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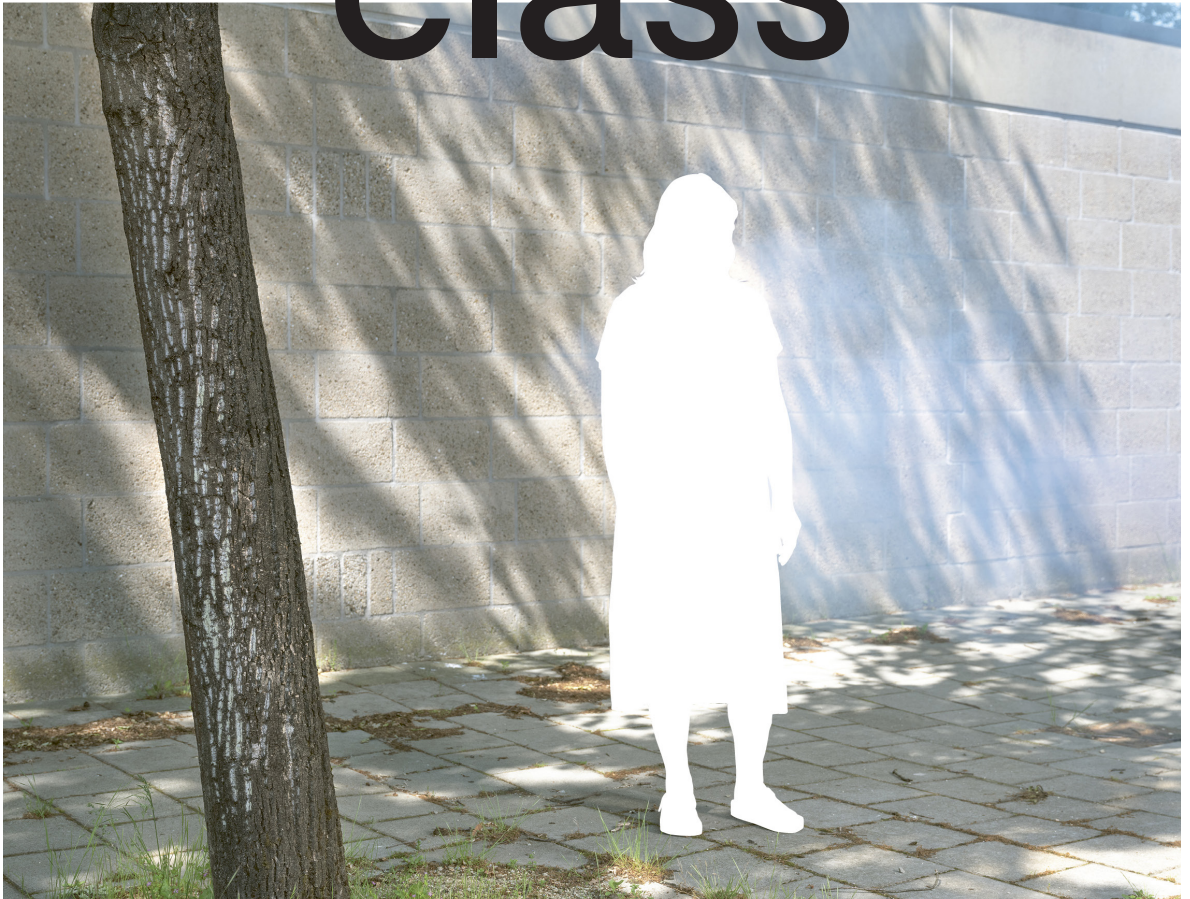
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the caring class



**Saskia
Elise
Duijs**

Precarization of paid care workers in
long-term care and its relation to health:
an intersectional perspective

the caring class

Precarization of paid care workers in
long-term care and its relation to
health: an intersectional perspective

Saskia Elise Duijs

VRIJE UNIVERSITEIT

The Caring Class

Precarization of paid care workers
in long-term care and its relation to health,
an intersectional perspective

ACADEMISCH PROEFSCHRIFT

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Prelude

This thesis started with me crying in the living room of my supervisor.

True story.

I had been researching participation practices of low-paid and unemployed women, most of whom had a migration background. Together with my supervisors, I aimed to understand how they participated – or were required to participate – in neighbourhoods, municipalities and care-organizations.

Understandings of how these participation practices were shaped by broader societal inequalities started to emerge, but remained invisible and unaddressed in my own research practices, which turned them into a painful affair.

I felt frustrated and powerless.

Hence, the crying.

Around 2015, we started searching for ways to address the gendered, classed and racialized dynamics which shaped these participation practices. I was strengthened in this endeavour by societal and women's organizations.

They expressed concerns about growing (gender) inequality as a consequence of budget cuts and policy transitions in the long-term care.

Simultaneously, the need for more scientific knowledge on gender health inequalities and opportunities for gender-sensitive medicine translated into the program Gender & Health, funded by the Netherlands Organization for Health Research and Development.

This programme granted us the opportunity to deepen our understanding of the gendered nature of participation practices in relation to the health of paid and unpaid caregivers.

So, while my family searched for eggs during a cold-easter weekend, I locked myself up in the bedroom of our small holiday house, to finish our research proposal, which ironically addressed the double burden of paid and unpaid (care) work.

From 2018 onwards, this research grant allowed me to unravel these issues together with paid and unpaid caregivers, community organizations and a professional photographer. Together we conducted several empirical studies that form the heart of this thesis (chapter 3-6).

Martha Nussbaum referred to emotions as 'values embodied'. Ethical research processes start with attention for emotions and acknowledging them as valuable sources of knowledge.



Therefore, in this thesis, I explore how researchers can respond to anger, frustration and powerlessness (chapter 7).

Embracing such emotions and having a vocabulary to interpret these experiences as structurally embedded, can contribute to ethical, critical and empowering research practices (chapter 8).

Only to conclude that crying in your supervisors living room might sometimes be a good idea.



Searching for eggs on a cold easter weekend, photographs from authors personal archive

Title // explainer

The Caring Class // *noun* // an activist approach, challenging class inequities, due to the lack of societal, political and economic appreciation of caring for older persons, and the impact this has on the health of paid care workers

Precarization // *noun* // societal dynamic in which increasing numbers of people who find themselves in precarious socio-economic positions as a consequence of a specific mode of governing, or: // *noun* // a politics and economics that is built upon – or even benefits from – the precarization of specific groups

Paid care workers // *noun* // people who work in the care sector, in this thesis particularly referring to low-paid care workers such as nursing aides

Long-Term Care // *noun* // care that is provided at home or in residential institutions, often for longer periods due to chronic illness or disabilities, in this thesis particularly referring to long-term care for older people, alternative; older person care

An intersectional perspective // *noun* // a normative, empirical and theoretical approach to health research taking into account multiple and intersecting differences, or: // *verb* // not overlooking how racism, (dis)ability, sexuality and life-phases (such as menopause) shape the health and wellbeing of paid care workers

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general introduction



In this thesis, I study the health and wellbeing of (un)paid care workers in residential long-term care for older people from an intersectional perspective. I describe how societal inequities permeate labor markets and workplaces, leading to precarization of paid care workers and impacting their health. But not for all workers alike. Not for all *bodies* alike. Therefore, in this thesis I unravel and address health inequities among paid care workers in long-term care.

CHAPTER 1

Societal concerns about the health of care workers in long-term care and the need for intersectional approaches

In this introductory chapter, I first sketch the policy context that shaped this thesis. I will focus on concerns about the growing inequalities in our 'participation society' and about the health of paid care workers in particular. Second, I will describe how intersectional approaches help to understand these growing inequities. Finally, I will present the research questions and participatory research approach that guided this thesis.

Societal relevance

Concerns about growing inequities in the participation society

This thesis was written against the backdrop of major policy changes. In 2015, the Dutch government enforced transitions in the health and social care domain. Two new policies came into force, the Social Support Act 2015 and the Long-term Care Act 2017, who re-allocated care responsibilities towards lower professional levels, and from formal to informal care. These policy measures were informed by austerity measures, enacted in the slipstream of the 2008 financial crisis, and were framed as an attempt to keep the welfare state affordable (Maarse and Jeurissen, 2016). Citizens had to take on more responsibility for health and social care, also framed as an 'active citizen-regime' (Tonkens, 2012; Grootegoed, 2013). Or, in the words of secretary of state Van Rijn: *'we have to start learning to help each other, instead of sending the bill to the government'* (NRC, April, 2013).

Several societal organizations and academic researchers expressed concerns, worrying that *'citizens'* would in practice mean *'women'*. Being the default caregivers, women were already overrepresented in unpaid caregiving roles (De Klerk et al., 2015). Evidence suggested that the moral appeal of the 'participation society' would affect women more than men (De Boer, 2017). At the time, a European study already showed that women's unpaid caring responsibilities increased due to the austerity measures in health and social care (Schenk, 2013). In an ageing society, a large proportion of these caring

responsibilities includes care for older people, such as people with (early stages of) dementia.

Concerns about paid care work

Concerns were not limited to *unpaid* care workers, but extended to *paid* care workers. The working conditions in residential long-term care (LTC, or: older person care) were most heavily impacted by the transitions. Residential LTC for older people suffered from the highest budget cuts, leaving many organizations deeply concerned about their organizational future, uncertain if they would survive beyond 2016 (Duijs et al., 2021). In the workplace, paid care workers had to provide more complex care with lessening financial means, and had to attend to more and more complex care-needs workloads and decreased working hours (NEA, 2015; SCP, 2016). Concerns also arose about the health and wellbeing of workers in LTC. Already before the COVID-19 pandemic, the absenteeism percentage in LTC was among the highest in the healthcare sector (Ernst and Young, 2019), turnover of staff was high (Ernst and Young, 2019), many older care workers opted for early retirement (VWS, 2020) and up to one-third of paid care workers intended to leave the sector within the next five years (V&VN, 2019).

Needless to say, the transitions thus mainly impacted *women's* work. In healthcare, around 80% of care workers are women. In the LTC sector, and toward lower-paid occupations, this percentage increases to 92% (CBS, 2022). Men tend to work in the more heroic and 'adrenaline charged' caring occupations, while women are overrepresented in the 'low-tech-

high-touch' sectors such as care for older people. This horizontal sex-segregation of our labour market is particularly pronounced in lower paid sectors, including in health care (Kreimer, 2004; Verdonk and de Rijk, 2008, Roeters, 2017).

Concerns about the double burden of paid care workers

In LTC, more than forty percent of workers combine paid work with informal care. This is higher compared to the general working population (De Boer et al., 2019; IZZ, 2018). These care workers faced a double jeopardy from the policy measures, as both their paid and unpaid care responsibilities increased. Carrying a double burden of care is a risk factor for feeling overburdened, for ill-health, reduction of working hours or leaving paid work altogether (IZZ, 2018; Plaisier, 2015). So, while caring for others, carers' own health may be compromised (Watts, 2015). Furthermore, combining paid and unpaid caring responsibilities not only impacts health, but also affects women's participation in the labour market. For instance, women combining paid work with informal care are more likely to decrease their working hours and/or exit from paid work than men (Josten and de Boer, 2015).

Concerns about the flexibilization of (care) labour markets

Budget cuts in LTC were mostly buffered at the expense of care workers' employment conditions (WRR, 2021). In 2014 more than 25.000 care workers lost their jobs (NOS, 2014). In 2015, an extra 17.000 care workers were fired (NOS, 2014; AD, 2016). In LTC,

mostly low-paid care workers, such as nursing aides (level 2), lost their jobs. Other care organizations, particularly those providing domestic care, filed for bankruptcy and transferred employees to acquiring companies against lower wages and more precarious contracts (De Koster, 2016). On the whole, flexibilization of the (care) labour market increased through the massive use of temporary work (Kremer et al., 2017; Scheer et al., 2016; CPB, 2016; Van Echtelt et al., 2016).

While all paid care workers experienced flexibilization of labour, more job insecurity and (a threat of) unemployment after the transitions (NEA, 2015; SCP, 2016; WRR, 2021), the precise impact differed per vocational level. In the Netherlands, many care aids (level 1) and nursing aides (level 2) lost their jobs, domestic workers faced more precarious working conditions, while advanced nursing aides (level 3) and nurses (level 4–6) experienced increased flexibilization of their care work.

Although flexibilization of labour is a worldwide phenomenon (Rodgers and Rodgers, 1989; Kallenberg, 2011; Conen and Schippers, 2019), the Dutch are ahead of the game. At the European level, the Netherlands has been pointed out as one of the countries with the highest and fastest rising rates of flexible and precarious work (Eurofound, 2017; CBS, 2022).

