Competing claims of justice in the private household: The Dutch case

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This Working Paper was written within the framework of Work Package 5 “Justice as Lived Experience” for Deliverable 5.3 (Comparative report on competing claims for justice and everyday practices of recognition and redistribution in the private household and a reflection on how those tensions affect the capabilities and functionings of the various individuals/groups studied)

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About ETHOS

ETHOS - Towards a European THeory Of juStice and fairness is a European Commission Horizon 2020 research project that seeks to provide building blocks for the development of an empirically informed European theory of justice and fairness. The project seeks to do so by:

a) refining and deepening knowledge on the European foundations of justice - both historically based and contemporarily envisaged;
b) enhancing awareness of mechanisms that impede the realisation of justice ideals as they are lived in contemporary Europe;
c) advancing the understanding of the process of drawing and re-drawing of the boundaries of justice (fault lines); and
d) providing guidance to politicians, policy makers, activists and other stakeholders on how to design and implement policies to reverse inequalities and prevent injustice.

ETHOS does not only understand justice as an abstract moral ideal that is universal and worth striving for but also as a re-enacted and re-constructed 'lived' experience. This experience is embedded in legal, political, moral, social, economic and cultural institutions that claim to be geared toward giving members of society their due.

In the ETHOS project, justice is studied as an interdependent relationship between the ideal of justice and its manifestation – as set out in the complex institutions of contemporary European societies. The relationship between the normative and practical, the formal and informal, is acknowledged and critically assessed through a multi-disciplinary approach.

To enhance the formulation of an empirically based theory of justice and fairness, ETHOS will explore the normative (ideal) underpinnings of justice and its practical realisation in four heuristically defined domains of justice - social justice, economic justice, political justice, and civil and symbolic justice. These domains are revealed in several spheres:

a) philosophical and political tradition;
b) legal framework;
c) daily (bureaucratic) practice;
d) current public debates; and
e) the accounts of vulnerable populations in six European countries (Austria, Hungary, the Netherlands, Portugal, Turkey and the UK).

The question of drawing boundaries and redrawing the fault-lines of justice permeates the entire investigation.

Utrecht University in the Netherlands coordinates the project, and works together with five other research institutions. These are based in Austria (European Training and Research Centre for Human Rights and Democracy), Hungary (Central European University), Portugal (Centre for Social Studies), Turkey (Boğaziçi University), and the UK (University of Bristol). The research project lasts from January 2017 to December 2019.

EXECUTIVE SUMMARY

This national case study on the Netherlands contributes to ETHOS Deliverable 5.3 by mapping everyday negotiations of potentially conflicting claims for justice with attention to the role of gender and ethnicity. The study explores the accommodation of justice claims in the lives of care users and – mainly female – care workers with focus on their capabilities and functionings. This is done by means of mini-ethnographies of five commodified care relationships, where disabled care users are cared for by paid care workers in private households. The mini-ethnographies are supplemented by in-depth interviews to examine the experiences of (in)justice by care users, care workers and close relatives, paying attention to conflicts, the impact of gender, religion and race on the relationship and how disabled people and care workers understand and manage potential competing claims for justice. For this task guidelines for mini-ethnographies were developed and discussed by the WP5 researchers at a workshop during the ETHOS conference in Coimbra in Spring 2018. National studies were then conducted by all partners except the University of Bristol.

The first part of this Dutch report focuses on the recognition and redistribution of care as fluid institutional practices of which the boundary lines are continuously redefined within a settled framework, that is redefinitions are ‘conjunctural’ and even experimental – regarding costs, accountability and responsible actors - while the cadres of the framework are rather stable. It presents and overview of national data on the provision of care in different settings – residual and in private homes and comprises an analysis of: a) demographic data, legal regulations and the social policy of homecare and its redistributive character as implemented by institutional actors - national and local governments, insurance companies and care providers – and professional and informal care workers; b) tensions inherent in the Dutch care system, in particular the free riders’ problem and private parties’ efforts to develop a niche market of live-in migrant care workers; c) giving and receiving care as recognized citizenship rights, and cooperation between paid and unpaid caregivers. The second part presents the results of the in-depth study on competing claims of recognitive and redistributive justice and how these affect the functioning of care recipients, paid care workers and informal care workers who are family members in their daily interaction. It focuses on the understanding of justice claims in the domain of home care, on negotiating potential conflicting justice claims, and on the perception of the role of the state in potential tensions between care workers and care users.

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LIST OF ABBREVIATIONS

AMvB	(Algemene Maatregel van Bestuur/ General Government Decision)
BIG	(Beroepen in de Gezondheidszorg/ Professions in Healthcare)
CRvB	(Centrale raad van Beroep/ Central Appeals Tribunal)
PGB	(Persoons Gebonden Budget/ Person Related Budget [– for care])
SVB	(Sociale VerzekeringsBank/ National Insurance Bank)
UWV	(Uitvoeringsinstituut Werknemersverzekeringen/ Employee Insurance Agency)
VIG	(Verzorgende Individuele gezondheidszorg/ Care Worker Individual Healthcare)
Wlz	(Wet langdurige zorg/ Act long-term care)
Wmo	(Wet maatschappelijke ondersteuning/ Social Support Act)
Zvw	(Zorgverzekeringswet/ Healthcare Insurance Act)

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PART I

1. *INTRODUCTION*

This national case study of commodified care relations in the Netherlands comprises an overview and analysis of: a) demographic data, legal regulations and the social policy of homecare and its redistributive character as implemented by institutional actors - national and local governments, insurance companies and care providers – and professional and informal care workers; b) tensions inherent in the Dutch care system, in particular the free riders’ problem and private parties’ efforts to develop a niche market of live-in migrant care workers; c) the rights to give and receive care as a recognized citizenship right, and cooperation between paid and unpaid caregivers; d) an empirical study on competing claims of justice and how these affect the functioning of care recipients and paid and unpaid care workers. The first part of this case study presents and overview of national data on the provision of care in different settings – residential and in private homes and focuses on the recognition and redistribution of care as a fluid institutional practice where the boundary lines are continuously redefined within a settled framework, that is redefinitions are ‘conjunctural’ and even experimental – regarding costs, accountability and responsible actors - while the framework itself is rather stable. The second part will analyse how care workers, care recipients (and their kin) experience redistributive and recognitive justice in their daily interaction, what tensions occur and how this affects their capabilities and functionings.

1.1. SELECTION OF SOURCES AND DATA

In addition to English language literature on home care in the Netherlands, which is mainly social policy oriented and also includes empirical in-depth studies on care relations, we have searched for Dutch language literature on home care. The Dutch language literature exhibits a wide variety of data-based overviews and scholarly studies on ongoing social policy reforms, including the most recent decentralisation of responsibility for home care to local municipalities, its effects on the quality of life of care recipients and – as yet unconfirmed - concerns about social inequality resulting from these reforms. Studies on professional care work mainly focus on the sectoral labour market while some studies investigate care ethics of professional care workers and their role in care networks. Most common however are studies on unpaid home care by relatives, an issue falling outside the scope of Deliverable 5.3 but summarized here because paid home care in the Netherlands cannot be understood without an analysis of the additional and very often central care work performed by unpaid – mainly female – relatives.

For the selection of Dutch language literature, we have applied inclusive and exclusive criteria. An initial search was conducted using Google Scholar for the Dutch terms ‘thuiszorg’, ‘betaalde thuiszorg’, ‘kwaliteit thuiszorg’ (respectively ‘home care’, ‘paid home care’ and ‘quality of home care’) and the more specified terms ‘thuiszorg gehandicapten’ (‘home care for people with disabilities’) and ‘thuiszorg ouderen’ (‘homecare for older people’). Interestingly the last two search terms only referred to publications on mentally and/or psychologically challenged care recipients. Studies on care recipients with bodily/physiological challenges were absent. A second search was performed by screening the websites of Dutch research institutes known for their regular reports on care and care work, including the Netherlands Institute for Social Research (SCP) and Dutch Statistics (CBS). Thirdly, we screened the internet publications of employer and employee organisations (Uitvoeringsinstituut Werknemersverzekeringen/ Employee Insurance Agency/ UWV, and trade unions) in the care sector offering data overviews related to labour market developments in the domain of care. Finally, we searched websites of Dutch scholars for Dutch language publications that might offer new perspectives that have not (yet) been translated and published in English but we found that these are scarce. We did not include White and Green papers on Care Policy as these are subject of D5.4, we also excluded newspaper articles, grey publications and social media on the transition of care responsibilities to local level governments because of time constraints. We finally have excluded scholarly articles on care support for psychologically challenged people (those suffering from dementia, and Alzheimer's, or born with Downs' Syndrome, etc.) because the focus of D5.3 is on people who are mentally sound.

1.2. THE RIGHT TO RECEIVE AND GIVE CARE

From a comparative perspective Dutch citizens' right to receive and to give care are generous and strictly regulated, and they are in continuous transition (Da Roit, 2012; Knijn and Verhagen, 2007). Both these citizens' rights, defined by Knijn and Kremer (1997) as additional to Marshall's five citizens' rights to work, income, health, housing and education can be viewed, from a justice perspective, as indicators of the recognition of care needs and care work. Recognition of care work in the Netherlands however, still does not mean that care work is considered of equal value. Knijn and Kremer (1997) as well as feminist social policy scholars (Ungerson, Daly, Lewis, Saraceno, Leira, Glendinning, Lister, Hobson, Orloff among many others) point out the highly gendered character of care work, and how it hierarchically divides and stratifies not only the labour market but also social positions and relations between men and women, and probably also between care recipients and care workers.

The generosity of the right to receive care implies that all Dutch adults – and parents of children below the age of 18 - in need of care can apply for a variety of care provisions, some of which come as rights, though others have recently been transformed into provisions depending on municipal discretion. Strict regulation means that the kind of care one receives, its duration, costs and the way it is compensated for by (public) insurance depends on the indicated seriousness of care needs. A major care policy assumption acknowledged by the majority of the population - although not always facilitated to everyone's satisfaction - is that people stay at home 'as long as possible'. Individuals only move into residential care if they can't live as an independent person anymore according to some very specified criteria (see below). Hence, the Dutch care system covers all care needs via stepwise care service provisions - from a low degree of home care comprising light housekeeping and support for daily activities to full residential care – with accommodating public insurance and income related individual financial contributions following these degrees. Major bottlenecks in guaranteeing the right to receive care include the increasing cost due to an ageing population, discontinuity in care policy caused by the political decision to decentralize care responsibilities to the municipalities, a fluid labour market, high workloads damaging the quality of care, and arbitrariness in the assessment system due to recent reforms affecting the lowest level of care. Other disputes in the right to give care are the still gendered character of formal and informal care work, the fluid boundary lines between – female – family and professional care, and the fragile care labour market caused by marketization and associated poorly paid and insecure job contracts for intensive jobs. Overviewing the Dutch literature on paid home care the main question appears to be: 'How do we care well in an efficient way?' That question includes the well-being of the care recipient - does (s)he feels well, what is his/her quality of life - as well as the well-being of the care worker - is (s)he overburdened, is (s)he well paid? - These questions illustrate the focus on the economic efficiency of care work that could be seen to contrast with the well-being questions that define care work from a moral perspective. Previously relatively well-structured and accessible care provisions have been challenged by policy reforms following the economic crisis and the associated decentralisation of the provision of the lightest forms of care (such as housekeeping for people who are unable to perform it themselves) which has been made the responsibility of local governments by the Social Support Act (Wmo/Ministerie van Volksgezondheid, Welzijn en Sport, 2015), substituting individual rights for local provisions, and accompanied by severe financial cutbacks.

2. *DEMAND AND SUPPLY OF CARE SERVICES*

2.1. RECEIVING CARE

In 2015 about two million Dutch people above the age of 18 (15 per cent of the population) received home care and/or social support. Some people combine forms of care resulting in nine per cent of the population receiving informal, six per cent publicly paid and three percent privately paid care and/or support at home. Most people who receive care and/or support at home are cared for by informal unpaid care givers (42 per cent), about 20 per cent use a combination of informal unpaid and formal paid care workers, and about six per cent use a combination of informal and privately paid care workers. Approximately 80 per cent of people living independently with severe disabilities receive care and support suggesting that the remaining 20 per cent do not receive such care. As might be expected, independently living people with a low degree of disability are more likely to receive informal (33 per cent) than publicly paid (25 per cent) care while people with more severe disabilities are more likely to be in receipt of publicly paid care (54 per cent) than informal help (almost 48 per cent) (Verbeek-Oudijk, Putman & de Klerk, 2017).

Nine per cent of the independently living Dutch population is 75 years or older of whom 44 per cent receive some kind of care and support; 24 per cent receive publicly paid care. High income populations often have a better health than low income populations, which may be one reason for them having lower levels of care and support. Nevertheless, the percentage of high and low-income groups receiving informal care and support is similar (nine per cent). Because the individual contribution for receiving publicly paid care is income related, high-income people in need of care more often use privately paid care in contrast to low-income people who more often use publicly paid care (Verbeek-Oudijk, Putman & de Klerk, 2017). In recent years, a decreasing number of people have become eligible for residential long-term care. People with a physical disability or psychiatric condition (not meaning mental disability) are less eligible for residential care following the 2015 long-term care reform (Statistics Netherlands, 2017). Data on the decentralised Social Support Act (Wmo 2015, see below) became only available in 2017. Statistics Netherlands has indicated that about one million people make use of this low-level care and support service, of whom 675 000 people (6,2 percent of the entire Dutch population) for housekeeping, daily activities, and personal care and support (CBS, 2017). Dutch municipalities have seen an increase of people who make use of the Wmo since the care reform of 2015, from 5,5 to 6,6 per cent of the population with variations between small and larger size municipalities (Binnenlands Bestuur, 2017).

2.2. DOING CARE WORK

The Employee Insurance Agency (Uitvoeringsinstituut Werknemersverzekeringen, UWV, 2017) nevertheless remarks that the social sector – including social care – still is the largest sector of the Dutch economy in which 1,24 million employees and 310 000 self-employed people are at work in 2016 although 80 000 jobs (six per cent) have been lost since 2012 mainly in nursing and caring work where 12 per cent of jobs have been lost due to government cutbacks. In 2017 the number of jobs in the sector increased for several reasons: the growing demand for care and nursing caused by population growth and ageing; economic growth; and a turn in politics supporting renewed investment in the sector, in particular in nursing homes. The political turn can be explained as the result of a widely supported citizens' initiative presented as national manifesto 'Sharp on elderly care' (Scherp op ouderenzorg) that made the newly appointed government decide to spend a higher proportion of the economic surplus on elderly care.

Labour market shortages are developing in the care sector with more vacancies for care workers, nurses, neighbourhood nurses, specialists in elderly care and doctors working for insurance companies or the Employment Insurance Agency. Young people do not see a promising career in this field. During the crisis young people did not start training in care as a response to the severe cutbacks in the sector, and the restricted access ('numerus fixus') to nursing education. The field of care also struggles with a negative image compounded by high work pressure and little excitement in elderly care work. One notable barrier is the highly regulated labour market for registered health care professionals (regulated by the Wet op de Beroepen in de Individuele Gezondheidszorg, BIG). Many nurses lost their jobs in 2013-2014 because of government cutbacks and consequently lost their BIG-registration as a qualified nurse because they had an insufficient number of working hours. In order to regain their registration, they have to re-educate and take new exams, which discourages many potential candidates (UWV, 2017).

Table 1: Job developments in the social care domain. Number of jobs (x 1.000) (average growth)

Number of jobs				Average growth		
Sector	2016	2017	2018	2016	2017	2018
Social care	1.240	1.252	1.270	-0,6%	1,0%	1,4%
Subsector						
Hospitals	288	287	291	-1,7%	-0,4%	1,4%
Nursing and caring	235	237	241	-0,4%	0,8%	1,5%
Mental healthcare	86	86	87	-1,5%	0,1%	1,1%
Disability care	164	165	167	-1,8%	0,6%	1,2%
Homecare	155	160	162	3,1%	2,8%	1,6%
Others healthcare	138	141	143	0,8%	2,3%	1,4%
Youth care	27	26	26	-7,4%	-3,4%	-1,0%
ECEC	74	77	79	0,2%	4,0%	3,0%
Social work	73	73	74	-0,8%	1,0%	1,0%

Source: UWV, 2017.

