informal caregivers has consequences beyond those recognized in nursing home policies. The micropolitics between professionals and informal caregivers are teased out, showing that the organization of care is dependent on the relational skills of those involved. Furthermore, findings show that mundane objects are used by informal caregivers to negotiate values in the care process. Policymakers, professionals, informal caregivers, and care recipients can use the insights of this dissertation in their future endeavors to better involve informal caregivers in care processes.

LEONOOR GRÄLER (1993) was born in ‘s-Hertogenbosch in The Netherlands. She had several roles in the care sector, amongst which caregiver, advisor, and researcher. As a researcher, Leonoor is skilled in both quantitative and qualitative research methods. Her multidisciplinary research focuses on the organization of care for older people.