Around 2017, the LTC labour market started to change (Kwakernaak, 2017) and critiques have been voiced about the fickle nature of labour market policies in the care sector (De Beer et al., 2020; WRR, 2021). Currently,

in 2022, we face shortages of staff and LTC organizations direct great efforts to enhance the quality of work to attract and retain workers (AZW, 2022). Temporary work in LTC, for example, has decreased. Many LTC organizations offer fixed employment almost immediately to attract workers. Yet, on the other hand, self-employment also increased (VWS, 2020).

Concerns about increasing self-employment

Whereas temporary employment has been popular in the LTC sector, self-employment is a new phenomenon, especially in lower paid regions of the health care sector (Schipper, 2019). In the slipstream of the policy transitions, increasing numbers of low-paid LTC workers opted for self-employment (VWS, 2019; Terpstra, 2019; Kennisland, 2020). In the health and social care sector in general, the number of self-employed workers has grown from 61,000 to 91.000 between 2010–2018 (VWS, 2018). Between 2017 and 2022, the numbers of self-employed workers further increased to 168.439 (KVK, 2022). Estimations of self-employed care workers in LTC amount to 16.000 (VWS, 2019). Self-employed care workers now make up around 16% of the entire total health workforce (CBS, 2020).

Policy makers express concerns that self-employed care work leads to higher health care expenditures (VWS, 2018; SER, 2021). Tax organizations worry about bogus self-employment (VWS, 2018). LTC organizations express concerns about the costs of self-employed care workers, the continuity of

care and higher (administrative) workloads for their hired employees (VWS, 2018; Kennisland, 2020). Policy makers, unions and pension funds worry about the lack of social security for self-employed care workers (VWS, 2020). Public health researchers worry about precarious work as a risk factor for health (Syed, 2020; Julia et al., 2017; Bodin et al., 2020; Benach et al., 2014; Vanroelen et al., 2021). Although self-employment is not necessarily precarious work, this may be the case for specific groups of care workers (Walls, 2015), dependent upon the circumstances, tariffs or the motivations of people to end up in self-employment (Vrooman et al., 2014; Vosko and Zukewich, 2006). Occupational health workers stress that temporary workers and self-employed workers have limited access to occupational health care or to vitality programs as organized by HR departments. General practitioners (GPs) often possess insufficient knowledge on work and health issues to provide adequate support (De Kock et al., 2018). Therefore, flexible and precarious workers are at risk to be underserved in terms of occupational health.

Scientific relevance

The need for diversity-sensitive research

From 2015 onwards, many societal organizations emphasized that we need gender and diversity sensitive measures to avoid growing inequities in our post-welfare state. The policy transitions were likely to not impact all care workers alike. Yet, policy measures were enacted without specific measures to avoid inequities. In general, one-size

fits all policy responses bear the danger of underserving specific subgroups who might be affected most (Hankivsky et al., 2014).

Therefore, several societal organizations, including Atria, NVR and WOMEN Inc., did plea for a gender and diversity sensitive monitoring of the 2015 transitions (Kruijswijk, 2015). They argued that such an approach is crucial to understanding how people are impacted differently by growing informal care responsibilities, increasing workloads in the LTC sector and the flexibilization of paid care work. Such knowledge can enable gender and diversity-sensitive policy measures. In the scientific community, attention to gender and diversity sensitive research in public health and healthcare is growing. In the past years, scholars in the Netherlands are increasingly looking at inequities between and within paid and unpaid caregivers and from an intersectional perspective (Hengelaar et al., 2018; Wittenberg et al., 2019). Yet, challenges remain, as many studies still tend to regard volunteers, informal caregivers or paid care workers in LTC as homogeneous groups (Hengelaar et al., 2021). Incorporating a gender or diversity perspective is not yet a common good in (public) health research. For example, the majority of COVID-19 related studies did not incorporate a gender perspective, even though early on in the pandemic scholars warned for unequal impact of the pandemic (Brady et al., 2021; Smith, 2019).

Diversity sensitive perspectives are particularly scarce when studying low-paid work. In general, diversity sensitive research

and organizational policies tend to focus on high-paid work (Van Eck et al., 2021). In LTC, most care workers find themselves in low-salary scales. Studies on diversity often focus on high-paid care professionals, such as (aspiring) medical doctors or specialists (e.g. Leyerzapf, 2019).

In relation to the flexibilization of paid care work, and increasing numbers of self-employed care workers, scholars argue that we are in need of more diversity responsive research on self-employment and its relation to health (Burke, 2015; Karatas, 2017). Feminist scholars indicate that precarious work will create new gender dynamics in the interplay between health, participation in paid work and informal care, that gendered negotiations play out differently according to age, class, race or ability, and that knowledge of these gendered dynamics is lacking (cf. Hyde, 2016). In public and occupational health, attention is growing for the importance of precarious employment for health (Bodin et al., 2020). Yet a critical analysis of the policies and economics that contribute to precarization of paid care workers are scarce (Lorey, 2015, cf. Bodin et al., 2020).

Advancing Intersectional perspectives increasingly in the context of health and healthcare, an intersectional framework is used to study intersections of sex and gender with each other and with other dimensions of difference and inequality, such as age, ethnicity or class. Intersectionality aims to move *'beyond single or typically favoured categories of analysis (e.g. sex, gender, age, ethnicity and class) to consider simultaneous*

interactions between different aspects of social identity as well as the impact of systems and processes of oppression and domination' (Hankivsky, 2012). An intersectional framework offers insight in the relationship between health, identities, and society, and helps to gain an insight in health disparities between and within groups, including those who are at with intersectional invisibility (Verdonk et al., 2015; Purdie-Vaughns and Eibach, 2008; McCall, 2005). Intersectional invisibility occurs when *'multiple subordinate group identities render a person 'invisible' relative to those with a single subordinate group identity'* (Purdie-Vaughns and Eibach, 2008). This concept is especially relevant for health scholars, as it helps to understand which groups remain unseen and underserved by care and health promotion practices.

Connecting Intersectionality and Participatory Health Research

Intersectionality and Participatory Health Research (PHR) share basic values including striving for social justice and human flourishing, provide tools to jointly inquire and reflexively understand gender and diversity dynamics and inequalities and contribute to social impact and change (Verdonk et al., 2015; Verdonk et al., 2019). PHR has a long tradition of doing research together with people with lived experience (Abma et al., 2019; Wright., 2015), but bears the danger of overlooking specific inequities among and between participants. At the same time, intersectionality can become a theoretic endeavor, losing its connection with those whose life or work is subject to the research.

Therefore, scholars increasingly bring both traditions together, as they can be mutually inspiring and beneficial (Fine et al., 2021; Fine and Torre, 2019; Teti et al., 2021; Kapilashrami and Marsden, 2018; Ferlatte and Oliffe, 2019; Heiskanen et al., 2018).

Research agenda on Gender and Health

In the scientific realm, a call from the scientific community, supported by the alliance Gender and Health and supported by WOMEN Inc., translated into the ZonMw knowledge program (2016–2020) and based on the Knowledge Agenda Gender and Health (ZonMw, 2015). This knowledge agenda voiced a broadly shared urgency for gender and intersectionality-based research on health. A key knowledge gap that was identified by the scientific community concerned:

'multi-disciplinary research to the consequences of the double burden of care (work, family and informal care) in relation to the health, position and societal participation of women. Especially in the light of recent transitions in healthcare and the fact that women are overrepresented in paid care work' (p. 36).

Research into the impact of the transitions on informal caring responsibilities and paid care work, in relation to health, was thus found missing. Due to the advocacy from women's organizations, researchers and funding agencies, knowledge on these issues begins to grow, and it was this societally prioritized research gap that brought this thesis into being.

Research questions

In this thesis, I aim to answer the following research questions:

- How is the health and wellbeing of paid care workers in long-term care shaped by gender in intersection with class, race, age/life phase, sexuality and (dis)ability?
- How is paid care workers' health and wellbeing shaped by gender, across its intersections, particularly in the context of self-employment?

As a PHR researcher, I wanted to understand how researchers can address health inequities in collaboration with 'those whose life or work are subject to the study'. Therefore, this thesis also includes a methodological and epistemological research question:

- How can intersectionality strengthen participatory health research?

Setting

Research Project 'Negotiating Health'

Most of the empirical sub-studies were conducted as part of the research project 'Negotiating Health' (2018-2022) which was funded in the Gender and Health program. This participatory study focussed on *'the interplay between health, labour participation and informal care responsibilities from an intersectional perspective'* and was conducted within the LTC sector for older people.

This project started with a photovoice project, guided by professional photographer Janine Schrijver. In this photovoice project, ten paid and unpaid caregivers in residential LTC set the agenda for next phases in the project. Five out of ten caregivers continued to participate as co-researchers (or: community researchers) in the next phases of the research project. Jointly, we conducted six empirical studies, in which we interviewed paid care workers, men and women, as hired employees and self-employed, and also professionals who were responsible for occupational health, such as managers, HRM professionals and occupational health physicians.

In the last phase of this research project, we developed a photo-exhibition and a book called 'What you don't see'. These contained four portraits of the co-researchers which captured the essence of our empirical studies and were used in dialogue meetings and educative sessions with care workers, board members in LTC, occupational health physicians and HRM professionals. An

overview of the different research activities within Negotiating Health are presented at the end of this chapter in table 2. Five out of nine studies within Negotiating Health are included in this thesis. An overview of studies in this thesis is presented in table 3, including the study (chapter 7) that led to the research project 'Negotiating Health'.

Long-term Care

This thesis focusses on the long-term care (LTC) for older people. LTC is located at the bottom of the care-care hierarchy, with the majority of care provided by low-paid care workers (WRR, 2020). There is a lack of political and financial appreciation for paid care work and salaries have been significantly lower than in comparable sectors (RVS, 2020; SER, 2021). (Advanced) nursing aides are the largest occupational group in this sector (Van Wieringen et al., 2022; Tuinman, 2021). LTC refers to different types of care, including extramural care (also: home-based or domiciliary care) and intramural care (also: residential or nursing home care). The terminology is under debate and different terms may be found in this thesis. In some areas scholars still speak about elderly care. This term has been critiqued as ageist, so nowadays scholars increasingly prefer older person care or ageing person care. Care workers go by many titles, which do not always correspond internationally (cf. Van Wieringen et al., 2022; Hewko et al., 2015; Tuinman, 2021). In this thesis, I use the terminology as presented in table 1.

Table 1: Terminology

Dutch	English
Zorghulp (MBO, niveau 1) Helpende Zorg en Welzijn (MBO, niveau 2)	Nursing aide (or: nurse assistant, or: healthcare aides)
Verzorgende IG (MBO, niveau 3)	Advanced nursing aide (or: certified nurse assistant)
Verpleegkundige (MBO, niveau 4)	Nurse
Verpleegkundige (HBO, niveau 6)	Nurse (or: registered nurse)
Specialistisch verpleegkundige (HBO, niveau 7)	Nurse specialist

Methodology

Participatory Health Research

I conducted my thesis at the department of Ethics, Law and Humanities at the Amsterdam UMC. The research at our department is strongly rooted in a Participatory Action Research paradigm (PAR) (cf. Visse, 2012; Baur, 2013; Woelders, 2020; Groot, 2021; Goedhart, 2021). PAR aims to realize social impact through and within the research process (Reason and Bradbury, 2008; Wright, 2015; Abma et al., 2019). Participatory Health Research (PHR) draws on both the Action Research as well as the Participatory Research, Participatory Action Research and Community-Based-Participatory Research traditions, all of which have their basis in broad social movements striving for a more democratic and inclusive society.

Participatory health research (PHR) aims to enhance participation of research participants whose life or work is subject of the research

and share power over the research process (Abma et al., 2019; Reason and Bradbury, 2008; Wright, 2015; cf. Woelders, 2021). Research is done ‘with’ rather than ‘on’ people as passive subjects. Research participants and other relevant stakeholders are invited to engage in inquiring and improving the quality of their lives and work. In our research project Negotiating Health, paid and unpaid care workers had power over the research process, by setting the agenda and initiating several sub-studies including those on men working in LTC and self-employed care workers. They participated as co-researchers in the empirical studies and took collective actions such as writing op-eds, dialoguing with other stakeholders and (co-)created the book ‘What you don’t see’.