3. *THE SOCIAL POLICY AND LEGAL FRAMEWORK OF HOME CARE*

Since WWII in the Netherlands, long-term care services comprised informal care, formal care at home and formal residential care either in elderly homes (for people who need little support) or in nursing homes if they need a lot of assistance. Since the 1980s care policy for elderly and/or disabled persons prioritises 'staying at home as long as possible' whereas previously the practice had been that people moved into elderly homes at the age of about 70. This new trope reflects a tendency to individualization of lifestyles and the idea of free choice in care support for a more self-aware generation of elderly people. In addition, and in accordance with neo-liberal politics, a market for home care was created in the 1990s by outsourcing public provisions to commercialised providers. At the same time, the urgency of implementing more gender-equal measures following EU directed guidelines for improving women's economic independence resulted in the recognition of informal family care work. In the mood of the time cash-for-care systems were introduced offering some form of redistribution by payments for previously unpaid, mainly female, care workers; the *Persoonsgebonden Budget* (PGB) (Ungerson, 1997; Knijn and Verhagen, 2009; Grootegoed, Da Roit and Knijn, 2009).

In 2015 major policy reforms transformed the Dutch home care system. They have been summarized by Oomkens and Lepianka (2015) as: homecare today can be provided by paid home helps, care assistants or (community) nurses as well as by paid kin. Home helps provide formal domestic help at clients' homes (i.e. perform household tasks such as ironing and cleaning). Care assistants perform caring services, including personal care (bathing/dressing) and social activities. (Community) nurses deal with rehabilitative, supportive, promotive or preventive and technical nursing care. Until 2015, formal care services at home – except domestic help and social services – were covered by the Exceptional Medical Expenses Act (*Algemene Wet Bijzondere Ziektekosten*, AWBZ). The services that were available at home under the AWBZ included: assistance, personal care, nursing care and some forms of curative treatment. The Social Support Act (*Wet maatschappelijke ondersteuning*, Wmo 2007) covered the remaining formal home care services: domestic home help, meals on wheels, home adjustments and transport.

From 1 January 2015, the Long-Term Care Act (*Wet Langdurige Zorg*, Wlz) replaced the AWBZ. This has meant activities of a curative nature, such as long-term mental health care including treatment and home care by community nurses, have shifted to the Health Care Insurance Act (*Zorgverzekeringswet*, Zvw). Aspects of non-residential care, specifically assistance and the protected residence of mental health care clients, now fall under the renewed Social Support Act (*Wet maatschappelijke ondersteuning* 2015, Wmo 2015), which is implemented by municipalities. The number of people in residential care has been reduced by providing more formal and informal care in the home. These changes leave a strictly defined Wlz for the elderly and disabled persons with acute care needs (NRP, the Netherlands, 2014). Whereas the AWBZ provided a right to care, the Wmo commands delivery of tailor-made support, substituting the individual and insured right to home care with home care as a provision to be delivered by local government if they consider it appropriate. Under the Wmo 2017, financial support for care provision is only awarded if the financial resources and social network of the person seeking support, are insufficient. Finally, the government has reduced the municipalities' budget for light forms of home care with about 15 per cent and, for some clients, higher contributions than in the AWBZ are now requested (NRP, the Netherlands, 2014). Decentralisation to local governments combined with a huge budget cut resulted in a gap in care provision for those in need of home care. Austerity measures during the economic crisis caused the bankruptcy of many commercial homecare providers and consequent redundancy for about 80,000 care workers. In the end the revised Wmo of 2015 for the lightest form of home care (housekeeping daily activities) caused a lot of uncertainty about the right to care for people in need of it. Furthermore, self-responsibility had to be negotiated with civil servants at the 'kitchen table' which was experienced as intrusive and undermining recognitive and redistributive justice (van Hees, 2017).

Implementing the Social Support Act 2015 is a municipal responsibility. Local governments must assess people and if deemed necessary, provide low levels of support for housekeeping, daily meals, shopping assistance, a wheelchair or a stairlift, daily activities in an activity centre and social participation. Wmo care can be either received in kind or in cash. Cash-for-care (Persoonsgebonden Budget/PGB) offers the care recipient a budget in line with the indicated care needs with which (s)he can buy care services, and/or equipment, whose quality has to be approved by the municipality. Rights and obligations of both parties (care recipient and care worker) are strictly regulated, and the PGB is only allocated after the municipality has approved the care contract. Obligations for the care recipient are well-described and in addition to a task description also include specified working time, dismissal and holiday regulations, payment per hour, taxation and premiums. Only if the client is assessed as needing less than 12 hours of care for a maximum of two days a week can they make use of a so-called ‘alpha-help’, an unqualified worker domestic worker doing cooking, housecleaning, the laundry, shopping, small repair and maintenance work, care for children or elderly, or gardening. The care recipient can also use the PGB to pay a family care giver but this must be under an approved contract. Hourly wage rates are between 10 and 15 Euros. Payments are provided by the national insurance organisation (Sociale VerzekeringsBank/SVB). Care-in-kind is the alternative option for home care meaning that the care user receives professional care service from a for-profit or non-profit care provider that is contracted by the municipality.

People identified as having a medium level of need that goes beyond assistance in the household or support in social participation fall under the jurisdiction of the Health Care Insurance Act (*Zorgverzekeringswet*, 2005), a compulsory insurance for all Dutch citizens. The Health Care Insurance Act covers the costs of general practitioners, medicines, dental care (for children under 18), ambulance transport, the costs of birth assistance and maternal care, and personal care by a neighbourhood nurse. Like the Wmo it offers a choice between cash-for care (PGB) and professional care in kind to be delivered by a recognized care provider. Care in kind is more costly - 38,76 per hour as compared to 23,00 per hour for care service and 57,00 compared to 23,00 per hour for nursing. In both cases care recipients have formal obligations, including offering and updating the formal contract, accounting for working hours per week (not more than 40 hours) and controlling the quality and effectivity of the provided care.

High level care needs are covered by the Long-Term Care Act (*Wet langdurige zorg*, Wlz, 2014) and are rarely used for care at home. Most people, both elderly and disabled, who have severe care needs live in residential care (verpleeghuizen/ nursing homes) but in this case they can choose between a PGB and care in kind, or a combination of both. Wlz is income related and covers the costs of staying in an elderly home, nursing home or disability home including meals, housekeeping assistance and leisure activities; the costs of daily assistance at home in case of intensive care needs, and specialised treatment for recovering and rehabilitation.

Cash for care systems (*Persoonsgebonden Budget/PGB*) are therefore available for all forms of care. They are intended to promote a competitive market, independent choice and self-responsibility of care recipients. In this way cash for care recognizes care recipients as people who have a say about the kind of care they receive, by whom and when. It is highly regulated (see below). The redistributive part of the Dutch care system is shaped by care recipients paying their own contribution towards the care they receive depending on their age, the number of household members, combined income per couple, the received budget for cash-for-care or cash-in-kind, and the municipality in which they live. The sense of unequal treatment among Dutch citizens has increased because municipalities differ in whether and whom they ask for a personal contribution and the amount of personal contribution required. Research shows that this feeling is not based on a real trend towards inequality but on an overall trend towards the bottom that hits all income groups to the same degree. The main discriminatory difference is that more highly educated people with greater communication skills seem better able to access the care service, regardless of their income (Da Roit and Thomese, 2017) while people without informal care networks and private resources are more eligible to receive public home care.

In sum: home care work is strictly regulated in the Netherlands covering all grades of care needs from very light housekeeping to very intensive care needs. The intention is to *recognize citizens' care needs* though recent reforms have undermined the right to light forms of care by turning it into a provision at the discretionary power of local governments. *Recognition* of care recipients' autonomy and self-responsibility is manifest in the options offered, either care in kind and cash-for-care; one can employ and pay for self-selected care workers as long as qualification (diplomas per care level) criteria and labour contracts are in line with regulations, or one can receive care from providers selected by the local authority. Thirdly, the Dutch care system appears to be *redistributive* in that it covers the costs of care via a public- private responsibility of the state and insurance companies – all Dutch citizens are compulsorily insured via a people's insurance paid for by all employees - with higher costs for those who can afford it and low costs for those with minimal budgets.

3.1. THE RIGHT TO RECEIVE AND GIVE HOME CARE IN PRACTICE

A first evaluation of the Wmo by the Netherlands Institute for Social Research (SCP) was published in 2018 as *De Wmo 2015 in praktijk. De lokale uitvoering van de Wet maatschappelijke ondersteuning* (The Wmo in Practice. The Local Implementation of the Social Support Act; van de Ham et al., 2018). For the evaluation SCP interviewed more than one hundred stakeholders including policy makers, professionals and volunteers and conducted a survey of local civil servants supervising the implementation of the Act.

The SCP has evaluated the triangle between care recipients, care providers and care financers (the state and the insurance companies). One important conclusion is that the principles of Wmo 2015, the decentralisation of responsibilities to local governments, supporting citizens' independence, participation, a more open approach to requests for help, customisation of support, and offering lighter forms of support if possible are recognized though hard to realize. The main barriers are the definition of independence and limits to the capabilities of unpaid help from the social network and family members. Furthermore, the national system of care support has fragmented because municipalities organise the Wmo 2015 in different ways. It is up to the local governments to commission care providing organisations and they are required to organize annual bids encouraging home care organisations to compete at the lowest price possible; This results in a very fragile home care labour market and considerable job insecurity for home care workers. In evaluations of the new care practices policy makers stress positive aspects such as the implementation at the local level, while care providers complain they need more regular consultation with local authorities and criticise the lengthy process of accessing support, with people in need constantly being referred from one party to another, sometimes with a lack of local contact points. Care providers also comment on the increased administrative burden caused by the many rules, procedures and accountability systems, which also differ from one municipality to another. Smooth collaboration with health insurers and other parties involved in long-term care represents a major challenge, as does the coordination between the various Care Acts, such as the Healthcare Insurance Act (Zvw), the Long-term Care (Wlz) and the Participation Act, which are less flexible than the Wmo 2015 and therefore offer less scope for delivering customisation. As a consequence, accessing support has become more complex, and it is not clear either to recipients or professionals where they should go with requests for help and which administrative body is responsible for what kind of support. Care providers complain about the 'short-term contracts' that local authorities have awarded them providing no incentive to think about the long term or to invest in care innovations. The SCP report concludes both providers and municipal staff have little insight into the specific results of supporting and promoting independence and participation.

Another conclusion drawn by the SCP report is that in the process of implementing the Wmo 2015 a significant mind shift appears to have happened: on the one hand citizens have become more aware of their rights and they successfully complain to the Central Appeals Tribunal (CRvB) when their local government fails to provide the level of support they were assessed as needing. On the other hand, there is an acceptance of the framing in terms of independence and participation. Policy makers and other stakeholders appreciate that citizens in need of care now refuse to frame themselves as 'victims' and want to assert their strengths and possibilities. Nonetheless, providers, policy staff and client advocates regularly encounter resistance in this area. The main issue here is the introduction of monitoring instruments such as the 'Self-sufficiency Matrix' and the 'Participation Ladder' which create an illusory picture of measurability and controllability, especially among vulnerable groups. Some policy staff and providers are unconvinced about whether progress in achieving independence and participation can be measured at all and warn about the danger of going too far in promoting independence and participation. Regarding home care the SCP report concludes that almost all municipalities are seeking to shift the use of support away from 'more intensive' (individual, specialist) to 'lighter' forms of support (general, collective). They offer certain services (e.g. day activities, transport or help with the household) much more often as general provisions than before 2015. Nevertheless, take-up of 'more intensive' provisions is increasingly likely because of ageing and growth in numbers of people with more severe or complex problems. The envisaged shift towards lighter forms of support was endorsed, but there was also heavy criticism of reductions in the number of hours of support allocated (especially for household help), which have been introduced by municipalities to save costs.

3.2. RIGHTS AND OBLIGATIONS OF CARE RECIPIENTS

For care recipients, recent home care policy reforms have varying consequences depending on care need and municipality. Most important is that people with lower levels of need, mainly older and/or disabled people who are unable to do the heavier housekeeping work, those who need support in collecting their groceries or attending leisure activities have lost their right to support for those activities. This concerns mainly persons who are not used to ask their relatives for this kind of support because they want to stay independent from their kin, friends and neighbours. Since the reform they no longer receive care support if family members are living nearby, though the strictness of that criterion depends on local care policy and its interpretation by the local civil servant – or the substitute care worker - that is conducting the assessment interview. In the process many people in need of care have lost their right to home care or receive fewer hours of care per week than before the reform. Some have withdrawn from the system, either because they feel ashamed to assert their needs, or they do not want to argue about why their children have no time to support them or they do not want to reveal their financial situation to the local civil servant. The flipside is that care recipients who are assessed still have a strong say in the kind of care they receive as long as they can find their way through the various and stepwise system to gauge the validity and extent of care related needs' provisions. The main problem is the complexity of the systems that determine if and how one gets what one needs (see below).

3.3. RIGHTS AND OBLIGATIONS OF CARE WORKERS

The variability in assessment criteria per municipality and local governments selecting the lowest cost providers thereby keeping wages of care workers at very low levels are both heavily debated. For over ten years (since the introduction of Wmo 2005) the home care market has been characterized by the aggression of its highly competitive pricing. Some equity funds own cleaning companies and contribute to the 'race to the bottom' with the inevitable consequence of very low wages for home care workers, lousy contracts and overloaded home care workers. Trade unions fought back and only recently successfully succeeded in reaching a collective agreement in the sector. Home care workers united, demonstrated and organised marches with banners saying *Valuable work deserves good salaries* and *We deserve wages for work.* The position of local governments is crucial here; home care workers, their trade unions and the care providing organisations together struggle with local governments that opt for the lowest bid, thereby undermining decent salaries for home care workers. Furthermore, multiple home care organisations went bankrupt and were sold to new investors that in turn offered workers even lower salaries and worse contracts.

One alternative to a professional home care worker employed by a care provider is to hire a care worker paid for by a PGB who might be a family member or an 'alpha-help'. The family member and the alpha-help who perform less than 12 hours of care for less than two days a week are not socially insured for unemployment benefits, nor do they receive travel expenses or a pensions contribution. They are paid a guaranteed hourly wage of between 10 and 15 Euros (including holiday pay) and are not obliged to pay basic wage tax and insurance premiums. All other rights and obligations are described in the contract between the care recipient and the care workers that must be approved by the municipality.

For all other paid care workers hourly wages differ by level of need and the qualification of the care worker, contracts are made up by care provider offering in kind service. Medium and high-level care workers' qualifications are protected by Article 34 of the Individual Health Care Professions Act (Wet op de Beroepen in de Individuele Gezondheidszorg, BIG). This covers nurses (Article 3 of the BIG Act) and care assistants in individual health care (Algemene Maatregel van Bestuur, AMvB). If a care assistant does not work alone, a Level 1 or 2 (vocational) training programme suffices. Nurses in the Netherlands generally complete a four-year training programme in higher professional education (Hbo). Dutch law does not regulate educational requirements for the provision of domestic home help services (Oomkens and Lepianka, 2015). The domestic work regulation does not apply when the hiring of a care worker by the private person is mediated by a temporary work agency. In that case the domestic worker is employed by the agency (Eurofound, 2009). Finally, it has proved impossible to find regulations for paid care workers at home in the sense of ethical or moral guidelines or even a description of activities. This could be viewed as an omission but in practice leaves a considerable amount of discretion of professionals. The regulatory governance is in the hands of the Care Institute (Zorg Instituut) that overviews the quality, accessibility and affordability of the Dutch (health)care system and of the people who are eligible for making use of Zvw and Wlz.

3.4. PAID FAMILY CARE GIVERS

As discussed above the PGB can be used by care recipients to pay for home care by family members. It recognizes the previously unpaid – mainly female - informal family care work. At the same time it transforms family relationships into commodified work relationships. Grootegoed, Knijn and Da Roit (2009) explored the meaning of commodified family care for the daily experience of the care givers by a qualitative interview and vignette study. Paid family carers appear to use various strategies to cope with the commodified nature of their work. One strategy is to strictly distinguish work and care by separating motherly or daughterly feelings from 'doing one's job' thereby creating a formal obligation in the private domain. A second strategy is to hide the business aspect as 'not fitting the familial logic of care' (Knijn 2004) by not telling outsiders that they get paid for the work. Both strategies need a lot of 'emotional labour' (Hochschild, 1989) to limit their personal emotional involvement in care, particularly when they care for a long period for a dependent child or when the care work takes a prominent place in a woman's life. From a redistributive perspective paid family care givers regard payment as beneficial both to the carer and to the chronically ill or disabled family member. The payment stimulates reciprocity in the relationship and compensates for onerous aspects of family obligations. It reformulates care givers' duties: they experience a stronger commitment, an increased duty to perform, and make higher demands of themselves. They feel a greater pressure to take care recipients' needs very seriously and to be more reliable than they do if they are not contracted. Also important is that they often care alone, are not trained for the job, and have no guidance, supervision or back-up. Although payments recognise the extensive family care work, it is without subsidiary employment benefits or pension rights. And while their wages are not taxed, they also lack basic social security and holiday rights. Therefore Grootegoed et al. (2009: 486) conclude: 'Giving long-term dependants the ability to exercise consumer choice in their care package is much praised, but it can have detrimental effects on close kin: welfare consumerism may create social inequities' (see also Glendinning 2008; Wellin 2006).