PHR is critical of the traditional power asymmetries in which the researcher observations are viewed as objective while participants’ lived experiences are viewed as

subjective – with the subjective considered less valuable or subordinate. PHR aims to counter such epistemic injustice (Fricker, 2007; Carel and Kidd, 2018; Groot, 2021) and aims to enhance mutual understandings among stakeholders, to build new knowledge, characterized as horizontal epistemologies (Abma, 2020).

To facilitate a space where people are able to contribute in an open manner, PHR and related research starts with building relationally based partnerships, either formal or informal. Essentially this requires an ‘open communicative space’ to discover jointly what moves and intrinsically motivates people to commit themselves to work together. The concept of communicative space has its roots in the work of Habermas (2003) who identified the ideal place for people to come together as a place of ‘...*mutual recognition, reciprocal perspective taking, a shared willingness to consider one’s own conditions through the eyes of the stranger, and to learn from one another*’ (in Abma, 2019; p.130).

PHR intends to create a platform for dialogue, learning together and change. In line with an intersectionality approach that will be discussed in the theoretical underpinnings of this thesis, it is essential to involve and integrate multiple perspectives to arrive at a joint and shared understanding, the starting point being that each person and perspective can illuminate only part of reality. Nobody can ever get rid of her or his standpoint and frame of reference; knowledge is therefore always partial and embodied, meaning that knowledge is related to one’s feelings and emotions and situatedness

(Hyde, 2018). To do PHR ethically, facilitators need to be responsive to emotions during the research process (Banks and Brydon-Miller, 2018; Abma, 2020; Groot, 2021). They are important sources of knowledge which can initiate and foster critical reflection. This is part of the recursive, and often messy process of community and participatory research necessary to develop the shared learning that is the seed bed for action (Cook, 2009;2020).

Within a PHR approach, different methods can be used. In this thesis, I employ ‘traditional’ qualitative research methods such as semi-structured interviews or focus groups, but combine these with arts-based and inclusive methods, such as photovoice. Creative, arts-based methods can draw upon different ways of knowing, are fun and inspiring to do as a group, and can therefore support inclusive research practices, which is important in this research project (Gergen and Gergen, 2018; Sergeant, 2021; Baur, 2013; Groot, 2021).

Reading guide

In the next chapter (chapter 2), I present the key theoretical concepts that form the lens through which I approach the empirical studies. In this section, I focus on the concepts that can be found in the title: caring, class, precarization, health and intersectionality. Chapters 3 to 8 present the empirical studies that I conducted together with academic colleagues and the co-researchers from ‘Negotiating Health’. This part is divided in three main sections, corresponding with the

three research questions of this thesis.

- In ‘responding to precariousness with gendered health strategies’ I describe how the health and health strategies of paid care workers are shaped by gender in intersection with class, race, sexuality, age life phase and (dis)ability. I do so based on two empirical studies, one focusing on women and one on men working in LTC.
- In ‘negotiating health in the context of self-employment’ I describe self-employed care workers experiences of precariousness before and during the COVID-19 pandemic. Based on two empirical studies, I address health inequities among self-employed care workers.
- In ‘the added value of intersectionality for participatory health research’ I offer methodological reflections on two research projects illustrating the challenges of doing PHR in deeply unjust landscapes and how intersectionality can strengthen critical consciousness and more ethical research practices.

Table 2: Phases and research activities in Negotiating Health

Period	Design	Participants	Aim of the study
Phase 1: Exploration			
2018-2019	Photovoice (Part I)	Paid and unpaid caregivers in LTC (N=10)	Agenda-setting: identifying important themes and topics in dialogue between academic researchers and paid and unpaid caregivers (published in factsheet)
2019-2022	Photovoice (Part II)	Paid caregivers in LTC (N=5)	Translating the main findings from our empirical studies into images and portraits together with the professional photographer, development of the booklet 'what you don't see'.
Phase 2: Clarification			
2019-2020	Interview-study	Women working as hired employees in LTC (N=20)	Understanding care workers' experiences in LTC, in dialogue between academic researchers, co-researchers and respondents
2019-2020	interview-study	Women working as self-employed care workers in LTC (N=25)	
2021	Interview-study	Men working in LTC (N=16)	
Phase X: Negotiating health during the: COVID-19 pandemic			
2020	Interview-study	N=23 self-employed caregivers	Understanding the <i>short-term</i> impact of the COVID-19 pandemic on (self-employed) caregivers in LTC
2021	Interview study	N=13 (self-employed) caregivers	Understanding the <i>long-term</i> impact of the COVID-19 pandemic on (self-employed) caregivers in LTC (published in factsheet)
Phase 3: Contextualization			
2020-2021	Interview study	Board of directors, HRM professionals and occupational health physicians (N=23)	Understanding paid care workers health issues in their organizational and political context, unravelling organizational discourses around occupational health in LTC (published in factsheet)
Phase 4: Action			
2021-2022	Dialogue meetings	HRM professionals, managers, occupational health physicians, care workers	Developing awareness and co-creation of possible organizational solutions and policy recommendations

Table 3: Overview empirical studies included in this thesis

Chapter	Period	Design	Participants	Publication
Responding to precariousness with gendered health strategies				
3	2019-2020	Interview Study	Women working as hired employees in LTC	Duijs, S.E., Wees, M. Abma, T., Jhingoeri, U., Plak, O., Senoussi, N., Jaspers, Y., Verdonk, P. (submitted) We just take care of each other: relational health strategies as mechanisms of exclusion in care teams.
4	2021	Interview study	Men working in LTC (hired employees and self-employed)	van Wees, M., Duijs, S. E., Mazurel, C., Abma, T. A., & Verdonk, P. (2023). Negotiating masculinities at the expense of health: A qualitative study on men working in long-term care in the Netherlands, from an intersectional perspective. <i>Gender, Work & Organization</i> . https://doi.org/10.1111/gwao.12952
Negotiating health in the context of self-employment				
5	2019-2020	Interview study	Self-employed care givers in LTC	Duijs, S.E., Abma, T.A., Plak, O, Jhingoeri, U., Abena-Jaspers, Y., Senoussi, N., Mazurel, C., Bourik, Z., Verdonk, P. (2022) Squeezed out: experiences of precariousness from self-employed care workers in long-term care, and intersectional perspective. <i>Journal of Advanced Nursing</i> .
6	2020	Interview study	Self-employed care givers in LTC during the COVID-19 pandemic	Duijs, S. E., Haremaker, A., Bourik, Z., Abma, T. A., & Verdonk, P. (2021). Pushed to the Margins and Stretched to the Limit: Experiences of Freelance Eldercare Workers During the Covid-19 Pandemic in the Netherlands. <i>Feminist Economics</i> , 27(1-2), 217-235.
The added value of intersectionality for participatory health research				
7	2014-2015	PAR/PHR	Neighbourhood citizens	Duijs, S. E., Baur, V. E., & Abma, T. A. (2019). Why action needs compassion: Creating space for experiences of powerlessness and suffering in participatory action research. <i>Action research</i> , 1476750319844577
8	2018-2019	Photovoice PAR/PHR	Paid and unpaid caregivers in LTC	Duijs, S. E., Abma, T., Schrijver, J., Bourik, Z., Abena-Jaspers, Y., Jhingoeri, U., Plak, O., Senoussi, N. & Verdonk, P. (2022). Navigating Voice, Vocabulary and Silence: Developing Critical Consciousness in a Photovoice Project with (Un) Paid Care Workers in Long-Term Care. <i>International Journal of Environmental Research and Public Health</i> , 19(9), 5570.

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CHAPTER 2

Key theoretical concepts

In chapter 2, I present the theoretical concepts of this thesis. First, I explain how I studied care as a gendered practice. Caregiving is shaped by gendered norms, organizational practices and public policies, which in turn (re-)produce classed inequities. Therefore, second, I argue that gender and class intersect in care practices and explain why I titled this thesis: the caring class. Third, I describe why I foreground the concept of precarization in this thesis. Fourth, I will argue that caring, class and precarization are in itself health issues. In the last part, I describe how intersectionality can enabled diversity-sensitive understandings of precarization and health inequities.

Aim of this chapter

This chapter describes my theoretical lens. It describes the larger theoretical perspectives that shaped how I approached the empirical studies in this thesis. I focus on the concepts that can be found in the title: caring, class, precarization, health and intersectionality. This section is not an exhaustive overview of theoretical concepts that are used in this thesis. In each empirical chapter (3–8), unique theoretical concepts are introduced that enabled me and the co-researchers to understand the findings in that particular sub-study. For example, in this chapter I describe the concept of *precarization*, and how this concept directed my attention to the politics and economics that produce precariousness in the lives of paid care workers. In my general discussion I then turn to political theories on capitalism (Fraser and Jaeggi, 2018) to unravel the politics and economics behind the precarization of paid care workers.

Caring: a gender perspective

Care and caregiving cannot be understood without taking gender into account. Caring is traditionally associated with femininity and motherhood, and women still carry the burden of unpaid and paid care work such as childcare, informal care for ageing parents, or nursing. Normative expectations and gender socialization render women as default caregivers and shape men and women's caregiving practices. This has major implications for how we negotiate, organize

and reward care within families, organizations and societies.

In this thesis, I approach gender as a dynamic biosocial process, in which the biological (often conceptualized as binary) distinction of sex is '*socially mobilized in determining who gets to do what, when, where, and how; under what conditions*' (Schofield, 2012, p. 210). In other words, I do not start from an essentialist perspective of men and women having different biological dispositions towards care. Or, for that matter, not even from a biologically binary perspective on men versus women (Fausto-Sterling, 2000; 2012). This thesis particularly focusses on how gender is *done* in different (care) settings. This is rooted in West and Zimmerman's notion of 'doing gender', who fostered '*an understanding of gender as routine accomplishment in everyday interaction*' (1987, p.125). In this respect, I am also greatly indebted to the work of Judith Butler and the notion of gender as performance (Butler, 1990). I consider gender a social construct that shapes our lived realities.

Rather than as an individual characteristic, Connell describes gender as a relational concept that operates at the intrapersonal, interpersonal, institutional and society-wide level (Connell, 2012). In a similar vein, Tannenbaum and colleagues understand gender as manifesting in four domains: gender identity, gender roles, gender relations and institutionalized gender (Tannenbaum et al., 2016). In the section below, I describe the specific theories that helped me to unravel how gender was done at these different

levels, although I am aware that distinctions are artificial and obviously more diffuse and complex in real life.

On the intra- and interpersonal level, I relied on theories that describe the gender socialization of men and women (e.g. Chodorow, 1978). For women, this socialization process is often directed to producing feminine-typed *caring identities*, which encompass *‘the compulsion to see and respond to other people’s needs, whatever one’s own situation’* (Forssén et al., 2005). This socialization process starts in women’s younger years is often (re-) produced in care workers’ vocational training and workplaces (Skeggs, 1997; Bates, 1991; Bates, 1994; Stam and Keskiner, 2020). Gender socialization is a lifelong process. During the empirical studies of this thesis, these theories helped me to direct my attention to how women negotiate their caring identities in the context of LTC. Vis-à-vis, together with the co-researchers in our study on men working in LTC, we turned to theories on masculinity to understand how men describe and perform their identity as men and negotiate masculinity in the context of LTC (Kahn, 2009; Connell and Messerschmidt, 2005; Elliott, 2016). In this thesis, I particularly focus on the implications of such negotiations for health (Burke, 2002; Courtenay, 2000; Mahalik et al., 2007; Tannenbaum and Frank, 2011; Verdonk et al., 2010).

At the institutional level, gender shapes labour market experiences, directing who gets to do which work and why, and how they will be rewarded (Kumra, Simpson and Burke, 2014). Labour markets are characterized by

horizontal and vertical gender-segregation (Kreimer, 2004). Horizontal gender segregation refers to the division of men and women over sectors and professions, with more women working in health care, and, in Western countries, more men working in industry and technology. Horizontal segregation exists because care is often seen as women’s work; around 80% of workers in the entire care sector are women. Vertical gender segregation refers to the division of men and women across hierarchical levels, with more men in positions of leadership and decision making. Although more and more, women take up leadership roles in health care, to date men in healthcare have more career opportunities than women. This process of accelerated careers for men in female dominated sectors is also referred to as the glass escalator (Williams, 2013). Vertical gender-segregation is most profound in the lower paid regions of the health care labour market, with more than 95% of workers in LTC for older people being women. Men are more often found in high paid, high-tech regions of care work, and have faster careers ending up in higher hierarchical positions.