3.5. LIVE-IN MIGRANT CARE WORKERS

The labour market conditions described above combined with the continuous restructuring of long-term care policies (a turn towards informal care and marketized care, increasing intensive care at home) have the potential to shape a new environment to develop a market of migrant care workers living in with people in need of care. However, Da Roit and Bochove (2017) found that this market hardly exists and as far as it is present is very regulated. They explain the absence of a live-in migrant care market by a combination of 'various institutional factors, related to the Dutch care, employment and migration regimes.' (2017: 91-2). Firstly, the care sector despite its deficiencies is still able to offer care services to the great majority of people in need. Secondly, the Dutch cash-for-care system (the PGB) is highly regulated and controlled, so does not allow for care workers who do not have the right qualifications, or proper contracts or who work longer than acceptable working times. Finally, according to Da Roit and Bochove neither managers of care organizations nor care recipients and their families have confidence in undocumented migrant care workers acting in an unregulated market, especially not if they are living in the home of elderly persons.

> In other words, the emerged LIMC work market in the Netherlands remains a niche because the demand has remained relatively low and there are limited opportunities to follow either the continental European route (unregulated payments for care) or the Southern European route (unregulated migration and employment).
>
> Da Roit and Bochove 2017: 92.

Nevertheless, there are some (a maximum of 200 according to estimates of Da Roit and Bochove, 2017) live-in migrant care workers in the Netherlands. Bochove, Kleinsmiede and Ashu (2017) succeeded in interviewing some of these workers along with managers of the care organisations that hire them. Managers state that they are aware of the precarious care relationship and follow strict procedures, such as selecting 'riskless' care recipients (those with a social network) and care workers (those without young children at home), offer duo jobs (two workers responsible for one care recipient) to care workers who can turn shifts, try to find a good match between care worker and care recipient, and develop a care plan based on mutual agreement. If necessary they build in an periodic evaluation. They also encourage care workers to visit their home countries between successive care clients. These strategies sometimes fail however because not all agreements are followed, the children of clients may be reluctant to substitute for the care worker on her days off, and care workers do not always report problems because they fear losing their jobs.

Live-in migrant workers explained that although the contracts and payments are fine, it is not always possible to follow the contract and to claim enough time off. Much depends on the health, the social network, and the housing situation of the care recipient, and the contract (as a solo or duo worker). Leisure time is mainly spent in company of the client and their relatives, days off with new friends or back home after having worked 24/7 for two weeks. Some had complained about too little free time and been moved by the care organisation to a more relaxed care job. Interestingly the live-in migrant care workers operating in solo jobs tend to feel more at home in the Netherlands, to have developed personal relationships with (the family of) the client, have their own family members in the Netherlands who may also be live-in migrant workers, or to have access to their own network of friends. Duo workers in contrast seem to strictly separate work (with the client) from private life (in the homeland during the two-week breaks).

This rather rosy picture of well-arranged care work performed by live-in migrants can do justice to both the care workers and the care recipient. However, recently some investigative journalists also discovered an informal and exploitive market of live-in migrant workers operating in Belgium and the Netherlands (Post and Hofkens, 2018). Their work shows that so-called entrepreneurs (from Bulgaria) benefit from the lack of control on private care contracts that are not covered by Wlz or PGB – although at the moment relatively small in numbers. So far care work in private homes mediated by care organisations does not fall under the Labour inspectorate. The danger is that the combination of high rates of unemployment and poverty in some EU member states, the demographic trends in the Netherlands and shortages in the care labour market, means that unjust and exploitive home care contracts with live-in migrant care workers will increase. This could be mitigated if European

Commissioner Marianne Thyssen succeeds in her call for support for a so-called European Labour Authority that promotes pan-European labour regulation.

3.6. A free rider's problem

Given that several Dutch laws impinge on long-term care (the Wmo 2015 as well as the Healthcare Insurance Act (Zvw) and the Long-term Care Act (Wlz)), coordination between these laws is needed. Wmo policy staff in the SCP survey (SCP, 2018) appear more positive about the collaboration with care professionals working under the auspices of the Zvw and the Wlz than they are regarding the coordination at policy level. There seems to be considerable room for improvement in the contact and communication between local authorities, health insurers, care administration offices and the Care Needs Assessment Centre (ciz).

In addition, the SCP evaluation of Wmo 2015 shows significant problems regarding the demarcation of the areas covered by the Wmo 2015, the Zvw and the Wlz, especially in relation to the provision of personal care. Whether personal care is provided under the Zvw or the Wmo depends on whether the client currently needs or is at high risk of needing medical care (Zvw) or has a need for social support (Wmo 2015); this difference proves difficult to assess in practice. A 'free rider' problem characterizes the main confusion in the demarcation between the Wmo and the Wlz due to the unclear criteria for transitioning clients from the Wmo to the Wlz, that is from the local governments' budget to health insurance coverage. It is difficult in these cases to assess whether the need for 24-hour care in proximity to the client is met and to what extent the role of the informal carer should be taken into account in assessing that need. A related problem is that people who are transferred from the Wmo to the Wlz are often worse off, both financially and in terms of the number of hours of care they receive. Clients receiving care under the Wlz pay a higher co-payment and receive fewer hours of care if they opt for the allocated care to be provided in their own home. In consequence, many clients and care providers are dissuaded from applying for help under the Wlz though the opposite is also going on; clients sometimes are too easily referred to help under the Wlz. The very different natures of the laws are cited, with the Zvw and Wlz being perceived as stricter and more protocol-driven than the Wmo that offers more scope and flexibility for customisation. Finally, the SCP concludes that the complexity of the long-term care system has increased since 2015, with the effect that citizens and carers are regularly unsure where to go with a request for help and which administrative body is responsible.

3.7. Care packages: cooperation between paid and unpaid care workers

Home care for frail and/or elderly people often come in 'care packages' a concept we introduced (Knijn, Jönsson and Klammer, 2005) analogous to the concept of 'income packaging' (Rein and Rainwater, 1980) by low income families. Care packaging is the assembling of various resources offered by various actors (paid or unpaid informal care workers, either family members or not, various paid care workers, GPs and medical specialists) to fulfil one's care needs. Balbo (1987) has discussed 'patchwork care' referring to the ways women stitch together different arrangements to get care responsibilities realised. From the perspective of people in need, packaging care resources and care workers is a complex management system demanding financial, social, organisational and emotional labour and skills. Involvement of multiple care workers in a private home in addition requires coordination and balancing of tasks among them as well as agreement on activities in the best interest of the person in need of care. Zwart-Olde et al (2013) conclude that paid and unpaid care workers who are taking care of an older person in his/her home rarely talk together about the care work provided that the care receiver is in a rather good health and can direct the activities to be done. In contrast informal care givers living in the home of the care receivers (partner, children) performing a lot of care work often discuss care work with paid care workers because they often experience a high care load, hesitate to ask additional informal care and try to avoid the elderly person being moved to a nursing home. These care givers mainly need advice and emotional support and are satisfied with professional assistance. Children of elderly people in need of care who are not living in their parents' home in contrast, express dissatisfaction with professional paid care workers' performance. They comment on the lack of adequate communication and irregular contact. They typically want to be well-informed about the care their parents receive. Zwart-Olde and colleagues conclude that existing care networks of elderly persons comprise (too) many care givers and care workers because various care tasks belong to various care professionals in addition to the informal paid or unpaid care giver. They advise reducing the workload of professional care workers to allow them to have little chats and to build up more personal relationships with the care recipients and other persons in the care network as the absence of such relationships can give rise to tensions. Although the care recipient often mentions one person in charge of the organisation of the care work, task division between several care workers happens on basis of the diagnosis and can hardly be discussed, resulting in inflexibility and underexploring of alternatives. Consequently, differences or disagreement about expectations can go unexpressed and there can be confusion about who is the main responsible care giver; both informal care givers and paid care workers point to each other in this respect and don't feel they have a say on the care work the other one performs.

4. *CONCLUSION*

The Netherlands has a multi-layered system of care services covered by a combination of public budgets and compulsory private insurances fit to recognize age independent degrees of severity of care needs of people with disabilities and to redistribute care in a just way. The system offers a choice, at low and middle levels of care between cash-for-care or in-kind care or a combination of both. In that sense it follows a users' preference for individual choice. The care insurance system at all levels of care needs is income related; high income populations pay more for home care and residential care, meaning that care provision is redistributive. When it comes to regulating care rights and obligations of care recipients and home care workers the care system very much relies on personal agreements between the parties though regulations are firmly set regarding qualifications for the various practitioners, and the tasks they can perform, but how they perform these tasks is up to the organisation they are employed by or the agreement they make with the care recipients. Salaries of care workers are nationally agreed upon though the decentralisation of home care accompanied by severe budget cuts has occasioned lots of problems because many local governments opt for the lowest bids undermining (mainly female) wages in the sector. Cut backs during the crisis have resulted in a loss of professional care workers, mainly female nurses.

PART II

5. *INTRODUCTION*

In Part II we explore, using mini-ethnographies and in-depth interviews, the accommodation of justice claims in the lives of three adult physically disabled care users (one single woman and an older couple) and their three professional care workers in a neighbourhood of a large city in the Netherlands. All three care workers are employees of an autonomous home care team which is a subdivision of a large home care company. We are interested in everyday practices of recognition and redistribution and how daily conflicts of justice claims are understood and managed (or not). The analysis will draw on a capability approach, considering people's capacity to achieve the kinds of lives that they value, and the achievements themselves. (See http://www.iep.utm.edu/sen-cap/. The main questions of this qualitative study are:

- How do people understand, claim and experience recognition and redistribution regarding care work and care use?

- What are the argumentative, practical and conceptual tools that people use to negotiate conflicting justice claims?

- Are contradictions and intersections between claims for and practices of justice present in the domain of care?

- How do care workers and care users understand the role of the state in creating conflicts and shared interests between care workers and care users (e.g. employment, immigration and taxation laws; support for the rights of disabled people and their carers; minimum care standards; cash for care arrangements; state engagement in private household);

- What are the specific challenges and opportunities for justice in the context of home-based care, and their link to ideas of the public and private spheres.

Although care work in private households is often informal in this study all care workers are professionals employed by a home care agency, though their work might also have some informal elements, such as additional hours and services not included in the contract. This form of commodified care for elderly and disabled people highlights how paid care work shapes, constrains and facilitates claims for justice. Attention to care in the private household will enable us to situate commodified care within the context of networks of interdependence that are not commodified, that is, explore how people who are paid to provide care interact with family members who also provide care but are not necessarily paid to do so. We will explore, not only how the care provider and care user interact and negotiate differences but also how both interact with family members.

As with the other countries involved in this study (Austria, Hungary, Portugal and Turkey) in the Netherlands the state augments rather than replaces family care for disabled and older people. A common policy concern seems to be that those needing care should be able to remain in their home for as long as possible. Consequently, families often end up arranging 'mixed care', whereby family members share care with paid carers.

This mini-ethnography is based upon participant observation over a week in July 2018 in the care activities of three different care workers (Barbara, Moniek and Selma)[1] as they cared for three different care recipients in their own homes: an elderly married couple (Henk and Jannie Jansen) and a woman with a physical disability living by herself (Adrienne Verheijen). The three care workers are colleagues working in the same nine-person team who are employees of a large, national care organisation. The observation took place in two different neighbourhoods of a large Dutch city. In what follows, first the methodology of the mini-ethnography will be described, second a description of the findings of the mini-ethnography; third an analysis of the ethnography; and fourth the conclusion.

6. *METHODOLOGY*

In this section, first the process of access will be described: how did we finally come to realize the fieldwork sites and what difficulties were associated with the process. Secondly, this section will discuss ethical considerations regarding doing ethnographic work in care relations situated in the private home. Finally, this section will reflect on the positionality of the researcher who carried out the mini ethnography.

6.1. ACCESS

Access to a fieldwork site proved difficult to attain and consequently delayed the work. The main reasons, as far as we could trace them are work-overload, privacy of care recipients and family members unwilling to cooperate. In this section we will report on this difficult process. We utilized two different strategies to acquire access. Firstly, a formal path was taken through directly contacting care organisations and organisations representing people with disabilities. Secondly, we utilized chain referral methods through our professional and personal networks.

Firstly, we did a web-search on Dutch care providers, care intermediary organisations (temporary work agencies mediating between people with home care needs and home care workers) and patient associations representing people with disabilities and/or elderly people. Following the list, we contacted five well-known and smaller care agencies at the same time. We received little response to our initial email and a phone call round followed in which two organisations declined to participate on the grounds of a heavy workload. The third organisation never replied nor answered our follow-ups. The fourth organisation expressed their interest, but at a certain point stopped answering our emails and follow-up calls. The fifth, a publicly well-known organisation representing the interests of people with disabilities explained they were unable to help us as they did not have direct contact with people with disabilities and referred us to another organisation that they felt would be more suitable. That organisation promised to reply to our email and phone call, which never happened not even after two reminders. Following this unsuccessful first round, we sent out various new requests to care organisations. A phone-call to an independent team of home care workers employed by a well-known, popular care organisation seems to be more successful; the team reacted positively and soon recruited a care recipient who consented to participate. However, family members of the care recipient decided

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[1] All names in this report are fictive to protect the privacy of the participants.

that he should not cooperate after which we had to start again. A final care organisation that had initially reacted positively, then decided they could not participate, due to scheduling conflicts and heavy workload. This led to further delay in our planning. In the meantime, we were looking for another fieldwork location.

At the same time, as well as the more ‘formal’ access strategy we attempted a chain referral strategy by contacting colleagues, friends and relatives, asking whether they were in contact with any care workers (organisations) or people who receive care at home. Through our personal network we acquired some leads but in the end these proved to be unsuccessful: firstly we found the case of friends of the researcher’s parents-in-law whose mother receives care at home. The friends were not very keen on participating because the mother was very ill. Finally, there were two care workers in the personal network of the researcher, but the first care worker (female, white Dutch, in her late twenties) depended on the consent of her employer (who was coincidentally one of the organisations that we approached through the formal access strategy) and this consent took too long to realize. The second care worker (male, Dutch Surinamese, in his thirties) was self-employed and willing to participate but explained that getting consent from his clients was very difficult, as he did not have any regular clients because he works as a substitute care worker.

The professional network would prove to be successful in the end although not all leads led directly to the realization of a fieldwork site: firstly, through a colleague within the ETHOS consortium, we got in touch with two advocacy groups that focus on migrant communities in the Netherlands. After a first very positive meeting with these advocacy groups they stopped replying to emails and phone calls. In the end it was via a Masters’ student of the department of Interdisciplinary Social Science that we were successful. This student wrote her thesis on care work and consequently had contact with an independent home care team in Utrecht. That team was very interested in joining a care-oriented study but to their regret they did not fit with the student’s framework. From the first contact they were happy to join our study and to provide us access to fieldwork sites; they very quickly contacted the care recipients who gave consent for the observations and interviews.

6.2. ETHICAL CONSIDERATIONS

Prior to the fieldwork, we explored the field by interviewing one of the home care team members in order to understand their way of working, the team composition, the management structure, the specificities of the neighbourhood and of the cooperating care recipients. Also at that meeting, the informed consent letter was handed over and the team members were informed about fieldwork procedures. Team members had several questions that were answered. The actual fieldwork started with the distribution of the informed consent letter to all study participants and all other members of the home care work team. The team also received an email asking whether any of them opposed the presence of the researcher at the home care work agency. None of the care workers within the team opposed the research. However, not all of them would themselves participate. Three care workers within the team that were involved in providing care for the selected care recipients agreed to participate in the study; to be interviewed and to allow us to participate in and observe their care activities. Before the initial interview took place, the researcher further explained the focus and aim of the study, her role in data gathering and asked all participants to sign the informed consent letter.

The hard copies of the consent letters are kept in storage at Utrecht University according to the ethical protocol.