Gender is also done within organizations. For theoretical insights on this topic, I am indebted to many Dutch scholar such as Yvonne Benschop, Mieke Verloo and Marieke van den Brink (Benschop and Doorewaard, 1998; Benschop and Verloo, 2006; Benschop, 2021; Benschop and Lewis, 2019; Van den Brink, 2010). Several other international scholars shaped my perspective on gender particularly in relation to entrepreneurship (Lewis, 2006; Lewis, 2014; Lewis and Essers, 2015; Kumra,

Simpson and Burke, 2014). A lot of work on gender in organizations is inspired by the work of Joan Acker (GWO, 2019). For instance, Acker proposed that all organizations have ‘inequality regimes’, that is: *‘loosely interrelated practices, processes, actions and meanings that result in maintaining class, gender, and racial inequalities within particular organizations’* (Acker, 2006, p. 443). Acker distinguished four organizing processes that produce inequality. Acker’s conceptualizations of inequality regimes helped to direct attention to implicit normative expectations around the ‘ideal worker’ (p.448) and the disadvantages that are faced by those who do not fit into this ideal image. Furthermore, job classification systems enforce inequities, for example when *‘responsibilities of frontline workers are increased, and their jobs become more demanding [...] but they were still on the bottom: they had more responsibility, but not higher salaries’* (p.449). Acker urges to be mindful of recruitment and hiring practices that reproduce inequalities, for example when certain bodies are preferred to certain jobs (p.448). And last but not least, Acker enabled us to look at wage settings and supervisory practices to understand how *‘supervisory relations may be affected by the gender and race of both supervisor and subordinated, in some cases preserving or reproducing gender or race inequalities’* (p.451).

To understand how gender operates at the societal, economic and political level, I turned to the work of Marxist Feminist and social reproduction theory (Vogel, 1983; Federici, 2004; c.f. Bergeron, 2016; Fraser

and Jaeggi, 2018). These scholars describe how the lack of appreciation for care work is ingrained in our economic systems and political discourses (Fraser, 2016; Bhattacharya, 2016). Social reproduction theorists challenge the production/reproduction division in capitalist societies, in which reproductive work is devalued and framed as a financial burden to societies, as a cost, and as an infinite background condition that does not require resources or replenishment. Since women are the default caregivers, such a production/reproduction division is based on, and reproduces gender inequality (Fraser and Jaeggi, 2018).

Class

Understanding caring solely from a gender perspective would obscure the fact that gender inequality intersects with other inequalities in particular with classed inequality. ‘The caring class’ as a concept emphasizes this intersection between gender and class which shapes the caring practices of paid care workers. Class is operationalized in multiple ways. I will elaborate shortly on these different conceptualizations and how they are used in this thesis, before I explain why I titled this thesis ‘the caring class’.

In the field of public health and medicine, class is often narrowed down to social economic status, operationalized as education level, income, or other measures such as postal code or professional level. In this thesis, I am particularly mindful of a lack of financial resources and how this shapes and restrains

the lives of many paid care workers. Socio-economic status or position (SES) as a social category does not just describe the presence or absence of financial resources, but it also has symbolic and political implications (Dijkstra and Horstman, 2021). In the field of public health, people with low SES are often regarded as *'inherently unhealthy'* and the concept of SES contributes to individualization of LSES *'by which a low SES personality is presented as an explanation of health'* (Dijkstra and Horstman, 2021). In this thesis, I distance myself from such individualistic perspectives on class or SES.

In the last decade, epidemiological institutes in the Netherlands, who have the responsibility to characterized groups of citizens, moved away from social categories that focus solely on financial resources or SES. Inspired by Bourdieu's work on social, cultural, symbolic and economic capital, and line with colleagues from the UK (Savage et al., 2013), several Dutch institutes employ new categories or operationalizations of class in their empirical research (Vrooman, Gijssberts and Boelhouwer, 2014). This is a step forward, as it embraces all and more subtle differences between privileged and underprivileged citizens. A new marker in this typology addresses insecure (or: precarious) employment relations. In this typology 'class' is mainly used as a descriptive category of social groups.

The Caring Class

In this thesis, and particularly the title, I use class in the political sense. I understand class

as normative statement that refers to unjust inequalities. This understanding of class is rooted in the Marxist concept of class struggle and the tension between labor and capital. Class as a narrative can, amongst other narratives, fuel collective action and social change. Therefore, the title of this thesis cites the work of Standing, who coined the term 'the precariat' or 'the precariat class' (Standing, 2011). Standing argues that those in precarious social positions are no longer united by a shared narrative or natural social ties. The concept of *'the precariat class'*, can *'awaken the precariat to its status as class'* (Standing, 2011). With the title 'the caring class' I envision such a collective movement, which aligns with the aims of PHR. In addition, the 'caring class' emphasizes the intersection between gender and class in caring practices, and particularly how the lack of societal appreciation for care work contributes to class inequities. Therefore, 'the caring class' is thus not only a descriptive title, but also an activist one, challenging the growing gender/class inequalities in the Netherlands and the impact this has on paid care workers.

Precarization

With Standings' concept of the precariat class, I move toward the third key concept of this thesis, namely precarization. In this part, I touch upon different concepts used, including precarious work, precariousness, precarity and precarization. I shortly describe how they are conceptualized in different disciplines and explain why I foreground the concept of

precarization in this thesis. A large part of this thesis focusses on self-employed care workers in LTC. Therefore, I will continuously link these concepts to self-employed (care) work.

In the field of public health, or more specifically, the field of occupational health, scholars tend to focus on precarious work. Traditionally, the international labor organizations regarded everything other than standard (unionized) employment as precarious work (ILO, 2011). This definition has been challenged by scholars, arguing that this overlooks differences among people outside of the standard employment relationships and how these differences changed over time. Conen and Schippers for example show how self-employment was traditionally associated with independent entrepreneurship, but is increasingly becoming a form of precarious work (Conen and Schippers, 2019).

The concept of precarious work, or precarious employment, is often used in the field of public and occupational health. Precarious work receives increasing attention from public health scholars, considering it a social determinant of health, and as such has been called 'an overlooked determinant of health' (Syed, 2020; Vanroelen et al., 2021). Public health scholars define precarious work as a multidimensional concept including at least four dimensions: (i) employment instability; (ii) low material rewards; (iii) little control over working conditions and work pace; and (iv) a lack of social rights and protections (Julia et al., 2017b; Van Aerden et al., 2014). In this line of reasoning, agency

work, temporary employment, part-time employment and self-employment can all be forms of precarious employment, but are not necessarily so. It is the combination of factors that determines if one engages in precarious work. Those with employment instability in combination with low material rewards often do not have the possibility to create financial buffers for themselves to back up their employment instability. Therefore, the SCP for example, focusses on the combination of low employment instability (I) and low material rewards (ii) as most important markers for precarious work (SCP, 2014).

Others argue that the reasons for self-employment are decisive for precarious work. Scholars often distinguish between voluntary and involuntary self-employment, between those who are *pulled* into self-employment by the allure of independence, flexibility, freedom, entrepreneurship, career advancement or financial opportunity, and those who are *pushed* into self-employment by eroding working conditions, job quality or work-family considerations (Vosko and Zukewich, 2006; Conen and Schipper, 2019), whereby some of the pull factors may in fact reflect the push factor, for example when workplace policies fail to take into account the responsibilities of workers outside the workforce (Vosko and Zukewich, 2006). These two routes to self-employment, also referred to as the 'high' route versus the 'low' route (Vanroelen, 2019), characterize the current polarization of the labor market (Bosch, 2004; Goos, Manning and Salomons, 2009; Fernandez-Macias, 2012; Kallenberg,

2011; Kallenberg and Vallas, 2016). These perspectives have directed my attention to the reasons paid care workers opt for self-employment, and insofar their reasons to opt out are in fact pointing toward precariousness as hired employees.

Sociologists and political philosophers more often speak about precarization as a characteristic of our current day society or governmental modes of governing. They argue that western post-welfare states become increasingly characterized by insecurity and flexibilization (Savage et al., 2013; Standing, 2011; Bauman, 1999). Scholars do not solely look at precarious work, but argue that precarious work is a characteristic of precarization as a societal process. Porta (2015, p.2) argues that:

processes of precarization start in the labour market due to ongoing economic, social, political, and even cultural transformations of capitalism. Precarization is not, though, limited to the labour market but can penetrate entire lifeworlds of individuals and groups of people.

The philosopher Lorey thus argues that *precarization* is a particular mode of governing. She directs our attention to the ways governmental policies and economic logics contribute to these societal processes of precarization. She builds her argument by distinguishing between precariousness, precarity and precarization. Lorey (2015) defines *precariousness* as an ontological characteristic of human

beings: we are inherently vulnerable and interdependent, but we differ in the way we experience this precariousness. When I speak about precariousness in this thesis, I rely on Lorey's definition, focussing on peoples lived experience. Lorey uses the concept of *precarity* to describe inequities between groups of people who experience precariousness and those who do not. In other words, precarity is used to address of social inequity. In this thesis, I will use precarity to pinpoint these inequities between groups, where they surface in peoples lived experiences. Lorey refers to *precarization* as a mode of governing, as a politics and economics that is built upon – or even benefits – from the precarization of specific groups. She argues that '*in neoliberalism, precarization is currently undergoing a process of normalization*' (p., 14). Lorey's conceptualization of precarization directed my attention towards the structural mechanisms that contribute to care workers experiences of precariousness or the inequalities between groups. In my empirical studies I focus on precariousness and precarity. In the general discussion of this thesis, I will therefore pay more attention to the modes of governing that shape care workers experiences, thus, to precarization.

Health

In this thesis, I focus on precarization and its relation to health. In the empirical studies, I approach health from a phenomenological perspective and focus on care workers lived

experiences. I do not objectify or measure care workers health, but focus on paid care workers narratives about their own health and health strategies.

In some parts of this thesis, the precariousness of paid care workers in terms of health and finances is foregrounded, while its relation to health remains implicit. Although people with low SES are not inherently unhealthy (Dijkstra and Horstman, 2021), financial insecurity does have major implications for people's wellbeing and health (Grootegoed et al., 2022; Goijarts, Vonk and 'S Jongers, 2022). Hence, when I speak about financial stress or precarization, this is by definition a health issue, as inequality in itself is a health issue as well as a determinant of ill-health (Nettleton, 2020). Research showed that inequality in wealthy countries is associated with ill-health, for society as a whole and thus also for people in higher socioeconomic positions, for instance because it erodes social cohesion which affects the health of every citizen (Wilkinson and Pickett, 2009; Nettleton, 2020).

Intersectionality

In the introduction, I sketch how intersectionality can be a useful normative, theoretical and methodological framework to study health inequities. Yet, it took some years for intersectionality to travel into the health and medical domain and to be embraced as crucial to study health inequities. As health scholars, we are indebted to many scholars and activist before us.

The term intersectionality finds its historical roots in the work of black feminist, queer and postcolonial scholars and activists (Combahee River Collective, 1997, Crenshaw, 1991; Anzaldúa, 1987, Collins and Bilge, 2016). Intersectional thought, *avant la lettre*, is found in the work of activist scholar such as Angela Davis, who critiqued single issue social activism, such as second wave feminism or the civil rights movement for their tendency to essentialize women's or black people's experiences, while overlooking black women's experiences and interests (Davis, 1983; hooks, 1981; Lorde, 1984). The term intersectionality itself was coined by Kimberlé Crenshaw who showed how the legal system was unable to address multiple and interlocking systems of oppression, arguing that '*contemporary feminist and antiracist discourses have failed to consider intersectional identities, such as women of color*' (Crenshaw, 1990, p.1241). Crenshaw spoke of *structural intersectionality* to point out how multiple and interlocking systems of oppression converge and of *political intersectionality* to address the way political discourse or activist movements exclude individuals who not identify with multiple subordinate groups. Many other key texts in postcolonial, queer and critical race theory offer similar conceptual frameworks or terms (Moraga, 1983; Smith, 1983; Moraga and Anzaldúa, 1987; Mohanty, 1988; Sandoval, 1991).

Intersectional thought became quickly popular in gender studies and feminist thought (Davis, 2008), but took some time to trickle down into the health and medical domain. International scholars such as Lisa Bowleg and

Olena Hankivsky played an important role in translating intersectional thought to the field of health, healthcare and health inequalities (Bowleg, 2012; 2021, Hankivsky, 2012), especially in the field of women's health care research (Hankivsky, 2019) and the analysis of health care policy (Hankivsky, 2012; Hankivsky, 2014). As a consequence, intersectionality is increasingly adopted in both qualitative research (Christensen and Jensen, 2012; Hunting, 2014), as well as in quantitative research (Richman and Zucker, 2019; Mena and Bolte, 2019; Green et al., 2017; Bauer and Scheim, 2019).

In the Netherlands, work on Intersectionality and health is done by Verdonk and colleagues at the department of Law, Ethics and Humanities of the Amsterdam Medical Centre (Verdonk et al., 2019). In the last years intersectionality, becomes increasingly adopted by (health) research institutes such as the Amsterdam Public Health Research Institute (Verdonk, 2022) or the SCP (SCP, 2021). Although intersectionality becomes increasingly popular, efforts still need to be made to make intersectional research mainstream (Kelly et al., 2021), as for example studies in the COVID-19 pandemic illustrated how scholars massively failed to conduct gender perspective, let alone an intersectional perspective (Brady et al., 2021). Furthermore, methodological issues arise. For instance, intersectionality assumes that intersections are more relevant than single issues, and that beforehand we cannot know which intersections are at play in a particular health problem, as intersections may be paradoxically associated with health

disadvantages and benefits. In this thesis, an intersectional lens was applied yet gender and class were unapologetically put on the agenda as relevant – based on the figures, the literature, and the theoretical base underpinning the concept of care.

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Responding to precariousness with gendered health strategies

Many (paid) care workers experience a lack of societal appreciation for their work and a lack of care for their health and wellbeing within long-term care organizations. I understand this as a form of precariousness: a lived experience of being in a vulnerable and precarious position.

In this section, I explore how paid care workers in long-term care, women (Chapter 3) and men (Chapter 4), respond to this precariousness and how their health strategies are shaped by gender, such as normative ideas on femininity and masculinity.

These health strategies are not the same for *all women*, nor for *all men*. Therefore, I address differences and inequities in health and health strategies and how they are shaped by class, race, (dis)ability and sexuality.



CHAPTER 3

'We just take care of each other'

Relational health strategies of paid care workers in long-term care as mechanisms of in and exclusion in care teams

Abstract

Objectives

The health of care workers in residential long-term care is under pressure. Scholars emphasize the importance of gender-sensitive and intersectional approaches to occupational health.

Methods

A qualitative participatory study, unraveling how health strategies of nurses and nursing aides are shaped by gender, class, age, sexuality and race. A participatory research team, consisting of academic scholars and nursing aides, conducted semi-structured interviews (N=20) and one natural group discussion (N=8 participants) to validate our findings. Thematic data-analysis was guided by gender and intersectionality theory.

Results

Empirical findings show that gendered norms limit possibilities for self-care for female nurses and nursing aides. Feeling uncared for by society and LTC organizations, paid care workers largely depend upon each other to protect, repair and maintain their own health. These relational health strategies require a feeling of sameness, limiting space for diversity and disability within care teams. Care workers seen as 'cultural other', or those who had to protect their boundaries due to health issues, financial struggles or informal caregiving, risked facing exclusion within care teams, negatively impacting their health.

Conclusion

Care workers' relational health strategies are a care-ethical response to the lack of societal

appreciation and organizational support. Occupational health interventions should not solely focus on individual autonomy of workers, but take their relational health strategies into account. Using the concept of 'horizontal violence' we argue that the lack of societal appreciation needs to be made political by occupational health physicians and LTC organizations, to counter mechanisms of exclusion among paid care workers.

Key terms

Employment, long-term care, nursing, nursing aides, occupational health, work characteristics, gender, intersectionality, the Netherlands.

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Introduction

Concerns about health and wellbeing of paid care workers are growing (EY, 2018; Peters et al., 2018). In the Netherlands, these concerns are especially pressing for nurses and nursing aides in residential long-term care (LTC) for older people. Sickness absence is among the highest in the healthcare sector (EY, 2018), staff turnover is high (EY, 2018), many older care workers opt for early retirement (Ministry of Health, Welfare and Sports, 2020), and about one-third of care workers intend to

leave the sector within the next five years (V&VN, 2018). Protecting, maintaining and repairing the health of care workers is especially urgent in the context of growing care needs and staff shortages (Ministry of Health, Welfare and Sports, 2020).

In the Netherlands, about 80% of paid care workers in the health and social care sector are women (CBS, 2020). This percentage is higher in low-paid caring occupation: the LTC sector has 92–94% women (CBS, 2020). Men and women occupy different spaces and positions in labor markets and occupational health needs may differ (Härenstam, 2009). Attention is growing for sex- and gender specific occupational health issues, such as menopause (Verburgh et al., 2020), post-partum depression (Hammer et al., 2019) or (return to work after) breast cancer (Lamort-Bouché et al., 2020). Dynamics around sickness absence are distinctly gendered (Laaksonen et al., 2010), just as the work/life conflict, due to women's larger responsibility for unpaid caring responsibilities compared to men (Bijnsdorp et al., 2022).

Yet, such a gender-only perspective runs the risk of overlooking inequities *among* men or women (Hankivsky et al., 2020). An intersectional perspective explores how people's lived experiences are shaped by multiple and intersecting systems of inequity including gender, but also class, race sexuality, age, life phase (Hankivsky et al., 2020). Intersectionality is rooted in black, feminist, queer, postcolonial, thought and activism and coined as a concept by Kimerblé

Crenshaw (Crenshaw, 1990). In occupational health, researchers are increasingly adopting intersectionality as a theoretical and methodological approach (Habib et al., 2016).

Gender studies has rich history of academic work showing how gender is being done in organizations and workplaces (Benschop & Verloo, 2012). Also, in occupational health to attention for the psychosocial work environment is growing (Härmä et al., 2015), with studies addressing gendered inequities, discrimination and abuse in the workplace (Bijnsdorp et al., 2022; Nielsen et al., 2016; Sibeoni et al., 2021). Yet, intersectional perspectives on the relationship between the psychosocial work environment and health remain scarce (Habib et al., 2016; Hankivsky et al., 2020; Härenstam, 2009). Such perspectives could advance occupational healthcare, by enabling gender and diversity sensitive measures in LTC organizations to support a healthy psychosocial working environment.

In this qualitative interview study (Green & Thorogood, 2018), we aimed to understand how the health and wellbeing of nurses and nursing aides in residential LTC for older people is shaped by gender in intersection with class, race, ability and age/life phase. We particularly focus on female nurses and nursing aides' subjective experiences within LTC organizations and teams. While quantitative research has been traditionally dominant within occupational health research, researchers emphasized the added value of qualitative research (Boot & Bosma, 2020), particularly to understand psychosocial work

environments (Boot & Bosma, 2020; Härmä et al., 2015; Lamort-Bouché et al., 2020). Qualitative research aims to understand people's experiences, behaviors and interactions, it can provide insights about new or relatively unknown phenomena and help to understand the larger social context that shapes peoples' subjective experiences (Boot & Bosma, 2020; Green & Thorogood, 2018). The research question that guided our study was as follows:

How are the health and health strategies of women, 45–67 years of age, working as nurses or nursing aides in residential long-term care for older people, shaped by gender, across its intersections?

Methods

The consolidated criteria for reporting qualitative research (COREQ) guided the reporting of the study (Tong et al., 2007).

Research team and reflexivity

The participatory research team consisted of four Dutch-majority women and Moroccan-Dutch woman, working as academic researchers. The academic researchers were experts in gender, intersectionality and (occupational) health (PV, SD), participation in LCT (TA), Islam, diversity and community health (ZB). The community researchers, four women and one man, from diverse cultural backgrounds, were experts by experience as paid and unpaid care workers, three of which were trained as advanced nursing aides.

Design

This participatory, qualitative interview study was a sub-study in a broader participatory health research project (Wright et al., 2018). This project Negotiating Health aimed to unravel how the health of paid and unpaid care workers in residential LTC was shaped by intersecting social determinants of health, such as gender, class, race, disability sexuality and age (Crenshaw 1990; Habib et al., 2016; Hankivsky et al., 2020). Participatory health research aims to understand how peoples' lived experiences are shaped by structural inequalities, together with those whose life or work is subject to the study (Wallerstein & Duran, 2017).

In Negotiating Health, we interviewed hired employees and self-employed care workers, men and women. In this article, we focus on the experiences of women working as hired employees within LTC organizations. Findings from other studies are published elsewhere or submitted for publication (Duijs et al., 2021; Duijs et al., 2022a; Duijs et al., 2022b; Wees et al., in press).

Participants of the current interview study were recruited through organizations (such as the professional associations for nurses and nursing aides, unions, LTC organizations, support organizations for informal caregivers), through social media as well through the personal network of community researchers. Participants were approached with a general invitation flyer. Inclusion criteria were: being an (advanced) nursing aide, 45–67 years of age, combining paid and unpaid care responsibilities.

Eventually, 20 care workers were purposively sampled, also including some nurses, who were higher paid, as a deviant case. Participants came from diverse geographical locations in the Netherlands. As a result of our sampling strategy, via mainstream channels and organizations, our sample largely consists of white, Dutch majority, women (see table 1). We included interviews until we reached data-saturation within this particular population. Interviews were conducted in a couple existing of an academic researcher (SD, ZB) with one of the community researchers (UJ, OP, NS, YJA). Interview were mostly conducted at home with the participants. Some participants wished to be interviewed or at their workplace, in a public space or at the university. In two instances, the interview was conducted in presence of a colleague or partner. One interviewee (R17) was so supportive of our study that she proposed to organized a meeting in her home to discuss our preliminary findings with her and seven of her colleagues (total N=8 participants). This natural group discussion (Green & Thorogood, 2018) was facilitated by two academic researchers and a community researcher (SD, ZB, OP). This meeting was audio-recorded and transcribed ad-verbatim.

Data collection

Participants provided consent before participating. The topic list for this study was developed based on literature and by the community researchers who identified themes and topics that were relevant to them during a six-month photovoice project that was conducted prior to this qualitative study (27).

Themes included balancing paid and unpaid care work, financial concerns, age-related health issues, such as menopause, and health strategies of care workers while working in LTC. Interviews are recorded and transcribed ad verbatim. Field notes were made by both interviewers separately, after the interview. Interviews were conducted in Dutch. Quotes in this article are translated by the first author. Member checks were conducted by feeding back summaries of the interviews when participants indicated that they would appreciate that.

Data-analysis

Data collection and data-analysis was done iteratively and collectively. First, data was discussed in monthly - audio recorded and transcribed verbatim - dialogue meetings with the research team, including the community researchers. Second, the first author conducted an inductive thematic analysis using Maxqda. Third, these findings were validated in the natural group discussion. Fourth, after the thematic analysis, we applied an intersectional perspective to deepen our understanding of the ways initial themes were shaped at the intersections of e.g. gender, class, race, migration status, sexuality, disability and age (Crenshaw 1990; Habib et al., 2016; Hankivsky et al., 2020). This round of data-analysis and coding in Maxqda was done by the second author, in close collaboration with the first author. This intersectional analysis enabled a more in-depth understanding about the societal inequalities that became visible in interviewees' experiences. The outcomes from

Table 1: Participants interviews

R	Age	Minority/majority	Relationship status	Unpaid care responsibilities	Profession
1	66	Surinam-Dutch	Heterosexual marriage	Niece	Advanced Nursing Aide (level 3)
2	51	Surinam-Dutch	Heterosexual marriage	Mother and brother	Advanced Nursing Aide (level 3)
3	48	Dutch-Majority	Heterosexual marriage	Parents	Advanced Nursing Aide (level 3)
4	54	Dutch-Majority	Divorced (heterosexual marriage)	Mother[†] Father[†] Two close friends	Advanced Nursing Aide (level 3)
5	52	Dutch-Majority	Heterosexual marriage	Mother and parents-in-law	Advanced Nursing Aide (level 3)
6	45	Moroccan-Dutch	Heterosexual marriage	Mother	Nurse (level 6)
7	47	Dutch-Majority	Heterosexual marriage	Mother	Advanced Nursing Aide (level 3)
8	58	Dutch-Majority	Heterosexual marriage	Sister	Advanced Nursing Aide (level 3)
9	50	Dutch-Majority	Heterosexual marriage	Mother-in-law	Advanced Nursing Aide (level 3)
10	45	German-Dutch (visibly Muslim)	Heterosexual marriage, divorced	Father	Nursing aide (level 2)
11	61	Dutch-Majority	Heterosexual marriage	Husband	Advanced Nursing Aide (level 3)
12	45	Dutch-Majority	Heterosexual marriage	Husband	Advanced Nursing Aide (level 3)
13	53	Dutch-Majority	Heterosexual marriage	Husband	Advanced Nursing Aide (level 3)
14	60	Dutch-Majority	Heterosexual marriage	Father, Mother, Daughter	Advanced Nursing Aide (level 3)
15	52	Dutch -Majority	Heterosexual marriage	Mother[†]	Advanced Nursing Aide (level 3)
16	+/- 55	Dutch-Majority	Heterosexual marriage	Father, Son	Advanced Nursing Aide (level 3)
17	62	Dutch-Majority	Heterosexual marriage, widowed	Husband	Advanced Nursing Aide (level 3)
18	57	Dutch-Majority	Heterosexual marriage	Godmother, mother	Nurse assistant (level 1)
19	52	Dutch-Majority	Heterosexual marriage	Children, mother, sister	Advanced Nursing Aide (level 3)
20	45	Moroccan-Dutch	Heterosexual marriage	Parents	Nursing aide (level 2)