During the fieldwork different matters relating to consent arose. The first issue was the office space of the care workers' agency which is in a community building which also houses other (health)care and welfare institutions. Issues of consent relate to observing persons frequenting this building who did not sign a consent letter such as care workers from another team, social workers or people from the neighbourhood visiting the office. Because the people were visiting public space, behaviour that could be outwardly observed are included in the data, but informal talks with persons are not included because no consent was given. Furthermore, the researcher would also be present at the early morning team meetings where attended by care workers who had not signed a consent form. General information obtained from these work meetings were used as data, but personal conversations between the researcher and care workers and among the care workers that did not sign a form were omitted.

A second issue that arose during the fieldwork relates to the aspect of observing nudity in care related work such as bathing and dressing. While all care receivers gave their consent to participate, the researcher continuously checked with them whether they felt comfortable with her presence at these private care activities. When inquiring with the care receivers, they all answered that they gave their consent and more so, that being there when they received these very private care activities is crucial for understanding care work. For these reasons, the researcher did observe these very private care activities, but tried not to intrude too much by taking some physical distance by not entering the bathroom.

To assure the anonymity of the participants, all names and personal details of persons have been anonymized and only aliases have been used. Furthermore, specific information about personal details of participants have been changed where possible.

6.3. POSITIONALITY

Because the home care team contacted their clients to participate in our research, the general assumption of the care recipients was that the researcher worked for the care agency. In spite of explaining at various times that the research was an independent study conducted by Utrecht University, the care recipients assumed that the researcher had an evaluative role. For example, Mr Jansen explained that he and his wife were very happy with the care agency and the care workers and emphasised that it was important that care recipients also show their gratitude when they are satisfied with care services offered. Furthermore, he suggested that the research shouldn't have negative consequences for Barbara and her home care team colleagues. Barbara replied to Mr Jansen, saying that she didn't feel this way about the research nor did she think that the research would impact on her negatively. In reaction, the researcher explained to both Barbara and Mr Jansen that the aim of the research was not to catch people out. Besides that, everyone will be anonymized. This example suggests that care recipients might have been hesitant to say negative things about the care workers because they did not want to negatively affect the home care team. This has potentially influenced the studies' findings. Indeed, during the interviews and the fieldwork the care recipients often emphasized how great the care workers were, suggesting both a form of solidarity and interdependence between the care workers and care recipients. Through the participant observation the impact of solidarity and interdependence on the data could to an extent be mitigated as it provided a look beyond words and the possibility to observe behaviours and the unsaid.

A different role that the participants attributed to the researcher was the role of a care work intern. At first, the researcher thought of herself as being an intruder at the private homes of care recipients. But during the fieldwork she learned that care workers and care recipients are used to having specific type of people looking over their shoulders: interns. Interns often tag along with care workers and care recipients are accordingly also accustomed to them. Furthermore, the appearance of the researcher as a younger person, made the role of the intern fit in the everyday meanings of the participants. Different situations suggested that both care workers and care recipients compared the presence of the researcher to the presence of an intern. For instance, at a certain moment Mrs Jansen suggested to the researcher that she could wash her (back) and put on her support stockings. By giving these suggestions, Mrs Jansen was effectively relating to the researcher as if she were an intern who had to learn how to carry out care work. The researcher replied that she would very much like to do that, but that she was not given any permission by the university to carry out care activities. The presence of the researcher was also compared with having interns around by Adrienne and she gave this as the reason why she had no problems with the researcher seeing her being washed. Although during the last interview Adrienne did reveal that she does find that her body was not for everyone to see:

> Adrienne: Yes, but not if I would have twenty or thirty care workers like you have so many employees in a business. It would be like if you work in a large company that you have so many people. But in hospitals you also have many people, so yes you accept it too. It has to do with the acceptance. You accept home care, but you also accept the hospital. So yes. It depends on what you have experienced, I think. Not everyone would like it [to have a lot of different care workers].
>
> Interviewer: Can you explain to me why most people don’t like to have different care workers?
>
> Adrienne: I think that has something to do with … I'm not ashamed of myself, but when I take off [my clothes] why does my body have to be exposed to someone else every time? Well I think it has nothing to do with being prudish, but then you don’t take your clothes off for every average Joe, do you?
>
> (Interview with Adrienne, care recipient)

That some care workers considered the researcher as having a similar role to an intern also became apparent at moments where care workers, while carrying out care activities, gave explanations about why and how they carried out care activities. Even in the final interview with care worker Barbara, she underlined that the researcher could have taken a more intrusive stance by asking more questions during the care activities.

Prior to participating the researcher did not have any experience with care for the elderly or people with disabilities and she had no idea how she would react to nudity or visible physical impairments. She was concerned she might feel uncomfortable when care activities related to people’s personal hygiene would be carried out - it is seeing humanity in its most vulnerable and mundane way. Furthermore, the researcher, while used to babies showing their nakedness, had never seen adults' bodily activities. The researcher feared to be perceived as awkward and clumsy and that this would have influenced the care work in a negative way, however when she inquired at the final interviews with both the care workers and recipients how they felt about her presence all reacted quite positively.

6.3.1. ‘MINI’ ETHNOGRAPHY AND RAPPORT

The mini-ethnography took place in the relatively short duration of a week. The final interviews also took place during this week, with an exception of Adrienne's final interview that was carried out a week later because she was unavailable during the last day of the mini-ethnography. Because the period of participation was limited, there was relatively limited time for participants to get to know the researcher better and vice versa. Yet passing of time is crucial for participants to be willing to share their (private) views on and experiences with care work, to build a form of rapport. Still, when comparing the interview materials of the initial interview with the closing interview, the materials of the closing interviews show that the participants were more willing to express more sensitive information, such as their discontent with past experiences of care work, than they would have during the initial interviews:

> During the initial interview and the participant observation, Mr and Mrs Jansen underlined strongly that they were very happy with the home care team and had no feedback as to their activities. But during the last part of the final interview, after the researcher probed about the different approaches between care workers, they admitted that they had also negative experiences with a particular care worker who would always rush through her activities. They admitted that the care worker team is also already aware of this issue. Furthermore, Mr Jansen admitted that he felt that some care workers would at times treat him in a patronizing (*betuttelende*) way – by laying down what he cannot eat.
>
> (Summary of diverse field notes July 25 - August 2nd 2018)

The above example shows that participant observation, even though it took place in a short period of a week, is of great additional value when compared to a stand-alone interview. Furthermore, the participant observation also gave the researcher the opportunity to contrast practices with expressed views during the first interviews and inquire about real life examples of care practices during the final interviews.

6.3.2. CARE WORKERS VS CARE RECIPIENT PERSPECTIVE

The researcher accompanied care workers in their visits to the care recipients' homes, and also hung around at the community centre and office where the home care team is based. Because of spending so much time in care workers' environment, there is a possibility that the researcher is more sympathetic to the perspective of the care workers and the researcher took this potential bias into account during the analysis and presentation of data.

6.4. CODING AND ANALYSIS

All interview and participatory observation materials have been written down, summarized, and/or transcribed. The analysis was conducted using NVIVO11 following an open and a simultaneous conceptual coding strategy focussing on care relationships, capabilities and functionings and justice and fairness in the context of care work. After the first initial open coding round, an axial coding round followed where codes were resorted and renamed (see appendix).

6.5. THE HOME CARE TEAM

The research was conducted with three care workers (Barbara, Moniek and Selma) and three clients (Adrienne and the married couple Henk and Jannie) of a neighbourhood home care team of nine different home care workers, all female. All are employees of a large national home care organisation that has won the municipal bid for this part of the city. Although they are employed by a large nationally operating care organisation, they operate autonomously in the neighbourhood.

The team does not have a manager or specific supervisor – according to the care workers interviewed – yet there are differences between formal functions within the team that define different responsibilities and tasks between team members. The functions within the team rank between Level 2 to 5 with Level 5 care workers receiving the highest and Level 2 the lowest pay grade. The relationship between the different levels is cumulative, which means that the higher-level functions may perform all tasks and activities that lower level functions carry out.

Level 2 care workers are called care auxiliaries+ (*verzorgende+*), which means they assist clients with personal care activities such as washing, dressing and putting on compression stockings. The '+' indicates that they may perform minor medical care activities such as taking care of wounds, providing medication, measuring blood pressure and stoma care. Level 3 care workers are referred to as personal healthcare auxiliaries (*verzorgende individuele gezondheidszorg/VIG*). Level 4 care workers are nurses (*verpleegkundigen*) who may perform most medical care activities except for specific complex catheters and specific medical injections that only Level 5 care workers may perform. Level 5 care workers are district nurses, (*wijkverpleegkundigen*). Within a team there is always at least one district nurse who in addition to carrying out medical and personal healthcare activities also performs the first interview with the client, administrative paperwork and indicates the capabilities and needs of (prospective) clients. The different home care worker ranks have a cumulative relationship, so higher level care workers are fit to perform all the tasks of lower levels. Because higher level care workers are more expensive, a team will be composed of a minority of Level 5 care workers (at least one) and a majority of mid-level care workers. Mid-level care workers are both able to perform most care activities and are at the same time relatively cheap.

The three care workers included in this research are Selma, Moniek and Barbara. Barbara is one of the two district nurses or wijkverpleegkundigen (Level 5) in the team. As well as care activities her tasks involve dealing with conflicts within the team and conflicts between care workers and clients. She also organizes meetings for locals from the neighbourhood, promoting information and knowledge on different healthcare topics such as Chronic Obstructive Pulmonary Disease (COPD). She attends consultative meetings in which other care organisations, social work organisations and other healthcare professionals deliberate on (health)care and welfare related issues in the neighbourhood. Moniek has the function of a home care nurse (Level 4). After direct care activities Moniek also coordinates the planning of the team's work schedule. The last member of the team included in this research is Selma (47 years old). Selma is a personal healthcare auxiliary, a Level 3 care worker. Selma is one of five VIG's in the team. She is one of two home care workers in the team with a Dutch Indonesian background.

6.5.1. LABOUR CONDITIONS FOR THE CARE WORKERS

The majority of the members of the home care team work part-time 'broken' shifts, meaning they work in the morning between 7/7.30-11/11.30, go home in the afternoon and work again for a three or five hour shift in the evening. These are regular working hours for care workers who do not have special tasks. All VIGs, so also home care worker Selma have these shift working hours. When asked about these broken shifts, Selma explained that it is the nature of these type of shifts that drew her into care work in the first place, as they made it for her possible to combine motherhood with work. This is in line with cultural attitudes and practices of many Dutch women combining work and care; in general they adapt working times to daily motherhood activities instead of vice versa (Knijn and da Roit, 2013). In addition to working these broken shifts, the majority of the care workers within the home care team work part-time, 28 hours. Only Moniek and Barbara work full-time that is 36 hours. This is the maximum permitted within the sector as home care work is very exhausting. Remarkably, the care workers working only 28 hours a week are also on call five days per week (including one day in the weekend). Since the care workers are an autonomous self-directive team, there are no different functions within the group other than the care worker function Levels ranging from 3-5 explained above.

Perspectives that the three care workers share on their income level are generally positive – although when Moniek compares their income to other occupations, such as teachers, some discontent is expressed that underlines that care work is certainly not less important and has just as heavy a workload. Selma and Moniek claimed that poor labour conditions are the reason why more highly educated personnel, those with Level 5 credentials, are scarce in the field. Furthermore, Barbara argues that while she as a Level 5 care worker receives a reasonable salary, her colleagues who are lower level care workers receive much less even though the work they do is not that different.

In addition to pay, the home care workers are very aware of the importance of working in a way that will do themselves no physical harm. Care activities often include physical work, such as helping a client out of bed or perhaps less heavy, but in the words of one respondent, 'mundane', putting on support stockings:

> Mrs and Mr Jansen tell Selma that there was a nurse in the hospital who put on the support stockings without gloves. That this particular nurse must have been strong and that it seemed that her work was almost production line work in the way she was putting on all those support stockings for patients. Later in an informal conversation with Selma, she explains that it at first may be easy to put on support stockings without gloves, for the long term this is bad for yourself. Because you still have to work using your body for the long term. Selma explains that for this reason, she always uses chairs and stools, even if it

takes her a longer time to put on support stockings. ‘Putting on support stockings without gloves is not ergonomic, just see whether you can do that for 10 years’.

Summary of fieldwork notes August 1, 2018.

6.5.2. CLIENTS AND PLANNING FLEXIBILITY

The team has on average 50 clients in a week. In principle, the whole team of nine care workers tend to care for all 50 clients although the planner does consider, where possible, that some clients have grown used to specific care workers within the team. Also, some clients need every day medical care and for that reason only Level 3 and higher-level care workers can work with them. Most of the clients are elderly, retired people. In terms of income divisions among the client population in this particular neighbourhood, Barbara explains that 50 per cent of the care recipients can manage their income well, but 30 per cent barely make ends meet and 20 per cent are well off. The health problems that clients suffer are related to their income level according to Barbara. Many of the home care team’s clients suffer for example from COPD, which in her perspective is associated with socio-economic status.

7. *CARE RELATIONSHIPS*

Before introducing the different participants of this study and how they relate to one another In the following first the specific background of the persons will be discussed, followed by a description of their care relationship.

7.1. LOCATION 1: ADRIENNE’S HOME

The first physical location where the ethnography took place was the home of Adrienne who is regularly visited by Moniek and Barbara who provide care for her at home. This section will focus on the relationships between:

1. *Adrienne and Moniek*
2. *Adrienne and Barbara*
3. *Moniek and Barbara (and Adrienne)*

Before describing these relationships, in the following the three different actors will be introduced separately.

7.1.1. ADRIENNE, CARE RECIPIENT

Adrienne, 50 years old, identifies as female, and lives together with her cat in a single-family home in a quiet neighbourhood in one of the four largest cities in the Netherlands. She is divorced, has a son, a daughter and a granddaughter. She is regularly visited by her daughter and granddaughter. She has received care from the same care organisation over the last 10 years since she fell ill with a cardiovascular disease and received surgery in 2009. On top of that, she had leukaemia. Due to the leukaemia she lost her right lower leg. Moving around has become more difficult since then – although she already had a lot of pain in her leg that made walking difficult and painful before it was amputated. In addition to receiving daily care, she also makes use of a two weekly housekeeping service of in total 6 hours per week paid for by the municipality from the Wmo budget.

MOBILITY AND THE HOME

Since Adrienne's left leg is amputated her home has been adjusted in order for her to be able to move around without a third person's help[2]. Her front door can be electronically opened with a remote control attached to a necklace that she often wears. She uses two different triple chairs[3] to move around in her home, one upstairs and one downstairs, and outside her home she uses a mobility scooter. Above her bed there is an arm pully, and she has a wall grip and a foldable shower chair in the shower. However, the doors in her home are narrow and not adjusted to the current legal standard and the kitchen and other cabinets have not been lowered to accommodate her mobility issues. When inquiring with Adrienne about the adjustments to her home, she explains that she feels 'lucky', as unlike others that she knows she was able to get most of the adjustments financed through the Wmo. Furthermore, she can lower and raise the height of her triple chairs, which makes it possible for her to move around the kitchen. Still, Moniek and Barbara have mentioned that Adrienne doesn't cook much. That is why Moniek drops off two portions of leftover spaghetti that she prepared for her family the day before, when she is visiting Adrienne to provide her care. This is Moniek's initiative, a gift that is not included in Adrienne's budgeted care dossier.

Adrienne goes grocery shopping by herself. She also makes use of a delivery service for her groceries and buys from her tablet. During the participation period she shows the researcher several items that she bought for her granddaughter from an online sale, such as slippers and shirts.

MEDICAL AND PERSONAL HEALTH CARE ASSISTANCE

Adrienne's care dossier consists of daily (medical) care: in the morning she gets help with washing, dressing, treatment for perspiration wounds, putting on a compression sock and they also help her with putting on her prosthetic leg. In addition to personal care and medical assistance, the care workers also have a coffee break at Adrienne's which lasts about 20-30 minutes of the 1.5. hours of care that they have in total. In the evening they help her getting ready for bed and taking off her prosthetic leg. Adrienne is capable of getting out of bed in the morning by herself and can move around using the triple chair and various other tools and adjustments to her home. Some days she doesn't feel well and those days she also needs assistance with getting out of bed.

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[2] Such adjustments are often subsidized by the municipal Wmo. People with a Wlz indication don't pay a personal contribution. See https://www.rijksoverheid.nl/onderwerpen/zorg-en-ondersteuning-thuis/vraag-en-antwoord/vergoeding-voor-woningaanpassing.

[3] A triple chair is a multifunctional chair on castor wheels that facilitates mobility.