Table 2: Participants Natural Group Discussion

FG	Age	Gender	Minority/Majority	Profession
1	+/- 50*	Woman	Dutch-Majority	Advanced nursing aide (level 3)
2	+/-55*	Woman	Dutch-Majority	Advanced nursing aide (level 3)
3	54	Woman	Dutch-Majority	Advanced nursing aide (level 3)
4	61	Woman	Dutch-Majority	Advanced nursing aide (level 3)
5	60	Woman	Dutch-Majority	Advanced nursing aide (level 3)
6	+/-55*	Woman	Dutch-Majority	Advanced nursing aide (level 3)
7	40	Woman	Dutch-Majority	Advanced nursing aide (level 3)

*Not everyone wanted to disclose their age during this natural group discussion. This is an estimation from the authors.

each round of analysis were discussed with the community researchers, who validated our findings and added insights from their own experiences as well as from the interviews they had conducted. The community researchers were not involved in the writing of this article, as they are not proficient in English. All findings and insights are discussed with them; all (co-authors) consent to the content of this article. The community researchers played a major role in the conception, preparation, data-collection and analysis of this study. Not including them as co-researchers was considered unethical to the academic researchers, particularly in a PHR process (Banks et al., 2013)

Quality and rigour

We employed the following strategies to enhance the quality and rigour of our study (Frambach et al., 2013). The study was conducted with a team of multiple academic and community researchers. The community researchers were experts-by-experience as low-paid care workers in LTC. The academic researchers had expertise in the field of LTC, gender and occupational health. Intensive dialogue about the findings contributed to the

credibility of our study. At the request of our participants, we conducted member checks on our study findings by sending a summary of preliminary findings and requesting feedback. Data collection and analysis were done iteratively and impacted following interviews. Data was coded by two researchers (first and second author) supervised by a senior-researcher (last author). We discussed codes extensively until we reached consensus (researcher triangulation). We continued until we reached data saturation, which supports the dependability of our findings. Findings were discussed with societal and LTC organizations in steering group meetings. Their reflections validated our findings, which contributed to the confirmability of our study. Although our study is restricted to residential LTC for older people, we are convinced that our findings contribute to a better understanding of gender in health care workplaces and how these gendered (work) environments affect health. This contributes to the transferability of our findings.

Ethical considerations

This study was evaluated by a Medical Ethical Review Committee which confirmed that the

Dutch Medical Research Involving Human Subject Act did not apply (dd. April 17th, 2018). Transcripts were anonymized and audio-tapes and transcripts are stored anonymously and will be archived until five years after completion of the study. Participants signed informed consent forms which are securely stored.

Results

Our empirical findings are described in four themes. In theme 1, ‘*You have to get sick first*’, we sketch the normative ideas that shape the ideal care worker including the taboo on self-care. In theme 2, ‘*They won’t say to us: go home and get some rest*’ we describe the lack of societal and organizational care for LTC workers. In theme 3, ‘*We just take care of each other*’, we describe how care workers respond to this lack of care by employing relational health strategies, which render them dependent upon colleagues to protect, maintain and repair their health. And in theme 4, ‘*Some just want to stick together*’, we describe how these relational health strategies can contribute to in- and exclusion within care teams.

You have to get sick first, before you can start taking care of yourself

In this theme, we sketch the normative ideas that shape the ideal care worker. In the interviews, we observed that many participants foreground their ‘caring identities’ as a prerequisite for being a good care worker. This caring identity is often performed through self-sacrifice and silencing one’s own body:

My mother likes clean curtains, so if she asks me to come, I won’t say no. And at the end of the day, you are in pain and then don’t even dare to say so. (..) So, yes, I go on even if I am in pain. (R3)

In practice, several participants use painkillers, to literally silence their own bodies. Many describe how self-care is not just out-of-character, but rather a taboo. Self-care is not socially accepted within care settings, as it would compromise their caring identity. Participants describe how self-care only becomes legitimate after having compromised one’s health at work, both physically and mentally, for example with burn-out:

You have to get sick first, before you can start taking care of yourself. (R5)

They won’t say to us, go home and get some rest

Many participants in our sample feel uncared for by society and LTC organizations, translating into feelings of pain, anger and frustration. Care organizations’ focus on production and quality of care comes at the expense of care workers’ health and caring responsibilities. Most care workers understand these problems as structural, and describe how ‘good’ managers have to deal with shortages of personnel and that a large ‘span-of-control’ makes it impossible to take care of their team:

Even if we would all be working seven days a week, we still couldn’t fulfill all shifts. Do you understand? So, the manager won’t see to us, just go home and get some rest. (R10)

Several care workers critique these larger structures and express hope that care workers will organize themselves to critique this lack of appreciation. At the same time, many care workers can hardly envision a different (political) reality, compromising their hope for change:

I: Does it make you angry?
R: No, I don't get angry. I do my work with love, so, no I don't get angry. I: But would you like it to be different?
R: Well, they won't allow it to be different because the insurance company won't pay for it.
I: Do you think it would be a good idea if the insurance companies would pay for it? R: Yes, but I don't think so... well, that won't happen.
I: but would you like it to happen?
R: definitely, because the people we care for really need it. (R2)

We just take care of each other

As a result of the lack of societal and organizational care, care workers turn to each other to protect, support and maintain their health. This relational health strategy is a response to the political and organizational context. Lacking hope for political change, they consider it their individual responsibility to find solutions within this system:

I have a great sense of duty, and loyalty to the organization that I work for, and my team, and if I have the drive to... I just don't like to quit. So, it puts me in the mode of, where are possibilities to keep going. (R9).

Their solution to the lack of organizational care and support, is taking care of each other:

If they don't take care of their employees, the employees just have to take care of themselves. (R19)

You receive more support from your own colleagues, than from a manager. (R4)

Many care workers speak of care teams in terms of a ‘family’ that takes care of each other:

We are just one big family (..) Because we work well together and keep each other safe. (R5)

Relational health strategies were strengthened by shared experiences, for example in this team where menopausal transition yielded solidarity among team members:

We take care of it together (...) We are all going through menopause. So, we all have moments that we just can't do it, and then we are there for each other. That is all really easy and good. (R5)

Some just want to stick together

In this theme, we describe how these relational health strategies can contribute to exclusion within care teams. Not everyone is equally included in ‘the family’ of a care team. This ‘family atmosphere’ often required the exclusion of those who did not fit:

I: How does this atmosphere came about? R: Well, that took us a long time. We had to throw all the rotten apples out of the basket. (R8).

Participants in our sample who were not financially dependent upon their care work, often because they could fall back on their male, high-or-middle classed, partner income,

and could afford to work part-time to restore their health or do unpaid care work, narrated more extensively about solidarity within teams. They embodied the ideal worker, and were easily included within the team. This respondent for example shared how not being financially dependent upon your care work made it easier for her to be a ‘good colleague’:

I have a small contract, for 8 hours. (...) See, if you work 24 hours a week then you have to work. But I can work. If a colleague is sick or has a party to go to, I can just see, no problem, I can take your shift. (R18).

Those who cannot adhere to the normative expectations of the ‘ideal care worker’, more often experienced exclusion from care teams. Exclusion was shaped by (dis)ability, for example because when participants suffered from health issues and had to set their boundaries (self-care):

You can just handle less. (...) And some colleagues don't accept it. (...) For example, when I said, I can't do it, it's just too heavy, they would say: well, just try anyway. (...) I would be like, come on. Some colleagues really had little sympathy for me. (R13)

The normative ideal of ‘being available’ was also reproduced with teams, as a marker of solidarity and involvement. Often, this availability was made possible by heterosexual relationships or not having young children. Women who are not always available, for example single mothers, do not fit the norm and could not always count on sympathy from team members:

This is a group of women who would say like ‘Well, I also had to take care of my children when I was your age. (...). So, I am not going to take her children into account now. (R8)

The participants in our study often expressed frustration about the ‘younger generation’ as they were not embodying the norm of self-sacrifice, according to the ‘older generation’:

Those young girls, they come and work with us, but then also want to play sports on Saturday, go to the movies on Sunday. They go to the gym two times a week and out to party one time a week. (...) I would be like, (cynically) you want to combine all of that with working in long-term care? (R22).

Women who are facing financial precarious situations, do not fit the norm and were othered. Many care workers, who were not financially dependent, implicitly stated ‘doing it for the money’ compromised women’s caring identity:

They told us: ‘In many nursing homes people work for the money, but here in (name organization), you work for people.’ To me, that was a great compliment. (R9)

Sameness was also challenged when women who were seen as ‘culturally other’ by the dominant group within a care team, also experienced exclusion:

Always these questions. Oh, you don't drink alcohol? No? I just get sick and tired of it. Also. Also, with Ramadan: ‘You shouldn't do it. It's not healthy’ [sighs]. Just very tiresome. (R10)

Those who faced exclusion within care teams, as they could not adhere to the norm, experienced negative health effects as a consequence of these experiences of exclusion, further stressing their health. Who does and does not fit in the team, was distinctly shaped by norms of the ‘ideal worker’, and embraced or pushed out by these relational health strategies:

I can understand if you don't feel well sometimes, and that you share it, so you can take care of each other. But after two to three times, you start thinking 'hmm'. And, after the fourth time, you are like, cursing to yourself, I am not here to do both our jobs. I am already running faster than I can. I know, we cannot all carry the same load, but after a while you just think to yourself, can we please get somebody else to work here? (participant FG).

Discussion

Our empirical findings show that gendered norms limit possibilities for self-care for nurses and nursing aides. Many care workers in our sample felt uncared for by society and LTC organizations, and, as a consequence, turned to each other to protect, repair and maintain their own health. These relational health strategies thrived by a feeling of sameness, limiting space for diversity and disability within care teams. Care workers that were seen as ‘culturally other’, or those who had to protect their boundaries due to health issues, financial struggles or informal caring responsibilities, faced exclusion within care teams, negatively impacting their health.

The lack of societal and financial appreciation for care workers in LTC is a persistent societal issue, also in the Netherlands (RVS, 2020). Feminist political scholars have theorized this as a *gendered* inequity (Fraser & Jaeggi, 2018). In our current neoliberal financialized version of capitalism, care is framed as a *costly burden* for society, rather than an *investment*. This discourse allows paid care work to be underpaid and re-allocated to lower professional levels, and from paid to unpaid care workers (Maarse & Jeurissen, 2016).

Our empirical findings show that this lack of appreciation is not always politicized – or that political change feels out of reach – by female care workers. In response, they turn to each other to maintain, protect and repair their health. This can be understood as a *care ethical* response to the given societal and political context. Care ethics – rooted in feminist thought – critiques individualistic notions of autonomy and emphasizes the interdependency of human beings. Therefore, care ethicists rather speak of ‘relational autonomy’ (Verkerk, 2001). This relational autonomy is reflected in female care workers’ strategy to protect their health, not as individuals, but in relation to each other (Jakobsen et al., 2018). These relational health strategies of female care workers contrasted with the health strategies of men in LTC, who employed more individualistic strategies in response to the lack of appreciation (25). From this perspective, HRM interventions for female care workers should not focus solely on individual health strategies, but take these gendered relational dynamics within care teams into account.

Our empirical findings also illustrate the flip-side of these relational health strategies, as they contribute to exclusion within care teams. In doing so, these health strategies become ‘inequality regimes’ within care teams and care organizations (Acker, 2006). Exclusion was distinctly shaped by gender, disability, class, age and race. This resonates with the work of Hankivsky, who argued that care ethics tends to focus on care ‘close’ to others, but often fails to address societal power structures and mechanisms of in- and exclusion (Hankivsky 2014).