HOUSEKEEPING SERVICE

As well as home care, Adrienne also receives six hours of housekeeping weekly and her daughter Lotte (now 34 years old) sometimes drops in at weekends to help with chores around the house. Adrienne only received assistance with housekeeping after her son (now 32 years old) left the parental home. While he was living with Adrienne, he was supposed to do the cleaning and housekeeping, and Adrienne was, according to the gender-neutral family based *Wmo policy,* not eligible to receive publicly supported housekeeping. Yet her son, besides vacuum cleaning, never did much housekeeping. He had a busy schedule as he was both in education and working at the same time but also Adrienne argued that his gender meant he was unable to do this kind of work. For that reason, Adrienne had tried to keep the house clean by herself with some assistance from her daughter who would help at the weekend (although she also had a job and her own home to take care of). After her son moved out, Adrienne was eligible for publicly financed housekeeping support by the Wmo. Now she is, in her own words, 'able to live in a clean house'.

TIME, ROUTINE AND GETTING AROUND

During the fieldwork period, Adrienne is often the second home address for the home care worker Barbara or Moniek to visit. Barbara sometimes takes the car, while Moniek always takes the bike. During the fieldwork the researcher cycles with Moniek from the community centre to Adrienne's home. They park their bikes in front of her house and enter with the key that the home care team has. Adrienne can open the door with a special device that she often wears around her neck but in the morning Adrienne is not up. The care worker will be the one to wake her. After entering her home there is a small corridor (about 3 x 1 metres), which connects the front door to the downstairs bathroom on the left side and the door to the living room upfront. Opening the living room door is a bit difficult, because, directly after this door, there is a triple chair which visitors have to squeeze past. That the triple chair has been put there is rather inconvenient for visitors, but very convenient for Adrienne because it is positioned at the end of the staircase where she descends using the stairlift.

When entering the house, Adrienne is still asleep. The care worker wakes her up by yelling 'good morning' from downstairs, in this way notifying Adrienne that she has arrived. Adrienne often replies by saying 'good morning'. Adrienne's living room (20m2) includes both an open kitchen and a living and dining area. The living room looks nice and tidy, but it often has a murky smell from the cat's litter box. Her living room has a love seat couch and a fauteuil sofa. During the week of fieldwork, the care workers never took a seat nor entered the seating area of the living room. Both walk about the kitchen and dining table area. The dining room table is also where Moniek and Barbara put their bag, on the same chair, right from the table. After putting down their bags, they feed the cat some milk from the fridge. Sometimes, when they are still downstairs, Moniek/Barbara are already chatting with Adrienne upstairs. After feeding the cat the care worker goes up, going around the (same) triple chair that blocked the front door, to climb the stairs. On the first floor another triple chair blocks the stairs' entrance from above. By passing the chair the care worker enters Adrienne's bedroom. Most of the time, Adrienne is still in bed, awake but drowsy. The home care workers often chat with Adrienne about how the night shift went and how Adrienne is doing. It was only once that Adrienne was already up and about when the care worker went upstairs – that morning she had to use the bathroom.

Barbara explains that Adrienne doesn't mind us being there when she urinates, but when she goes to the toilet to defecate, she prefers to do that in privacy.

The triple chair will be already at Adrienne's bedside for her to use to get up and about on. Adrienne gets out of bed by herself – using the arm pully that hangs above her bed- although it takes her quite some effort to do so. When she is up she rolls towards the bathroom on the triple chair. Before she enters the bathroom, the care worker has already made her way into the bathroom. While Adrienne is urinating and gets undressed, the care worker warms up the shower.

While this is all happening, Adrienne will be chatting with Moniek or Barbara. They will often talk about Adrienne's cats, or granddaughter. Barbara often also talks about her personal life, such as the visits of her little cousin or that she recently moved and still has to unpack. Moniek is a bit more reserved and doesn't talk as freely about her personal life. The talks between the care workers and Adrienne often revolve around care related activities, like whether Adrienne has taken her medication and how her leg is doing.

After the shower Adrienne's wounds are tended to and she receives help with dressing, especially needing help with putting on the bottoms. After she has dressed, we are finished upstairs. Adrienne will take all the things she needs from her bedside table, such as her smart phone, her tablet, medicine case and books, storing them in a big plastic (grocery) bag on her lap. Barbara carries the bag for Adrienne while Moniek lets Adrienne carry it herself. Adrienne will then roll from her triple chair to the staircase, climbing on the chair lift that will bring her down to the living room. We wait until she has reached the middle of the stairs before also heading down the stairs. Now it is time for coffee.

7.1.2. MONIEK, CARE WORKER

Moniek, a woman in her mid-fifties, is married and has been working in the care sector since she was 17 years old, i.e. for the last 35 years. She has largely worked for the same care company that currently employs her for over 28 years in a row with a short interruption of six weeks for bureaucratic reasons. Her long experience means she has experienced many organisational changes within the company but also societal developments concerning the nature of home care and the shift from institutionalisation to in place care.

Moniek works 36 hours per weeks, which is according to her, 'fulltime' in the home care sector. She has worked in different sectors of care work, including elderly homes and hospitals, but she prefers home care because she enjoys the 'one on one relation', and the autonomy and responsibility she is given. In addition to her care responsibilities as a nurse, Moniek also takes care of the planning schedule within the home care team. For this reason she works 'regular' office hours. In the mornings she often plans her care provision activities and in the afternoon she focusses on what she calls 'office work'. This office work gives her, in her own words, at times a challenging position within the team. This is because she has to 'chase' her co-workers in signing up for shifts. Her co-workers experience the signing up for shifts as doing overtime, although in reality the home care team gets scheduled 90 per cent of their hours upfront and 10 per cent will be scheduled later on – this to keep some more flexibility in being able to address to clients' needs.

In addition to the way her position is sometimes perceived within the home care team, she also feels that she is not nominally valued, she explains:

> Yes, I think that's [labour conditions] quite an issue. You are paid according to the salary scale to what your job is, but not in terms of what you do. […] I am a Level 4 nurse, in the mornings I usually work in the neighbourhood [providing care to clients] in the afternoon I have other tasks, including planning and so on. There are also enough nurses who only work in the neighbourhood and go home and that's it. But they get paid exactly the same as me. I don't want to sound unhappy, but I do not think it's right […] I mean in the corporate sector, when you get a certificate at some point or whatever, then you will also be paid for it. Or you can get bonuses, or you name it. But that is not really the case with us.
>
> (Interview with Moniek, care worker)

Because Moniek lives in Utrecht, she cycles from home to work and to her clients. Being outdoors during the periods in between her care activities is also something she values about her working conditions.

7.1.3. BARBARA, DISTRICT NURSE

Barbara, a female, 27 years old, has been working in care for about six years. She started out as a nurse, but she enrolled in a bachelor course three years ago and started in her current job as a district nurse after graduation last year. Within the home care team she is the youngest, but also one of the most well paid because she received additional (medical) training. When Barbara reflects on the labour conditions of the home care team, she explains that she very much feels appreciated for her work done, although she finds that care work is in generally less well compensated than other jobs, especially the Level 2/3 functions:

> I really cannot complain [about the labour conditions]. But when I see for example what [name of a colleague] works for and I see, she works really hard and a lot and she is Level 2, that is three levels lower [than me], but that is a lot of difference in salary. A nurse with higher professional education is paid very well. Still much less than other jobs requiring the same educational level, but then I think, they should take a good look at it. You have a job with considerable responsibility and you cannot make mistake. It just does not work if you know you can become a teacher for 1000 euros more. Working in care is something, it has to be intrinsically motivated. If you think hm hmn hmn, then you will not choose care work, it is in you or it is not in you. But it is also not made more attractive.
>
> (Interview with Barbara, district nurse)

These unattractive labour conditions are also the reason why the number of district nurses are very limited. District nurses however are in an important position within home care. Barbara for instance, together with a more senior district nurse, plays a coordinating role within the team. Furthermore, due to her broader medical training, Barbara notices things that her other colleagues do not:

> Because I had a client last week, who was four or five weeks out of hospital and it turned out he still had two stitches in. I had to follow it up and take out the stitches, he still had a small wound. Those are the days that you really have to think and adjust all sorts of diagnoses, you name it. None of my colleagues had noticed and that wound there would have festered. I think that is typical of my colleagues. How is that possible? It is even in his care dossier that you have to check that wound. How is it possible that you miss it? […] and that is also an important part of my role.
>
> (Interview with Barbara, district nurse)

7.1.4. CARE RELATIONSHIP I: MONIEK <-> ADRIENNE

Care worker Moniek has been providing care to Adrienne for the last ten years and visits her regularly. During the fieldwork week, she visited Adrienne three times. Moniek performs all medical and personal hygiene care activities for Adrienne, treating her perspiration wounds, helping her with showering and dressing, putting on the support stocking and shoe. In addition to the formal care tasks she feeds Adrienne's kitten milk as soon as she arrives at Adrienne's home in the morning and enjoys a cup of coffee together with her in the afternoon. She sometimes brings a meal and during the participant observation period, she brought two leftover portions of spaghetti. Moniek explained that Adrienne never cooks for herself and that her own children refused to eat spaghetti. Furthermore, she also argued that she can bring Adrienne spaghetti, because Adrienne will not try and cross social boundaries. Moniek is well acquainted with Adrienne's daughter Lotte, because they have met during Moniek's care activities. Moniek is also the member within the care team who keeps in touch with Lotte so she is informed about her mother's wellbeing, especially when something has happened to Adrienne and Adrienne herself is unable to communicate clearly:

> For example, when I have to go to the hospital, and because Moniek and Lotte also know each other, then Lotte will also receive a call from Moniek: 'Hey, Adrienne is being hospitalized' […] Otherwise I have to do it myself at that moment and sometimes I am not able to do that. I have had a very high fever twice, that I no longer knew that I was there. I felt very far away.
>
> (Interview with Adrienne, care recipient)

Moniek seems also to be the care worker to whom Adrienne feels closest to. For instance, at the end of the fieldwork week, Adrienne fell out of bed in the middle of the night and had to push the emergency button. The emergency service found her after 30 minutes and she had to spend the night at the hospital. Although the fall did not inflict any serious wounds, Adrienne did text Moniek in the morning about what had happened. The next day, Moniek visited Adrienne to care for her after she got home from the hospital. When inquiring about the relationship that Moniek has with her clients, she admits treating the relationships with:

> Appropriate distance […] sometimes I will tell them something about my private life, but I will not reveal everything. For example, if I, well that I told you that my friend passed away last week, I would absolutely not tell my client this because I find that information

> burdening information that they have nothing to do with and cannot do anything with it. […] I can tell that I went to the beach yesterday. I can also tell that I went [to the beach] with my children, I can also tell them I have four children. But that's where it stops.
>
> (Interview with Moniek, nurse)

In her dealings with Adrienne, Moniek emphasizes the importance of encouraging self-sufficient behaviour:

> It would be much faster for Adrienne if I would wash and dry her. But I do not… but I would almost finish a half hour earlier if I would take everything off her hands. But then the result is that in six months she cannot do anything anymore. She will have become completely passive, sitting in her chair and that is something you have to prevent at all times.
>
> (Interview with Moniek, care worker)

Moniek argues that encouraging self-sufficiency is a principle held by all who work in home care.

7.1.5. CARE RELATIONSHIP 2 BARBARA <-> ADRIENNE

Barbara is the second home care worker who regularly visits Adrienne. Like Moniek, Barbara performs all medical and care activities that Adrienne needs. Barbara's relationship with Adrienne seems however to be more challenging despite their friendly chatting back and forth. During the observations, Adrienne explicitly mentions that Barbara has a coordinating position within the care workers' team. Furthermore, Adrienne seems to be more careful in the way she approaches Barbara, her voice is always pleasant, and during the care activities she often makes jokes, suggesting that she wants to keep the interaction happy and light. However, several times during their interaction, Barbara's authority is displayed. An example is during Adrienne's shower:

> Adrienne and Barbara chat about how nice it is to take a cold shower when it is hot. Barbara admits she took a cold shower yesterday but that taking a cold shower in hot weather is bad for your health. Barbra argues that what you should do is change the temperature of the water from hot to cold […] that would be good for the blood circulation. Adrienne says she agrees, Barbara reacts cheekily, but with a smile: 'It doesn't matter whether you agree, I am saying that it is beneficial to your blood circulation'.
>
> (Summary of field work notes July 26, 2018).

These types of mini interactions occur more often between Barbara and Adrienne. Barbara explains during her interview that she is often considered directive by clients and that sometimes being directive is also part of her function as a district nurse. Sometimes she also has to address issues that the other nurses don't have to. For that reason, some clients don't like her, but she thinks that is also part of her job and personality.

When asking about an interaction concerning making the coffee, Adrienne points out that she and Barbara have differences in terms of age and therefore also different ideas about values. Age difference in the relationship of Adrienne and Barbara thus seems to be something to take note of.

In addition to the care and medical care that is provided to Adrienne, the home care workers also provide her with 'extra's' and Barbara even manages to arrange a free holiday for Adrienne:

> One morning Barbara talks about how in a couple of weeks she will be going on leave. During her leave she will volunteering for a charity that provides a week of free holiday to people who suffer from rheumatoid arthritis and who need 24-hour care. The aim is to include people who don't have the income to go on holiday because of the need for care and/or because they cannot afford to do so. When Barbara talks about this charity, Adrienne mentions that she also hasn't been on holiday for a long time and that she also longs for a get-away. Barbara replies that she will inquire with the charity whether Adrienne would also be eligible to participate in this programme despite Adrienne not being diagnosed with rheumatoid arthritis. Two weeks later Adrienne has been accepted to the programme because some of the original participants withdrew at the last minute. Now she will be able to go on holiday for a week.
>
> (Summary of fieldwork notes and interview with Adrienne 25 July – August 8)

7.1.6. CARE RELATIONSHIP 3 MONIEK <-> BARBARA & AND ADRIENNE

While Moniek and Barbara have different positions, their coordinating tasks seem to unite them within the home care team. During the participant observation period, Moniek and Barbara are often discussing team issues amongst themselves during coffee breaks or just before meetings. A main topic of discussion is the planning of the care schedules. While it is Moniek's responsibility to take care of the planning, Barbara also takes notice of this issue when there are gaps in the planning and accordingly has to address the other colleagues to sign up for a shift. In addition to addressing the planning issue among colleagues, Barbara has to tackle issues concerning conflicts within the team and between team members and clients. Moniek and Barbara also work a regular working week and office hours because they have these additional other tasks, while the other members of the home care team only work in the mornings and evenings.

Still, the primary job of Moniek and Barbara is to carry out care work and share Adrienne and the family Jansen as clients. Adrienne and Moniek have different approaches to carrying out their care work. In the following two different situations will be described when carrying out care work at Adrienne's shows a negotiation and diversity in approaching care work.

WHO BREWS THE COFFEE?