Exclusion can be understood as horizontal violence, conceptualized as ‘*violence in the form of action, words, and other behaviors that is directed toward one's peers*’ (Blackstock et al., 2018). Studies in the field of nursing argue that horizontal violence is connected to the lack appreciation and care for care workers (Blackstock et al., 2018; Sibeoni et al., 2021). Activist-scholar Paolo Freire stated that if oppression is not made political, it can lead to ‘horizontal violence’ among oppressed groups (Freire, 1970). According to Freire, horizontal violence can be countered by political action. Occupational health researchers, including HRM managers and occupational health physicians, often experience powerlessness in relation to governmental policies impacting the health of individual care workers. Occupational health researchers can help to make these issues political by addressing these issues to LTC organizations and on a political level. Theories on moral distress suggest that this will not only benefit the health of care workers, but also their own (Lamiani et al., 2017).

Interviews for this study have been conducted pre-pandemic: but the dynamics in our paper have been exacerbated in corona times. In the Netherlands, the LTC sector was at the bottom of the cure-care hierarchy, and lacked political and societal attention in the first waves of the corona crisis (OVV, 2020). Studies done among care workers during the pandemic suggest that these mechanisms of in- and exclusion within care teams became more pressing, but more evidence is needed to support this claim.

Conclusion

The empirical findings from this study provide openings for gender and diversity-sensitive occupational health care in LTC, by taking women's relational health strategies into account. At the same time, HRM professionals and occupational health physicians should be aware of the flip-side of these strategies, as they contribute to exclusion at the workplace, negatively impacting psychosocial working conditions in LTC.

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CHAPTER 4

Negotiating masculinities at the expense of health

Experiences of low-paid men working in long-term care for older people

Abstract

Introduction

While some areas of care work show increased recruitment of men, the care-gap remains, especially in low paid occupations. Questions arise how masculinities play a part in this, and if *caring masculinities* obscure gender inequities while at the same time perpetuating them. This qualitative study focusses the negotiation of *hegemonic* and *caring masculinities* of men working in residential long-term care in the Netherlands, and its consequences for health.

Methods

Semi-structured interviews (N=16) were analyzed thematically, drawing upon gender and intersectionality theory to understand inequities between respondents.

Results

Findings describe how men move through long-term care. On entry, men negotiated *hegemonic* and *caring masculinities* to gain access, with black men having to work harder. Once inside, men experienced status-loss and performed *hegemonic masculinity*, materializing in financial and sexual rewards, especially for white heterosexual men. In time, this performance of hegemonic masculinity backlashed with respect to their own health; herein racialized and homosexual men were hit harder. Consequently, all the men in this study aspired to move out or up from low-paid care work, with white heterosexual men doing so more successfully.

Conclusion

Our study illustrates the importance of an intersectional perspective on *caring masculinities* at work, showing how *caring masculinities* perpetuate male privilege for some men more than for others, creating health and labour market inequities among men. In terms of health, this study shows that gender, racism and sexual discrimination need be on the occupational health agenda.

Key words:

Hegemonic Masculinity; Caring Masculinity; Intersectionality; Health; Long-Term Care

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Introduction

Background

In gender studies, attention for men, masculinities and male privilege is substantial and increasing. Much of this work builds upon Raewyn Connell's concept of hegemonic masculinity (Connell and Messerschmidt, 2005). Connell explains hegemonic masculinity as the configuration of gender practice that embody the legitimacy of patriarchy, which guarantees the dominant position of men and the subordination of women. Connell also describes how certain forms of masculinity

are dominant in different times and spaces; so-called idealized and socially desired ways of 'being a man', while other masculinities are subordinated, complicit, or even marginalized. Therefore, there is no such thing as 'masculinity', but rather many ways of doing masculinity, hence the term 'masculinities'. What constitutes dominant masculinities is socially constructed and thus, continuously contested and (re-)produced within a given context. Although masculinities vary over time and place, dominant masculinities tend to be white and heteronormative, display oppressive, aggressive and hierarchical attitudes, and value physical strength and leadership of men

In the European context, Elliott and colleagues (Elliott, 2016) describe how some men resist dominant masculinities by embracing and advocating for *caring masculinities*. The concept of caring masculinities rejects domination and its associated traits, and aims to integrate caring values and practices into masculine identities (Hrženjak and Scambor, 2019). Caring masculinities are conceived of as '*men's investment in gender equality*', aiming to engage with caring to support gender equality and social change. Embracing feminine-typed traits, such as caring, by men, is characterized by others as a strategy to 'undo gender' or a transformation into 'hybrid masculinities' (Bridges and Pascoe, 2014). Simpson and Lewis theorize these hybrid masculinities as emblematic of a postfeminist gender regime (Simpson and Lewis, 2019). While some have argued that this is a movement towards more 'inclusive masculinities' (Anderson, 2009), others have raised question in how far these

hybrid masculinities can be employed to obscure gender inequities while at the same time perpetuating them (Bridges and Pascoe, 2014; Elliott, 2016).

Empirical work on men, masculinities and male privilege is often carried out in the context of caring occupations. These are characterized by many as 'feminized spaces'. Understanding space as an embodied experience and materialized power relations, feminized spaces can be understood as held by women and noted for skills that are rendered feminine, e.g. sensitivity and nurturing (Simpson, 2009; Taylor and Spicer, 2007). In long-term care for older people, not just the workforce, but also the clients, are predominantly women (CBS, 2021). Also, long-term care is at the bottom of the cure-care hierarchy, reflecting a gendered hierarchy between feminine-typed care work that is '*low-tech-and-high-touch*' and masculine-typed caring occupations that are technical and heroic, such as emergency care (Simpson and Lewis, 2019; Kvande, 2010). Unsurprisingly, men's experiences in these 'feminized spaces' provide a unique insight in how masculinities are experienced, resisted or reproduced in the health care sector (Hanlon, 2012).

In particular, important work on men in caring occupations has been done by Elwér, Williams, Schwiter, Lupton, Kvande and Simpson, amongst several others. For instance, Elwér et al. shed light on the horizontal sex-segregation, and the experienced status-loss of men in care work, describing how

'... *men avoided or left woman-dominated jobs because of social reprisals in terms of being looked down on by friends and acquaintances that did not see caring work as a proper job for a man.*' (Elwér, Alex, and Hammarström, 2012, p. 6; cf. Lupton 2000). Williams illuminated the '*glass escalator*' of men in caring occupations, having disproportionate chances for promotion to specialty and leadership positions (Williams, 1992; cf. Kvande, 2010). Simpson describes how men adopt a variety of strategies to re-establish masculinities within non-traditional-work settings (Simpson, 2009), so does Lupton (2000), and describes how this is shaped in the context of post-feminism (Lewis, Rumens, and Simpson, 2021; Simpson and Lewis, 2019). Schwiter et al. showed how men silence their privilege by actively re-framing it as an 'individual achievement' or a 'natural advantage of their male-bodies' (Schwiter, Nentwich, and Keller, 2021).

Theoretical approach

Only recently, studies on men in caring occupations are beginning to address class, race and sexuality and other intersections, illustrating how the above-mentioned dynamics do not play out for all men alike (Kalemba, 2020; Wingfield, 2009; Lupton, 2006). Intersectionality, first introduced by Crenshaw (Crenshaw, 1989) in legal and critical race theory, later embraced by gender scholars and now increasingly adopted by health scholars, aims to unravel and illuminate the complexity of lived experiences, shaped at an intersection of all their social identities, and by multiple and interlocking systems of oppression, altogether creating one's experiences and

privileged or marginalized position. We take an intersectional approach to show that there is not one type of man or masculinity and to not reproduce intersectional invisibility. The latter refers to how people with '*multiple subordinate group identities are rendered invisible relative to those with single subordinate group identity*' (Purdie-Vaughns and Eibach, 2008, p. 377).

Intersectional perspectives on healthcare workers' work and health related experiences remain scarce, as studies often lack a critical gender and intersectional perspective. Studies, especially in *feminized and low status* care sectors, such as long-term care for older people, tend to focus on women, as they make up the vast majority of the paid workforce (CBS, 2021). A horizontal gender-segregation of our labor market, the division between masculine and feminine-typed occupations, is more pronounced in low-paid regions of the labor market, and plays out differently for women and men across diverse backgrounds (Kreimer, 2004).

Social identities and systems of oppression shape peoples' social and economic disadvantages, which are generally reflected in health disadvantages (Hankivsky, 2012). But not necessarily so. Therefore, we need better understandings of the complex relationship between social privileges and disadvantages in relation to health (Hankivsky, 2012; Verdonk et al., 2019). In relation to masculinity, Verdonk et al. (2010) described how health promoting behaviors in the workplace were hampered by masculine ideals. In their study on worksite

health promotion in particular company exercise, men distinguished two normative categories as regards masculinities and health. First, they perceived the ‘ideal man’ as competitive and noticed by other men, and real men should not be whiners and not disclose vulnerabilities when they had health issues. Nonchalant attitudes towards health were therefore a display of masculinity as men continued behaving as if they could not be bothered by health issues.

Information on policy system

In the Netherlands, the experiences of workers in long-term care are to be understood within their socio-political context. The health of healthcare workers is under pressure, with shortages of staff high job strain, high sickness absence and staff turnover. This is not for all healthcare workers alike. In 2015, policy measures were enacted in response to the 2008 financial crisis and in the context of an ageing society, aiming towards (financial) sustainability and cost containment (Maarse and Jeurissen, 2016). These policy measures allocated care responsibilities towards lower professional levels and from paid to unpaid care givers. In practice, these policies heavily impacted paid caregivers in long-term care, as they were required to attend to more and more complex care needs with less financial means (Maarse and Jeurissen, 2016). The Dutch context is comparable to other post-welfare states in Europe.

This has been further exacerbated by the COVID-19 pandemic, which exerted a great sudden pressure on the already worn-out

sector and affected the health of many care workers (Ernst and Young, 2020; Pappa et al., 2020). In the last decades, neoliberal policies have fostered precarious and temporary employment and pushed tax regulations that made self-employment more attractive, also in the care sector (Stanford, 2017). Self-employment traditionally attracted high-paid care professionals, such as specialists and nurse specialists (Conen and Schippers, 2019). Recently, increasing numbers of low-paid care workers such as nursing aides opt for self-employment (CBS, 2020). Most self-employed take shifts in long-term care organizations (contracted care), doing more or less the same work as hired employees, but they can also have their own clients (non-contracted care). This may lead to precarious situations due to a lack of adequate social benefits and regulatory protection, and uncertainty of continuing work, all having an impact on health (Conen and Schippers, 2019; Duijs et al., 2021; Duijs et al., 2022a).

Problem statement

The focus on women as default caregivers may cause academics to overlook men working in healthcare roles in general, and in long-term care in particular. Available studies cannot be applied to men, since research on men or women respectively, is not interchangeable (Watts, 2015). Furthermore, intersections of gender with other social identities are widely neglected and as a consequence some groups suffer from intersectional invisibility (Purdie-Vaughns and Eibach, 2008).

Hence, studies on the health of healthcare workers tend to focus on lower educated

women in long-term care, and on higher educated men in hospital and mental health care, largely overlooking low-paid men in the long-term care sector (Watts, 2015), and even less is known about the experiences of racialized and gay/queer men in this sector. Exploring men's experiences is not only important for men's health but may also provide clues for further research on how to recruit and retain men for this sector, which might resolve problems such as staff shortages, low status and low wages (Elwér et al., 2012).

In our study, we aimed to understand how men in low-paid care work negotiate their paid and unpaid care work, especially in relation to health, and how this negotiation is shaped by *masculinities* in intersection with class, race and sexuality. To link our empirical findings to current academic debates on masculinities, we focus on the way men negotiate hegemonic and caring masculinities, and on their experiences as paid care workers in long-term care (Connell and Messerschmidt, 2005; Elliott, 2016). We focus on the different ways men ‘do’ masculinity in long-term care as a feminized space (West and Zimmerman, 1987). The relevance for occupational health is illuminated by how the negotiation act of hegemonic and caring masculinities materializes in men's health, and in health inequities between men and women, and among men. We argue that the negotiation of caring and hegemonic masculinities results in the perpetuation of male privilege, for some men more than for other, and that this negotiation act backlashes in terms of health.

Methods

Study design

The qualitative interview study is part of a larger Participatory Health Research (PHR) project ‘Negotiating Health’ (Duijs et al., 2022b), which is conducted by academic researchers and co-researchers who have experiential knowledge as paid and unpaid caregivers in long-term care (Wright, 2015; Abma et al., 2019).