The observation at Adrienne's place shows differences between Moniek's and Barbara's approaches. Some differences relate to how they speak talk and joke with Adrienne and share personal stories. Moniek is more reserved than Barbara is. Whereas Barbara talks more openly about her private life, Moniek does not. Yet one difference that really stood out in terms of care activities during the mornings, was the making of the coffee. While Barbara would brew Adrienne's coffee Moniek would let this be done by Adrienne herself. When inquiring about my observation to Adrienne on the different approaches towards preparing the coffee between the care workers she answers the following:

> Adrienne: Barbara usually does it [brewing the coffee] herself. So that I can unpack my things that I brought from upstairs. But if I ask Moniek, if [she] wants to make coffee, then then she'll do it. I also have the idea that it is a difference between young and old, that Moniek has more respect to wait and not just say, ok, I will make the coffee. I would find it okay if she does, but I think that also has to do with age, as I would feel the same. I think it has to do with age.
>
> I: A kind of politeness to wait for you to make coffee instead of doing it herself?
>
> A: Yes yes.
>
> I: I find it interesting, because when they were brewing coffee, I was thinking, ah, so [Barbara] does it to help [Adrienne], but I can also see it the way you said it, Barbara feels very free to do it and does not wait for you.
>
> Adrienne: Yes, it is both actually, because she also does it to help me […] but it is also the case that otherwise it will take longer for her. And I think that's fine too, if she helps me.
>
> (Interview with Adrienne, care recipient)

While the first impression is that Barbara is helping Adrienne, the making of the coffee could thus also be interpreted as an aspect of time management and doing injustice to Adrienne's own agency and tempo of doing things. On the other hand, in the interview with Barbara when the structured way of organizing care at Adrienne's is discussed, Barbara reveals the following:

> You have to work efficiently because otherwise you will be out of time. It also tires me, going back and forth. And Adrienne has to be corrected in what is logical in terms of work […] Previously she would first go down in the morning. Then we would drink coffee first, downstairs. Then we went upstairs, then she would first go to her bedroom, getting her clothes. But then I think, do it [getting clothes] after the care. When I'm cleaning up the shower, you can choose your clothes […] and when she was already practically in the shower, she would go like 'Oh I forgot this or that'. Then she has to go back to get those things. With her, you have to teach her how to work systematically.
>
> (Interview with Barbara, district nurse)

WEARING OR NOT WEARING THE PROSTHETIC LEG

A final care activity that is on the care schedule, and should take place after the coffee break, is putting on Adrienne's prosthetic leg. Yet Adrienne never wore it during the research period and the prosthetic leg has come up during the care activities in the morning. During the first day of the research, Moniek asks Adrienne whether she would like to wear the prosthetic leg. Adrienne says that it is too hot to wear it (it is currently 36 degrees Celsius outside). Moniek does not press further. But Moniek does show the researcher the care file of Adrienne in which it is stated that her colleague has reported on how Adrienne does not want to wear the leg. The next day when Barbara is the care worker to visit Adrienne in the morning, she also asks about the leg. Adrienne tells Barbara that she doesn't have to wear it according to Moniek because the weather is too hot at the moment and the prosthetic leg causes rashes on Adrienne's upper-leg. The way Adrienne tells this is of course not entirely how events occurred yesterday. In response, Barbara tells Adrienne that if she doesn't want to wear the prosthetic leg she doesn't have to. Nobody is making her do anything. Adrienne admits then that she doesn't like wearing it now with this hot weather, but that she would like to do so later:

> I don't have to, but I can. Even if I would pick up that leg and [throw] it in the corner of the closet […] I could. And if I would never be able to use the leg anymore, I would also make peace with it. But as long as I can, I will keep trying. [with the leg on] I sit better, and it looks better but if it hurts [with the leg on], then I will only suffer from it. And you can say, nice two legs, but if it hurts then I feel like, I have less pain without putting on the leg and this way [without leg] is fine too. […] but when I visited the physiotherapist and I was not wearing the leg, he would say that next time we are going to work with walking using the bridge again, so you should next time wear your leg.
>
> (Interview with Adrienne, care recipient)

The interesting thing about the situation with Adrienne's leg is that when the care workers bring up the prosthetic leg, Adrienne seems to feel pressure to do something with it, even though the care workers may not intend to cause this reaction or to put pressure on Adrienne. This situation shows firstly, how having different care workers can give the care recipient, Adrienne in this case, space to negotiate her needs and wants - whatever they may be; secondly, the pressures of fulfilling the ideal of able-bodiedness – and the role healthcare providers can play in informing this ideal. This point is also made during the final interview with Barbara:

> I think I have the responsibility to explain to clients what the consequences are of the particular choices they make, some people cannot make their own choices, but that is another story. But with people who can think and can make decisions themselves, I will explain, this or that is better […] or if you do that, that happens […] I also think that clients may point out things that I do not do well or what they do not like or what I should do differently […] and I think you can treat each other with equality in this way. Adrienne for example, she had to visit the physiotherapist and she had to put her prosthetic leg on, but if she does not feel like it, she does not feel like it. It really isn't the case that she must walk a marathon. If she can walk to the storage room once in a while with her walking frame on, that will already be enough. If this is enough for her, who am I then, or who is a doctor to say, you must be able to walk several miles? Sometimes things are also good as they are. [sometimes] we impose people to do things differently. And when I notice that, I tell Adrienne, it is your choice, you are competent, you can make your own choices […] So now it is the case that Adrienne has to visit the physiotherapist and walk there. But she said, that she has not been wearing the leg for a few days and if she will suddenly wear it, it will not work. But then I think, for whom is it a problem that it does not work? She does not seem to be bothered by not wearing the leg. She will still be using that triple

> chair and she cannot function in her home with using her both legs, she will never be able to do that. Then I think, for who is that [the leg]? And then I sometimes think that it is good to say something to her, that she also has to stay close to herself, that she shouldn't always do what others expect from her, and she is a vocal person, but now I thought, I should say something to [encourage] her.
>
> (Interview with Barbara, district nurse)

7.2. LOCATION 2: THE JANSEN'S APARTMENT

The second location of fieldwork was the apartment of Mrs and Mr Jansen. Both the Jansens received home care from Selma. In addition to receiving care from professionals, Mrs Jansen also played an important role in caring for her husband. The following discusses the care relationships between:

4. Henk <-> Jannie
5. Jansen couple <-> Selma
6. Home care team <-> Jansen couple

7.2.1. JANNIE AND HENK JANSEN, CARE RECIPIENTS

The second care observations have been conducted with the care recipients Henk (male, 73 years) and Jannie (female, 72 years), a married couple who live together in an apartment and started receiving home care recently after Henk had been sick for about a year. Henk and Jannie were interviewed together (instead of separately) as they preferred to. Henk and Jannie have two sons and a daughter who do not live very nearby, but with whom they have regular and good contact.

Henk is an against his will an early retiree. The company he was working for was reorganised and he was fired and lost his job. After losing his job, now more than 14 years ago, he was diagnosed with several health conditions implicating his thyroid and lungs and was also diagnosed with diabetes. A year ago he was diagnosed with heart disease and after his heart surgery the couple started needing care at home. During the entire first year of Henk's illness, Jannie took care of him but eventually she was no longer able to continue. She also has COPD and needs to take enough rest. Jannie contacted their physician to arrange care at home. Before they started receiving care at home, they also took care of Henk's parents. Today, Jannie still arranges and coordinates the care for herself and Henk, including arranging doctor's appointments and when to take medicine.

In the first three days of the research week, Jannie received daily care for helping with washing and dressing and putting on her compression socks. Henk received care twice a week help, comprising support with showering and getting dressed. During the second half of the fieldwork, Henk suddenly fell ill with a thrombosed leg and was hospitalized. The home care team was directly informed by Mrs Jansen and a member of the home care team immediately went to visit her at her home to see what help she needed in the meantime. While Henk was able to return home on Monday, the care activities for both were expanded and the care schedule and plan were adjusted. Previously Henk had helped

Jannie with dressing and taking off her compression socks, but now he is unable to. The home care workers increased their visits to the couple to mornings and evenings.

During the fieldwork period, all three care workers, Moniek, Selma and Barbara have cared for the couple. They live in a neighbourhood that is not part of the district that the home care team normally takes care of but is part of the district of home care team B that works for the same healthcare organisation. But home care team B did not have the capacity to take care of the Jansen's and for that reason home care team A took them as clients. The visits to the couple are always planned as a first stopover in the care schedule of the day, as they live very near to the community centre where the office of the home care team is located.

7.2.2. SELMA, PERSONAL HEALTHCARE AUXILIARY

Selma, 47 years old, is a personal healthcare auxiliary (Level 3 care worker) who started working in home care as a housekeeper 15 years ago because the working hours were convenient to combine with single motherhood. She started studying part-time next to working in home care and became a Level 3 care worker. She intended to further her studies to become a Level 4 nurse but had to pause because she suffered from depression and burn-out and had to take sick leave. She currently works 24 hours per week and is still in her re-integration period. She feels that her employer (the care agency) and the home care team were very supportive of her and have offered her a lot of help in recovering:

> A good employer is someone who, I experienced it myself, I found my employer very involved with me, the team was involved, there was good communication which is very important and you are not a number. He asked: what we can do for you, he was being vulnerable, asking the questions to us, showing that he does not know but also asks whether you know.
>
> (Interview with Selma, personal healthcare auxiliary)

In addition, she feels that this attitude is generally important of a good employer: asking questions and taking the care workers seriously. The employer should acknowledge that the care workers are the experts and are closest to the clients. Finally, attentiveness is also mentioned as an important aspect of a good employer. For instance, during the participation period the care agency sent an email around informing home care teams that they should take it easy because of the hot weather and that they were allowed to buy ice cream from the work budget because the temperatures were rising immensely: 'It's a small gesture, but those things are just', Selma explains.

Selma explains that she feels that care work is her calling:

> My calling is to be helpful to people, so that they can stay self-reliant and still be able to participate in society. It gives me a very good feeling if I can assist people with that. And this [assistance] can be very big but also very small. It can lie in the smallest suggestions of, 'Oh why don't you try that' and then a world can open to them. That is why I like to work in home care, because it is 'warm' care, and that is my strength. Warm care, being very empathetic, compassionate.

> (Interview with Selma, personal healthcare auxiliary)

And she adds that, to do care work, one must be do it because of this calling, the income is not attractive enough for people to want to work in care.

Selma is one of two care workers within the home care team who is a woman of colour as she has a mixed Indonesian background. When inquiring about whether she ever found that her ethnic background mattered in her work she says the following:

> From the Indonesian cultural perspective it was difficult. I was used to take a subordinate attitude towards the Indonesian elderly, but in my job I had to learn to say no or tell others what should be done and that was difficult at first […] I never heard anyone mention my ethnic background and I am not even aware of that it matters to others in my job.
>
> (Interview with Selma, personal healthcare auxiliary)

7.2.3. THE HOME CARE TEAM

As described in section 6.5. The home care team consists of nine members, all women and taking different care worker positions, ranging from Level 2 to 5 with associated pay grades. Yet the clients that the team provides care to are generally the same, with an exception that there are some cases of patients that need care that demands medical expertise. In these cases, only Level 4 and Level 5 care workers can provide the service. Thus, the care workers often share clients and cooperate with each other on working with clients. To establish good cooperation, members of the home care team meet every morning between 7:45 and 8:15 at their office to discuss how things are going and whether there are any important issues. This meeting is compulsory. Thus, during the fieldwork period, every morning the care workers would meet at the office and discuss how clients are doing; raising issues regarding planning and sometimes also giving feedback on behaviour of co-workers. In addition to these morning meetings, the team also keeps in touch during the day through a WhatsApp group where they communicate to each other about clients that they had visited.

Working in a team brings many benefits. Sharing clients gives space to workers to keep their relationship professional and personal at the same time, as emphasized by Moniek. Another benefit is that they keep each other sharp, generating a system of checks and balances. They can help each other out, but at the same time also keep each other in check to prevent mistakes from happening. Moniek underlines the importance of having different care workers providing care to one client:

> It is also to check-up on myself, because you can fall into habits and it may happen that you miss things. I think it's good that someone else regularly takes over from you, and can rap your knuckles, saying “I think it's more convenient if you do in that way or that way”.
>
> (Interview with Moniek, nurse)

Yet this system of checks and balances can also result in tensions:

> It has caused some trouble over the weekend. There was one colleague who was just very busy with these clients and she dropped some stitches on things that were less important,

> such as marking eye drops. She did give them eye drops but did not sign off on doing that. So she did carry out the activities but did not finalize everything completely, and [care worker X] was very active on WhatsApp and sent many messages on the group app saying "This was not signed off, that was not signed off" and that has caused tension. I'm going to talk to [care worker X] about this coming week. Because it is important that you address each other personally […] instead of putting these messages in the group app which can be very annoying for those who have been working hard and well and have been busy all morning.
>
> (Interview with Barbara, district nurse)

Different examples above have also shown that having different care workers from the team providing care also generates space for clients to negotiate their interests and wishes (indirectly). Clients can for instance complain about a specific care worker indirectly. Yet there is a fine line between gossip and taking complaints seriously as Barbara explains:

> If a client complains about a colleague I will check first, is this just whine, yes, she was late, I can't do much with it. I would say it is a vacation period and you have to take that into account - that's what I would try to do. But if there really are things, then I will talk to my colleague about why that client is pissed off and how that could happen. So I try to approach these issues in that way and then I hope that the client and colleague will be able to come to terms, or else, there will be a conversation where our senior colleague or I will be present to talk things over. But that doesn't happen so much.
>
> (Interview with Barbara, district nurse)

7.2.4. CARE RELATIONSHIP 4: CARING FOR YOUR SIGNIFICANT OTHER: JANNIE AND HENK

While the care activities that the home care team carries out for the Jansens are quite basic, involving mainly personal hygiene activities (daily help with washing, dressing and putting on support stockings for Mrs Jansen; twice a week help with showering for both) the care workers also interpret their task as to lighten the workload for Mrs Jansen – as she tends to take all responsibility for the care of herself, her husband and their home:

> With married couples it is often that if the one is sick the other is inclined to take over a lot and that the chance of work overload is very large for [example] family Jansen. Mrs Jansen is inclined to do a lot for her husband. We come there twice a week to help them taking a shower and she is inclined to when her husband wants to shower earlier [on those days], she will help him. This way she uses up all her energy and is caught out of breath. So then I say [to her] you should not do that anymore. We come twice a week to relieve you [and you should make use of it]. On the other days you already do enough for him.
>
> (Interview with Moniek, nurse)

Still, Mrs Jansen takes the main responsibility of taking care of her husband. She manages his doctor's appointments, is aware of all the medication he takes and because of his diabetes she always brings a can of cola in her bag wherever they go. Furthermore, Mrs Jansen also takes main responsibility for housekeeping and cooking food, although Mr Jansen says he does help her with housekeeping. Mrs Jansen in an earlier stage requested help when Mr Jansen had fallen ill. However, and probably due to long waiting lists, the organization that arranges housekeeping only got in touch with the Jansen's after three months of waiting. Because of that the Jansens feel they are being treated disrespectful by the care organization:

> The care work is good. What they [the home care team] are doing for us right now, we are happy with that. Only the domestic help failed. They are short of staff. But they must handle the process correctly. They told us that they would call us within 14 days, but they called after three months. Then I called them a few times myself [and they would say] 'No, it will take some time, it will take some time'. From the neighbours upstairs we received a direct number, but that did not help either. Then I said, you do not have to take me anymore [as a client] if I need help again. I don't want to have anything to do with this organization.
>
> (Interview with Jannie and Henk Jansen, care recipients)

Because they felt ill treated by the housekeeping organisation, the Jansens are taking care of housekeeping themselves for the time being.

7.2.5. CARE RELATIONSHIP 5: JANSEN COUPLE AND SELMA

During the fieldwork, Selma visited the Jansens twice on a regular basis and several times in the weekend when Henk suddenly fell ill. When inquiring whether their relationship has developed because of her presence in the weekend, she says that it indeed has, but that clients should not get attached to her too much. Otherwise you will start hearing 'Oh, we expected her', people can start experiencing it as inconvenient when it is another colleague who turns up. This is not only important for clients, but also for care workers when they have to replace a colleague who is loved a lot by the client.

The care that is provided by Selma to the Jansens not only follows a certain structure, but is also restricted to certain areas of the home where the care activities take place:

> When Selma arrives in the hallway, the front door of the apartment is already open. Selma knocks on the door and enters, Mrs Jansen comes out to greet Selma. Selma walks towards the dining table, places her bag there and takes a seat at the table. She doesn't ask how the couple is doing, but they chat about Mr Jansen's experience at the hospital last weekend. Selma starts reviewing the Jansen's care plan. During this whole time, Mr Jansen is seated in his fauteuil in the living room, reading his newspaper and chats with Selma and Mrs Jansen while Mrs Jansen sits opposite to Selma at the table. After reviewing the care plan, Selma and Mrs Jansen go directly to the bathroom to help Mrs Jansen with washing and dressing. Mrs Jansen fills up the sink with water and drops of

> shower gel and starts washing herself. The care worker helps her wash areas of her body that are more difficult for her to reach, such as her back and her legs. After finishing washing, Mrs Jansen puts on her underwear, with help from Selma, in the bathroom and then she and Selma return to the living room to finish dressing there.
>
> (Summary of fieldwork notes August 1, 2018)

As the fragment shows, Selma never enters the bedroom, nor the kitchen or the seating area in the living room. Selma only treads where the care activities take place, which is in the dining area, the living room and the bathroom. Selma only heads over to the seating room area when she is helping Mr Jansen with the compression socks. In other words, Selma only enters areas of the apartment when there is a certain functionality to it.

Care workers work from the principle of accommodating the different preferences and personalities of their clients, but the fieldwork also suggests that this attitude is mutual. The Jansens also accommodate the different ways of working and preferences of the care workers. For instance, after Selma enters the apartment, they immediately ask whether she wants the fan to be put on, so she can keep cool while she is doing her job. They are aware that Selma gets hot more quickly than the other care workers during these high summer temperatures.

7.2.6. CARE RELATIONSHIP 6: JANSEN COUPLE AND THE CARE TEAM

When inquiring about the way the Jansens feel about the home care team, Jannie and Henk call out in unison: ‘Great!’:

> Henk: [They are] always friendly, asking us whether they can do anything [for us]. The staff are really great, it is not them when things go wrong. Jannie: Even when he was in the hospital “Is there anything else we can do for you?” No, I can try I by myself, but if it doesn’t work out, then we’ll see again. But I am really happy about them, I almost had all of them [workers part of the home care team] visiting me. They are all equally good’. Henk: All equally sweet and caring. Jannie: And always a friendly word or joke. Henk: People need that and if they give that to people, they will also recover much faster. If they don’t give that, people will become more miserable and they will also become more hateful and then it will result in how people will be working against each other. That won’t do.
>
> (Interview with Jannie and Henk Jansen, care recipients)

For Jannie and Henk, it is very important to have care workers asking them about how they are doing and to an extent also developing personal relationships. Developing personal relationships is also the reason that Jannie and Henk are unhappy with one specific care worker within the home care team:

> There is one that I do not like. I have not said that she may not come, but when she comes, she does things quick, quick and then she is gone. […] usually you’re filling in the care dossier together or you're just chatting, but with her, you have to go directly into the

> bathroom. She is always in a hurry, she says that this is because she has to go to another neighbourhood later on.
>
> (Interview with Jannie, care recipient)

The Jansens are unhappy with this particular care worker because she reserves no time for a friendly chat and does not show any interest in them. Accordingly, the Jansens have let the home care team know that they prefer not to have this specific care worker and where possible, the home care team takes their wishes into account.

Care workers too find this attention and personal approach important. For instance, the morning after Mr Jansen's hospitalization, Moniek visits the Jansen's home and finds a distressed Mrs Jansen and the following ensues:

> Upon entering the Jansen's apartment, Mrs Jansen seems to be doing fine, she smilingly says hello to us. But after Moniek sits down at the dining table and asks Mrs Jansen how she is doing, Mrs Jansen breaks down, crying quietly. Moniek stands up and walks towards Mrs Jansen, lowering her head a bit and places one hand on Mrs Jansen's shoulder. Moniek looks at Mrs Jansen attentively, standing with an open attitude, arms around her body, with her body turned towards a sobbing Mrs Jansen. She listens to Mrs Jansen telling her story. Mrs Jansen talks about the hospitalization of her husband and although Mr Jansen will be able to come home soon, they still have to go back to the hospital two times next week to wrap the leg of her husband. Moniek explains that she can also have the leg bandaged by the home care team. In this way the Jansen's don't have to go up and down to the hospital multiple times. After further discussing the planning of the care activities, Mrs Jansen also confides in Moniek about her worries regarding her son.
>
> (Summary of fieldwork notes 27 July, 2018).

The talk with Mrs Jansen took more time than was planned, but when inquiring with Moniek about it after having left the Jansen's home, she explains that she think it is of great importance to also provide space to her clients to express their worries and problems, especially because of specific events that took place.

As underlined above that care work professionals find it important to incorporate a personal touch in their relationships, care work professionals also function according to a certain ethical principle. Professionals focus on clients' needs, but also aim to keep a distance, while care recipients would like to build personal relationships with those that care for them. To ward off this emotional dependency, the home care team also makes sure that clients do not have the same care worker visiting their home every day:

> It is not desirable that only one specific care worker visits a client. A. I am not available seven days a week and twice a day and B. people are going to get attached and that is not bad to some extent, but I can never guarantee 100 per cent that I will be there. I can be on holidays, I can get sick, I can even get sick for a long time and then you get problems. Of course, it is nice when you are with a few people and not too many, but it is always

> good if there are more [colleagues within the care team] who take care of a client. (Interview with Moniek, nurse)

8. *THE PRIVATE HOME AS THE PLACE TO STAY*

Being cared for at home has for a few decades been regarded as the optimal solution for people in need of care in the Netherlands (see Part I). It drives care policy reforms including the most recent one of a large-scale reduction of the number of places in elderly homes. Such elderly homes offered services to older people fit enough to get themselves dressed, to get out of bed themselves and to eat without help. Nursing homes in contrast are available for those elderly and disabled people who are restricted in those functions. As a consequence of these changes there is hardly any option left between staying at home as long as possible and moving in to a nursing home. This approach has become a hegemonic discourse shared by politicians, practitioners and a majority of the population alike. Here we present the reflection of the care workers and the care recipients on the divide between residential care and home care and on the unavoidable consequence of family members involved in the care network. Finally, care workers and care recipients reflect on the (policy) aim of living at home as long as possible, on how its fit with clients' and care workers' evaluation of professional home care work, and the implications this has for the recognition of agency, self-reliance and justice related issues.

8.1. DICHOTOMIES HOME VS RESIDENTIAL CARE

> It is a very different way of providing care. [In the institution] the clients are your guests, and they have to keep to the rules of the hospital [or elderly home]. [With home care] you visit your clients at home, in their own environment […] I have to stick to their rules and how they want me to care for them […] that's a whole different way of providing care. And also [clients] prefer to be at home rather than in the hospital, so therefore the atmosphere is different […]
>
> (Interview with Barbara, district nurse)

This dichotomy between care work within the private home and within the residential sphere is not only a main aim of the Dutch care policy (see above) it is also often emphasized by the care workers. They consider home care as more personal in terms of relationships between care providers and care recipients; recipients have more agency, because they are still fit to live by themselves, and they are functioning in their own environment according to their own rules. Interestingly they consider all institutional settings such as the hospital and nursing homes to be equal in delivering impersonal care. According to them clients have less agency and must stick to the institutional rules. While this might be true for hospitals it is not per definition the case in nursing homes that show a lot of variation in regimes from very client-oriented to more rule-based approaches. Indeed, clients in nursing homes are sicker due to the live as long as possible policy that has limited accessibility of elderly who are seen fit enough to stay home':[4]

> If you look at nursing homes, people become in a matter of time accustomed to the daily rhythm. At 7 o'clock they are woken up to take their medicine. They get breakfast at 8 o'clock. At 12 o'clock they get hot food. They get a sandwich at 5 o'clock. At 11 they are helped to the toilet. At 3 o'clock they get to go to the toilet one more time. In the course of time you will notice that as soon as something deviates from this rhythm, they will become completely unbalanced. Completely disrupted. They also cling to each other a lot, 'You have me, you belong to me'. And that is much and much less the case in at home situations.
>
> (Interview with Selma, personal healthcare auxiliary)

By comparing their type of care work with residential care in a nursing home, the home care workers express their appreciation of their work while at the same time showing support for the recent policy turn towards care at home that is supposed to be more personal and tailor made. This is again underlined by Barbara who explains that the home care team must adjust the planning of care activities to the day schedules of clients:

> I find it very different. As I have said, as a home care worker you have to adapt to the situation of a client. We have many clients who have appointments. For example, Adrienne asked whether she could make that appointment [with the physiotherapist] later, because in the morning she has home care. They will say that home care has to take their appointment into account. It is often thought to be this way. Hairdressers, physiotherapy, that is all done in that morning, while we provide care in the morning. So you should always take these appointments into account. Also, some people have a day care programme. We have to take care of them very early. They can be picked up at 9 o'clock. So you have to take all of that into account.
>
> (Interview with Barbara, district nurse)

In addition, the home care team also adjusts to the preferences that some clients have. For example, there have been female care recipients in the past that prefer a female care provider. The home care team will take their wishes into account, when these women have in their eyes very good reasons to do so, such as a history of abuse or when they have reached a very old age holding traditional ideas about gender. Yet the boundaries as to what motivations for preferences are considered as being acceptable, are vague:

> Barbara: Well if someone is 90 or 100 then I understand, she has had one man, that [having a male care worker] comes too close. Or in case of abuse we take it into account. Yes, of course we do. We will ask if there is a reason for why you do not want a man to come. If there is no reason then it is not possible [to take that into account getting a male

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[4] Researcher's footnote; own experience based on her mother living in a public nursing home where the daily routine is completely adapted to the living-in clients, and in contrast to Selma's description.

> care worker]. In the hospital you also get a man. But if there really is a reason for it, we'll keep it into account.
>
> Interviewer: And religious beliefs such as Muslim women?
>
> Barbara: We have almost no Muslim women, but […] .. there was a Muslim woman next door [a client of another care team] and it was taken into account that she did not want a man [male care worker]. But sometimes if you have two men working in the evening and you don't get care from the family…. it is often the case that the family is very involved when it concerns Muslims and yes, then the family does it.
>
> (Interview with Barbara, district nurse)

Furthermore, the fragment above also shows that there is still some overlap between care at home and care in a hospital as Barbara underlines how in the hospital one cannot refuse to be treated by a man – so only in special cases, care workers should also take into account the preference of certain clients for a female care worker.

That care at the hospital is less personal is sketched by Mr Jansen's telling of his last experience in the hospital when he was hospitalized due to this thrombosed leg:

> Mr Jansen argues that it was assembly line work at the hospital. The patches and bandages are prepared in advance for the next patient. But he [Mr Jansen] was still not bathed and washed. Selma answers that bathing him is not their first priority in the hospital.
>
> (Summary of fieldwork notes on Mr Jansen and Selma chatting during care activities, August 1, 2018)

8.2. WORKING TOGETHER WITH AND FOR FAMILY MEMBERS

One consequence of staying at home as long as possible is that family members are more involved in the care work. Or as Finch (1990) stated: 'care in the community' turns into 'care by the community'. Inevitably, family members share an increasing part of the care activities and home care workers develop also care-related interactions with those kin: '[…] and I also think that you [in home care] have much more to do with the family at home, you have that less in hospitals. Regularly a son or daughter also lives at home or they live close by and you also have to deal a lot with that' (Interview with Barbara, district nurse). Home care workers thus deal more often with family members and this contact with family members is both needed, not always reliable and fragile as experienced by Adrienne:

> Interviewer: Does she [your daughter] help you with health care activities?
>
> Adrienne: Uhm, yes sometimes, sometimes not […] she has helped me a lot in the past [but] more [with] little things and she is also very [emotionally] involved with how I am doing. (Interview with Adrienne, care recipient).

Furthermore, when a client has been taken care for by the home care team for years, the contact with the family also builds up as home care providers learn about the relationships between the care recipients and his/her family members. In addition, the home care team perceives it as their task to lighten the work load for informal family care providers, as the above example of the Jansens underlines. Nevertheless, the home care workers confirm the common opinion that informal care by family members can be more flexible and even more personal than professional care:

> Moniek: I sometimes think that a family member can provide much better care than a paid person […] There is a bit of emotional involvement and bonding and that is very different from when you have the sister on your bed.
>
> Interviewer: And you have experienced it yourself. Because you also took care of your parents yourself?
>
> Moniek: Yes and my mother-in-law, and a friend of ours and ... Yes, that is quite different type of care […] At the moment you provide care, you will wear the cap of a professional because you must of course provide official care. You do not want to miss anything. But you do it very differently. You will wash someone at 11 o'clock in the evening if that is desirable. You cannot do that as a professional healthcare provider. And you can leave someone in bed until 12 o’clock if that is desirable. But we [as professional care providers] have to move on to the next one. We cannot leave you in bed until 12 o'clock. Sometimes that also makes it more difficult […] but it [family care] is much more flexible […] you can respect the patient’s timing better.
>
> Interviewer: And that is less with professional care?
>
> Moniek: Yes, that is just ... of course we take the preferences [of patients] into account as much as possible. But we have so many people and so many different preferences, so you will have to find certain agreements on. Time slots for meetings. And you cannot expect that someone can be helped every day at 8 o'clock.
>
> (Interview with Moniek, nurse)

Interestingly, in comparing care by family members with professional home care, Moniek explains that home care is at times inflexible, an argument that she elsewhere made to negatively evaluate residential care. Here she explains that home care too requires a time regime that does not allow for client adjusted preferences. Time pressure and the workload constrain the flexibility of the home care worker who is probably even or more restricted than care workers in a nursing home to consider the needs of the living-in care recipients. Moreover, principles of self-reliance, flexibility and a communitarian interpretation of active citizenship in a context of welfare state cutbacks moves current developments in Dutch care policies to encourage more informal care provision by family members. Despite the advantages of informal care by family members underlined by Moniek above, it is something that does not fit well with contemporary Dutch family life, as Selma explains:

> Society is moving in a direction in which we will be working more and more with informal care providers, which is very difficult, because on the other hand, you are expected to move for your job. Before, Dutch culture [and society was organized] in a way that you

> would all stay together and you would take care of each other. Women worked less, so care was already a joint effort. And that is not feasible today, people no longer live together in the neighbourhood, so they can no longer mean much to their children, the children are getting older so they themselves will become grandparents and they will have their own obligations again. That is where you see a gap and that is why we [home care providers] provide care.
>
> (Interview with Selma, personal healthcare auxiliary)

8.3. STAYING LONGER AT HOME: (MIS)RECOGNITION, AGENCY/SELF-RELIANCE

A very important principle that the home care team departs from is the principle of self-reliance and emphasis on people's own agency. This is understandable given that home care aims to have people still living at home although they might need assistance in carrying out certain activities in their lives. The principle of self-reliance plays an important role in also the everyday care activities:

> Self-reliance must always be encouraged, because what the client can do her/himself must be done by client […] [for instance] It would be much faster for Adrienne if I would wash and dry her, but I don't. […] Or if I would get all her things for her. I would probably finish a half hour earlier if I would take everything off her hands, but then the result is that in six months she can't do anything [by herself] anymore. She will be sitting completely passively in her chair and that is something that you have to prevent at all times.
>
> (Interview with Moniek, nurse)

However, not all care recipients always agree, and they try to negotiate that care workers do things that they are still able to do themselves:

> You have to stimulate self-reliance, it can be very small, if someone is paralyzed half-sided, even if he can do just 'this', then that is good for his self-esteem […] I will also explain that muscles must be stimulated, and you are able to do this, with the other things I will support you. But if someone is out of breath, then you can say okay I'll take over. But if it is not the case, we will give that washcloth [to the care recipient]. And [in this case] she does not want that [to use the washcloth herself] and then that will be a fight. You will think by yourself 'What am I going to do? Shall I engage in the fight because I can substantiate it [my claim] Or will I choose peace?' Some colleagues choose sweet peace, others stand more on their stripes. You have to take one position together. So, nobody likes to go there, and if nobody likes to go there, I will go. Of course, there will be another fight, but I will explain [to the client] again why [s/he must wash herself]. And that washcloth you give her/him will be thrown away angrily in the sink. And that is of course boundary-crossing behaviour […].
>
> (Interview with Selma, personal healthcare auxiliary)

Agency is also experienced as incredibly important by Adrienne. She explains that in her case, because she is seated in a wheelchair (at times), people often address the person wheeling the chair instead of the person sitting in the chair. She however feels that people, even those with disabilities should be considered equal to a person without a disability. And if it is the case that persons, any persons, are unable to do something, they will tell you themselves:

> Every person, in whatever state s/he is, whether s/he is walking or sitting in a wheelchair, you have to treat the person equally. Because when you are sitting in a wheelchair, the person pushing the wheelchair is often addressed, while someone who is in a wheelchair can still be very smart and is still able to do everything […] and then I think, address those people [in a wheelchair] and you will know if they can or cannot do it. When I am together with my daughter and someone asks my daughter something, I will deliberately answer to show that while someone is in a wheelchair, the person does not always have to be crazy.
>
> (Interview with Adrienne, care recipient)

This issue of agency also comes up in the interview with Mr Jansen when it concerns his health behaviours. At times he feels that care workers can take a bit of a patronizing tone as to what he eats or what he does. The perspective of Barbara on this issue of agency of clients from the perspective of care workers is very telling:

> At the beginning I had to get used to it very much. Because then I thought, 'Hello, it's better for you [the care recipient], so you will just do it [act the way I think the client should do it]'. But I smoke, I know it's better for me to stop. And everyone can tell you to stop and pull the cigarette from my hands, but that does not make any sense. You [as a care worker] have the responsibility to explain the consequences of certain choices but in addition you have to learn to let go. People make their own choices.
>
> (Interview with Barbara, district nurse)

On the other hand, care recipients also take the expertise of care workers very seriously and ask them for healthcare advice. For instance, during the home visit of Mrs Jansen, before carrying out all the care activities, Mrs Jansen talks about the way she has helped her husband Mr Jansen with his diabetes injections. Moniek advises that doing the injections without a schedule is not beneficial at all to his diabetes. Moniek will make a schedule for Mr Jansen next week. Care recipients often feel the need to explain their healthcare behaviour to the care workers, and to get their approval:

> During the morning home visit of Adrienne, we find beside her bed a can of sprite. Although nobody mentions anything, she starts to explain that she saw these [cans of sprite] in the supermarket and thought to buy them because this way she will taste something else in her mouth besides water. And in sprite 'There's nothing' [no calories]
>
> (Summary from fieldwork notes, 27 July 2018)

9. NATURE OF CARE WORK: BUDGETED CARE VS REALIZING FUNCTIONS AND CAPABILITIES IN PRACTICE

The home care team performs far more caring activities than is prescribed in the budgeted medical care and personal healthcare schedule of the care recipients. They make quite an effort to support care recipients in living valuable lives for which they need more than only practical care, but also emotional and social forms of care. Care practices therefore involve emotional assistance in specific times of need and a social function for people who are more socially isolated. These more socio-emotional aspects of the care work are not budgeted in the healthcare plans of care recipients, but the home care workers are very much aware of the importance of such aspects of care. These 'caring about' activities as distinguished by Tronto (1993) from the 'caring for' activities, are underlined as crucial also by care recipients. Although the way care work is organized considers the limited time care workers have for their clients, this function of care work is misrecognized in care policies and related budgets:

> Mr Jansen: They [elderly care recipients] look forward to that half hour [of care]. But sometimes they [care workers] have to hurry so much that they don't even have the time to have a cup of coffee with a person [that receives care/care recipient] that just sits there, by herself. When you [the care worker] leaves, you just shut the door behind you and continue to your next client. But that person is alone. And after that hour, [that she receives care] that will feel like five hours for her, she will suddenly have to return to the empty silence. Mrs Jansen: Even if they only get fifteen minutes longer to stay with a patient who really needs it. I think that's important. Mr Jansen: Look, some things are unnecessary, but sometimes it would be good to grant them [care workers] some more time in between the visits. Because that's what it's all about.
>
> (Interview with Mrs and Mr Jansen, care recipients)

The importance of the social-emotional aspect of care is underlined again when the nature of care work and housekeeping are compared. Care workers agree that the nature of the activities between care work and housekeeping might be different as to the necessary training and skillset relevant to be able to carry out care work, but the social factor of housekeeping might be even more important:

> I do not see much difference [between care work and housekeeping], no. The people who come to clean people's homes, I think that housekeepers are just as important as we are. We usually spend only 10 to 15 minutes at people's homes and then we leave again. A domestic worker is there for two to three hours. They pick up on signs more than we do. So they have a very important function.
>
> (Interview with Selma, personal healthcare auxiliary)

As indicated above, care recipients like the Jansen family negatively evaluate care workers who seem to focus only on performing the care activities in a strict sense. However, they feel secure and independent enough to complain at the home care team about that attitude. Yet many of the care workers are aware of the social and emotional aspect of care and informally, outside of their care workload, make time for that. The case of Adrienne is a good example of where they have purposely planned coffee breaks within her care schedule. This coffee moment is considered very important, a way to connect socially and emotionally yet formally it is not part of her care budget nor could it ever be. Adrienne's example shows how care workers take the initiative to schedule 'moments of connectedness' while the case of the family Jansen shows that they also take time to emotionally console their clients when events occur that have been unpredicted, such as the discussed case of hospitalization of Mr Jansen. For the care workers in this study, being empathetic is considered part of their job and motivates them to being involved in care work. They consider it as a 'warm job' relational and compassionate because of the support they can give to people who are not fully able to help themselves. This does not mean that they allow the care relationship to evolve into a personal relationship. There are boundary lines to be drawn between the professional role and the private commitment. The term 'appropriate distance' is used to define those boundary lines, meaning that not too much information on one's personal life is shared with the client, even if the care recipient would appreciate a more personal relationship. From that perspective there seems to be some ambivalence in the relationship; care workers are much more involved in the clients' personal life than vice versa. The ethical principles of professional work involve that some distance is kept, a main reason – aside from practical considerations - for assuring that clients do not have the same carer visiting their home every day. In addition to care work, social interaction and emotional support, care workers also form a network for their clients. For example, Adrienne was only able to tag along on a trip organised by a charity for people with disabilities because of Barbara's social network. Finally, care workers also provide additional 'services' to their clients when they deem necessary. While providing food (spaghetti) was already mentioned, during the participation period also bouillon Sackets were provided by Barbara to her clients, because the weather was so hot, and the care workers were afraid their clients would become dehydrated. Other examples are how another care worker in the team provided washing clothes to one of her clients because the lady did not have enough washing cloths and was often using dirty ones. While another member of the team felt that buying or spending money on a client is not done, this member would shorten pants for one of her clients, because he was wearing pants that were too long for him. The care workers try to help where possible and all in their own way.

To conclude, the understanding of care by both care workers and care recipients is much broader than is scheduled in the budgeted care plans. Care involves medical care and personal care assistance (as budgeted) but has even significant social and emotional functions which are necessary for care recipients to live their life in a decent and satisfactory way. Unfortunately, the latter aspect of care is not recognized formally. This broad understanding of care brings many benefits to the care recipients yet can at the same time pose challenges to the relationship between care workers and care recipients.

10. *RECOGNITIVE OR INTERACTIONAL JUSTICE IN CARE RELATIONSHIPS*

Despite care workers being considered healthcare 'experts' in relation to the care recipients, equality and mutual respect is most frequently mentioned explicitly in the interviews when inquiring with both care recipients and care workers about justice in home care:

> [Justice in home care is] that you deal with each other in a good and honest way and respect each other. I think it [the respect] must be mutual. I do have clients who do not

> respect me, I address them about it, or I simply have no respect for them. Then I think, you can just hang yourself if you approach me like that. For example, with one client we also agreed that if you get angry or become aggressive to a colleague [within the home care team] they will stop providing you care and nobody else will come either. Because sometimes that specific colleague [whom he was aggressive to] will stop with providing care and another colleague will come. But no, it has to be mutual.
>
> (Interview with Barbara, district nurse)

This form of justice, which in the ETHOS programme is called ‘recognitive justice’, has also been described in organizational studies as interactional justice. It refers to the interpersonal behaviour of people and whether they believe they have been fairly and appropriately dealt with (Major in Yerkes, Martin, Baxter & Rose, 2017). Respect, honesty and even politeness are key terms in the concept of interactional justice (Bies, 2015). Although the aim of interactional justice focusses on the relationship between the employee and the organization, the concept can also be relevant in understanding the relationship between care recipients and care workers even if the latter are not literally ‘employed’ by the first. Interactional justice has been applied to various settings, such as hospitals (Greenberg 2006), public sector banks (Ghosh, Rai & Sinha 2014), manufacturing companies (Skarlicki & Folger 1997) and home care (Barling, Rogers & Kelloway 2006). These studies show strong empirical support for the importance of interactional justice compared to for instance redistributive justice and procedural justice. For instance, the research of Yerkes et al. (2017) shows that women working in organisations value the respect, dignity and flexibility that they receive from their employers concerning their care responsibilities as more important than higher salaries. Greenberg (2006) researched the buffering effects of interactionally fair treatment of nurses’ reactions to underpayment. He finds that nurses whose pay was reduced suffered more from insomnia than nurses whose pay remained unchanged. The degree of insomnia was however significantly lower among nurses whose supervisors were trained in interactional justice. These studies both underline that interactional justice might be perceived by – female – employees as more important and can even substitute for distributive justice (e.g. Yerkes et al. 2017; Beugre & Baron 2000). Crucial here is how interactional justice – or recognitive justice – is, as other ETHOS studies show, intertwined with redistributive justice and might be explained by the gender dimension of the above-mentioned studies; Yerkes et al. (2017) not only show that women perceive interactional justice as more valuable than redistributive justice. Women also compare themselves in terms of redistribution to *other* women instead of men. These two factors might serve as major explanations for persistent gender inequality.

Interactional justice is a two-way process of mutual respect, not only the care worker but also the care recipient appreciates to be treated in a respectful way. Transparency and open communication are part of that process. For instance, while care recipients do expect to receive care during the morning, they can accept changes to their schedule when communicated clearly and upfront: “…and if something happens, that they let us know, that they may be an hour later, for example that there are people who have to go to the hospital. Yes, they should go first, I wouldn’t mind” (Interview with Mrs Jansen).

11. CONCLUSIONS AND REFLECTION

The mini-ethnography and related in-depth interviews in the Netherlands have been conducted in the setting of a professional neighbourhood home care team that is part of a large home care organisation though operates autonomously. All care workers are professionals with several degrees of qualification and the team itself decides on their task-division. The care workers are paid for by several care insurances depending on the care need indications of their care recipients. In our case, the care recipients are a single disabled woman and a couple of whom both partners need care. The study has focused on the relationships between the two care workers and the single female care recipient, on the relationships between the couple and their care workers and on the care relations within the couple. In addition, some attention has been paid to informal care relations of the care users and their adult children.

A first question to be answered is: how do people understand, claim and experience recognition and redistribution regarding care work and care use? From the perspective of the care users a large degree of satisfaction with the currently received care is expressed. They are - more than - satisfied with the care they receive because it helps them to overcome daily life problems they are confronted with due to their handicap or illness and supports them in staying at home as long as possible, which is a hegemonic discourse shared by elderly and disabled people, care workers and politicians. However, some complaints about previous redistributive injustice have been heard. One was about the long waiting lists for receiving support, which refers to the bureaucratic procedures that followed from the decentralization of care responsibility to the municipal level of the city of research. The second was about the new gender-neutral assumptions of the Wmo in which it is supposed that also male in-living family members should be responsible for housekeeping. That assumption not only goes against the attitudes of quite a few people but also is not practised leaving people in need of care without support. Hence, they feel redistributive injustice. From the perspective of care workers, redistributive justice is experienced as a matter of payment for qualification. The rather strict qualification system for care professionals does not always reflect the tasks that are done and result in tensions within the home care team. In addition, we notice that care workers perform more tasks than are prescribed because they feel the need to also emotionally support their clients, to give them additional attention, offer food because they see their clients need it and arrange extras for them. These are all activities they are not paid for, can’t be registered, but are time demanding.

Regarding recognition care users and care workers agree on mutual respect and recognition as a condition of the care relationship. For care users an important aspect of recognitive justice is that they can decide themselves on how they want to live their daily routines, that care workers respect the way they deal with their handicap and inform them in time on deviations of the appointments. For care workers recognition seems to be more complicated. They struggle with the ambivalence of professional distance and commitment to their clients. On the one hand they want to be a near-by person but on the other hand they don’t want to share too much of their private life with the clients. It is interesting to note the careful way that care workers deal with advice and comments on their clients’ autonomy. They seem to successfully balance giving good advice and suggestions without dictating how care recipients should behave. Their attitude in the end is respect for care recipients’ decisions even if these go against their opinion of what would be done to make a healthier living.

The second question of the study is: what are the argumentative, practical and conceptual tools that people use to negotiate conflicting justice claims. We signalled few conflicting justice claims and these were of minimal importance. The care workers in our study did not experience any conflicting claims from the side of the clients. In contrast, even if the clients did not ask for extra support the care workers signalled additional needs and provided immediate support to cover those needs. An unexpected visit, because the husband suddenly had to go a hospital, bringing some fresh food because the care user doesn't eat healthily, or arranging a holiday, were all instances that were offered to the care users at the initiative of the care workers. They appear to be fully committed to giving extra attention even if it disrupted their daily routines and the clients did not ask for it, let alone claimed it. Commitment and recognitive justice are the main arguments for offering such extra help. Only on minor issues did practical and conceptual tools for negotiating conflicting justice claims come to the fore such as if the care recipient feels that the care worker for reason of time pressure does not allow her to make coffee herself.

Regarding the question of whether contradictions and intersections between claims for and practices of justice are present in the domain of care, the study shows that most of these contradictions and tensions have to do with the work schedules and time constraints of the care workers. Their work shifts (working in the morning and the evening) as well as the number of care users they assist does not leave much room for flexible time slots that might suit better the care recipients. The scheduled routines are needed for assisting an x number of care recipients per day in a secure chronology from which deviations are only permitted in exceptional cases.

In general care workers and care users well understand and agree with the role of the state in the provision of care work in the Netherlands. Most agree with the 'staying at home as long as possible' discourse and see home care work as the best alternative to residential care on the one hand and family care on the other hand. Therefore, the 'participation paradigm' that prioritizes family care above professional care as much as possible has been met with scepticism. On basis of bad experience (the adult son that does not perform the expected housekeeping tasks), traditional gender attitudes but also on basis of evaluated impossibilities (adult children have busy jobs, take care for their own children and live far away) one disagrees with this paradigm. Care workers in their turn do not always agree with the qualification schemes and related salaries but have no problems with the unusual work shifts, mainly because this is what they expect that home care work involves and fits well with running a family life.

Finally, the main challenges for home-based care are a shortage of home care workers due to the fact that the previous government in times of austerity has fired about 80,000 women working in the care sector (nurses, home are workers, child care workers etc.), who have not yet all returned to the labour market. Yoyo policies in the public sector generate short-term solutions with long-term effects and this represents a major political problem in combination with the rather low salaries in the care sector. Redistributive justice is a major challenge in keeping professional (care) as an attractive employment sector. The main justice challenge for care recipients is being recognized in their needs, to be approached with dignity and being seen as autonomous individuals who can decide on how they want to live a decent life. Long waiting lists are an obstacle in this respect. However, once they are recognized as in need of care and become assisted by home care workers, they feel recognized by the care system as well as by the home care workers.

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APPENDIX – CODE LIST

1. Nature of home care work	1.1. How care activities are impacted by the way care is socially organized as a team effort 1.2. Characteristics of care in public institution vs private home 1.3. Social control of health behaviours by care worker OR care worker as health expert 1.4. Routine and structure in care work 1.5. Social function of care work 1.6. Type of care activity 1.7. Chatting as a function in care work 1.8. Centrality of the care plan representing indicated needs 1.9. Skills and expertise to be learned vs being made for care work 1.10. Spatiality of care in the private home (care is restricted to specific areas in the home) 1.11. Managing family of care recipients as part of care work 1.12. Care work embedded in the neighbourhood
2. Nature relationship care worker and care recipient	2.1. Perceptions on what entails (a) 'good' care work(er) 2.2. Negotiations on the micro level of social interaction 2.3. Perceptions on what entails (a) 'poor' care work(er) 2.4. Making the home and work comfortable to the care worker 2.5. Appropriate proximity and distance OR boundaries to sharing personal information with clients 2.6. Interactional justice in care relationships 2.7. Examples of conflict situations 2.8. Space for negotiating agency and interests because of having multiple care workers 2.9. Care workers as family 2.10. Interests of care workers 2.11. Privacy of care recipients
3. Capabilities and functionings	3.3. Autonomy and self-sufficiency as important principle in care work (policies) 3.4. Accommodating (changing) needs and preferences of the care recipient as part of care work 3.5. Privacy of the human body 3.6. Taking agency of care recipients seriously 3.7. Gap between formally indicated care needs and needs that are not taken into account 3.8. Adjustments of home to the capabilities and functionings of people are also a form of justice which gets too little attention at the moment in the Netherlands 3.9. Importance of housekeeping for care recipient

4. Labour conditions care workers	4.1. Care work as undervalued 4.2. Flexible (and thus insecure)work hours and planning 4.3. Care workers are similar to any other type of category of occupation 4.4. Dearth of care workers as a consequence of poor labour conditions 4.5. Care work and the labour union 4.6. Lack of diversification in functions and pay grade in home care team 4.7. Working ergonomically 4.8. (Good) Employers of care workers
5. Methodology	5.1. Presence of researcher 5.2. Reflections researchers positionality 5.3. Political correctness emphasizing how good the care relationships are 5.4. Representation of respondents experiences
6. Background information care receivers	6.1. Background information respondent health status 6.2. Background of respondent history of receiving care work 6.3. Background information respondent family 6.4. Background of respondent work history 6.5. Background information respondent living circumstances 6.6. Background information demographics
7. Informal care and support	7.1. Informal care as very adaptive to specific situations such as lack of formal care or emergencies 7.2. Reciprocity in informal care and social assistance 7.3. Care and social assistance as gendered 7.4. Informal care burdens informal carers 7.5. Informal care as more flexible (and personal)
8. Perspectives on governmental policies of care work	8.1. Choice of care the choice of care agency depended on the health insurance she had 8.2. Standard of living at home longer
9. Ideas on redistributive justice in the care landscape	9.1. Care organizations benefit the managers over the care workers on the ground 9.2. Efficiency thinking in care has negative consequences for the quality and social aspect of care 9.3. Current care policies impact the right to care of the vulnerable socio-economic groups