This sub-study was initiated by a male co-researcher (Mazurel), and focused on men and masculinities to gain a wide understanding of men's subjective experiences about health, working in long-term care, and perceptions of masculinities (Green and Thorogood, 2018). Our epistemological approach is grounded in critical theory, to recognize how subjective experiences are shaped by multiple and interconnected societal inequities (Green and Thorogood, 2018; Hankivsky, 2012).

Research team

Understanding how researchers' social positions influenced the results contributes to the quality of the study (Frambach, van der Vleuten, and Durning, 2013). The academic researchers were four white, highly educated, cisgender, women who were in a heterosexual relationship at the time of the study. The first author is a medical student. The second, fourth and fifth authors are academic researchers experienced in PHR, gender and intersectionality. The co-research team consisted of four heterosexual women of different colours and one heterosexual white man (the co-researcher, Mazurel). The

male co-researcher (Mazurel) initiated the study, co-created the topic list and regularly reflected upon (pre)liminary findings. Due to personal circumstances and the pandemic, he did not want to participate in data-collection. The female co-researchers reflected upon the findings in a focus-group meeting, specifically focussing on the differences between their experiences as female paid care workers in long-term care. The team allowed for investigator triangulation increasing the confirmability of the study (Frambach et al., 2013). Also, a critical friend (male, white, high-educated, cisgender, heterosexual) was consulted several times to provide a fresh perspective on the data, further increasing the critical reflexivity and confirmability (Cebrián, 2016).

Research population

We included sixteen men working in the long-term care sector for older people. What constitutes a ‘man’ can be defined biologically in terms of sex (Fausto-Sterling, 2012) or seen as a social role shaped by gender, which is relational and performed (West and Zimmerman, 1987; Connell, 2005). In this study, we included people who self-identified as men. Three respondents had been previously included in the study. Additionally, thirteen men were recruited and interviewed by the first author, until data saturation was attained (Frambach et al., 2013).

Respondents were recruited via the network of the researchers and co-researchers, yielding ten interviews, including an interview with the co-researcher. The positionality of the researchers, and

particularly our whiteness and the whiteness of our network, has shaped the recruitment process, leading to an overrepresentation of heterosexual white men in our sample. Additionally, we recruited three respondents through a Facebook page for self-employed care workers. We purposive sampled across age, race, migration status, sexuality, years of employment and occupational level. This both increased the transferability of the study and facilitated an intersectional approach. Although the overall diversity of our sample was limited, we were able to observe how men’s experiences were not only shaped by masculinity, but also by racism and homophobia (Frambach et al., 2013).

Data collection

Data was collected via semi-structured interviews. The topic-list was based on existing literature, the interview with the co-researcher, and themes emerging from transcripts from earlier interviews (N=3, RA-RC). We drew upon Oliffe and Greaves’ work on interviewing men about health (Oliffe and Greaves, 2011). Thirteen extra interviews (R1-R13) were conducted individually, in Dutch, by the main researcher. Before the interview, respondents were informed by e-mail about the topics. Respondents chose the locations, to provide a safe and comfortable environment, however due to COVID-19 and safety guidelines, plus personal preferences of the respondents, four interview were conducted face-to-face. Nine interviews were conducted via an online video-call, three by telephone. Listening was done according to the Integrative Listening model (Thompson,

Table 1: Respondents

	Age	Sexuality	Self-identified colour of skin	Country of birth	Profession	Years in caring work	Sector (-mural)	Employee or Self-employed
RA1,2	40	Heterosexual	Brown	Morocco	Advanced Nursing Aide (level 3)	11	Extra	Both
RB1	57	Heterosexual	White	The Netherlands	Advanced Nursing Aide (level 3)	25	Intra	Self-employed
RC1	48	Heterosexual	White	The Netherlands	Advanced Nursing Aide (level 3)	15	Intra	Employee
R1	62	Heterosexual	White	The Netherlands	Advanced Nursing Aide (level 3)	11	Intra	Employee
R2	43	Heterosexual	Black	Suriname	Nurse (level 4)	22	Intra	Self-employed
R3	46	Heterosexual	White	The Netherlands	Nurse (level 4)	14	Intra and Extra	Self-employed
R4	32	Heterosexual	White	The Netherlands	Advanced Nursing Aide (level 3)	1	Intra	Employee
R5	34	Heterosexual	White	The Netherlands	Advanced Nursing Aide (level 3)	10	Intra	Employee
R6	43	Heterosexual	Brown	India	Nurse (level 4)	4	Intra	Employee
R7	26	Heterosexual	Brown	The Netherlands	Advanced Nursing Aide (level 3)	0,5	Intra	Employee
R8	40	Homosexual	White	The Netherlands	Nursing Aide (level 2+)	2	Intra	Self-employed
R9	31	Homosexual	Black	Ghana	Advanced Nursing Aide (level 3)	10	Extra	Self-employed
R10	25	Heterosexual	White	The Netherlands	Advanced Nursing Aide (level 3)	7	Extra	Employee
R11	27	Heterosexual	Brown	The Netherlands	Advanced Nursing Aide (level 3)	6	Intra	Self-employed
R12	43	Heterosexual	Brown	The Netherlands	Advanced Nursing Aide (level 3)	4	Intra	Self-employed
R13	31	Heterosexual	Brown	The Netherlands	Advanced Nursing Aide (level 3)	15	Intra	Employee

1 Earlier interviews of the PHR-project.
2 The wife of this respondent participated in this interview

Leintz, Nevers, and Witkowski, 2004). Respondents consented both orally and written to recording and transcription of interviews. Presenting a summary of the interviews plus the interviewer's impression to the respondents increased credibility of the study (Frambach et al., 2013). Further data were collected in a logbook with memos based on observations before, during and after the interviews, which enabled an audit trail.

Data analyses

Data collection and analysis were done iteratively, allowing for emerging insights. Quality was protected by applying the principles of Frambach et al (2013). Thematic content analysis was applied (Green and Thorogood, 2018), alternating with Jackson and Mazzaï's analytic of 'thinking with theory' (Jackson and Mazzei, 2017). Intersectionality and gender theory (especially hegemonic and caring masculinities) were taken into account as theoretical framework which guided the analysis of our data. Coding of the data was done by first author, and first and second author compared, discussed and examined the codes and categories closely, unravelling themes from the data. These themes were critically appraised and fine-tuned together with the last author, in dialogue with the critical male friend, and in two focus groups with the co-researchers and consortium partners of the study. Formulating for whom and in what context results are relevant increased credibility and transferability (Frambach et al., 2013). This repeated checking and adapting with others, increased the quality of the study in terms of confirmability, credibility and dependability (Frambach et al., 2013).

Ethical considerations

In this project, we took both procedural and relational ethics into account (Wijngaarden et al., 2017). First, to address procedural ethics, the research project was presented and approved by the ethical committee of Amsterdam UMC. All researchers consent to anonymity and carefully handling all information such as informed consents and recordings were deleted after completion of transcripts. To address relational ethics, a logbook was kept by the first author to document ethical uneasy moments, which we reflected upon with the entire research team (Wijngaarden et al., 2017). One ethical issue stood out. Power dynamics of age and gender shaped the interview process and our data (Oliffe and Greaves, 2011, cf. Pini, 2005; Arendell, 1997). Being a young, white, heterosexual female student, the interviewer often felt that she was being underestimated, felt powerplay, and observed that men would sometimes try to impress her.

Even though such interactions render unique insights, two lessons are learned. First, a warning should go out to future researchers as such dynamics may lead to uncomfortable situations, experienced as bearable in video-calls, but triggering feelings of unsafety at the men's home; and second, it exemplifies how social locations of researchers influence results (in this case men's outspokenness about their male privilege), and how reflexivity towards this is essential when researching lived experiences in qualitative research.

Vis-à-vis, for the male co-researcher, the research process was also not always a

comfortable place for him and therefore, after this study, he decided to stop participating in the broader PHR research project.

Results

Overview

We unravelled five themes based on the interview data, characterizing the experiences of low-paid men in caring occupations:

- **Gaining access** through a (strategic) negotiation of hegemonic and caring masculinities;
- **Clashing** with the feminized space of care work endangering their status as men;
- **Re-claiming status** by performing hegemonic masculinity;
- **Health as battlefield:** displaying hegemonic masculinity at the expense of health;
- **The privilege to exit:** leaving long-term care to regain status and health.

Gaining access through a (strategic) negotiation of hegemonic and caring masculinities

Most men gained access to paid care work by a strategic negotiation of hegemonic and caring masculinities. Hegemonic masculinities shaped men's motivation for care work and became visible in the interviews as several men described themselves as breadwinners.

They had started their careers in other, more masculine-typed sectors, but had experienced difficulty in finding work. The latter intersected, for at least two respondents, with being a migrant:

So, I arrived here [the Netherlands] to live together, with the goal to study IT, but I couldn't, due to circumstances. ... So, when I came here, I applied for a school, but it was very expensive. ... So, the only option I had, was the care sector. (R9)

Care work provides job security and career prospects. Many considered their current job in long-term care as a steppingstone to move upwards, often toward a more masculine-typed healthcare speciality such as mental or hospital care, reflecting the gendered cure-care hierarchy:

I figured: first, I will do a nursing course and once I would have finished that, I would immediately proceed and do a scrub nurse training, and then I'd find it appropriate. (R10)

Most men implicitly or explicitly stated that they didn't enter paid care work as a deliberate or long-term career plan. For example, one respondent got in, to his own surprise, after sending a semi-joking application when a colleague told him that an organization was looking for 'ass cleaners':

I thought I'd never hear of it again. But then I was invited for an interview. And I just went there with a clean slate, did the interview, and a day later my phone rang: 'you're hired'. 'Well,' I thought, 'then I better go take a look at what it's all about [laughing]. (R5)

Hegemonic masculinities were silenced in relation to possible employers, whereas caring masculinities were strategically emphasized. Most respondents expressed and identified with a caring masculinity by being attracted to the social aspect of care work. Some experienced how providing informal care for a relative had been gratifying, but most men had little to no involvement with informal care. Others compared their previous jobs in catering services with care work, framing it as socially acceptable to care for people as a man:

In the catering industry, I also tended to people, but with a nice plate of fine food. And now, I tend to people with basic healthcare: washing and showering, helping them by providing basic healthcare. So, in that manner, the catering industry and caring industry do not differ all that much. You just want to make someone happy or tend to them. (R7)

Most men were seen as ‘caring’ by others such as their partners who then advocated them into care work. Many respondents had a female relative recommending a job in long-term care as a career option. In heterosexual relationships in particular, the female partner paved the way for the men to start a new career.

I wanted him to proceed you know, not to continue that job. ... And then we made his resumé ... And from there he got accepted for a job as nursing aide. (wife RA)

Once they applied, they emphasized their caring masculinity, and as a consequence men felt welcomed with open arms. On

respondent describes how he got told he had a ‘magnificent resume’, while he only had experience as informal carer. In general, men were easily seen as competent carers, according to themselves:

If there would be five applicants, of whom four women and one man, then the man might be preferred. Provided that none of the women would have considerably better qualifications ... I would be picked first. (R10)

The privilege of a swift entry was most dominantly present for men who identified as white or brown. However, the experience of a Ghanaian respondent who identified as a black migrant, stood in stark contrast. He had work harder to be seen as a competent carer, and could only gain access to this privilege through formal education, and even then, he did not easily receive his qualifications due to experiences or racism:

*R: And never have I been offered some sort of training. Never.
I: Never been offered?
R: Never. Never. Never. Never have I been offered a training by a supervisor. [...]
I: I also wonder, ..., you think it might have had something to do with racism?
R: Now, you ask the question. Look. At [organisation] I have worked in paid employment for two years and it all went very well. Also, I did my training and I worked hard.*

And in the traineeship, we had to lead our colleagues, so, I took the lead, and I did

well. We even had a client with a wound with MRSA, at whom all nursing procedures could be signed off, and I took care of her all by myself, which takes around two hours, and I did it all good. And even then, when my teacher came for a review of the traineeship, she wanted to give me a failing grade. (R9)

Clashing with the feminized space as a man, endangering their status as men
After gaining access to paid care work, many men clashed with the feminized space of long-term care at different levels: personal, relational, job-content and institutional. Overall, men described long-term care for older people as sector with low-status, which endangered their status as men.

On the personal level, they shared how they were seen as less of a man by their social environment because of their job. Some men engaged in this line of thinking themselves, which can be seen as a form of internalized oppression, saying that they ‘missed some kind of masculinity’. As a consequence, they felt out-of-place as men in a feminized sector:

Even my manager said: what is a man doing in a long-term care sector? (RC)

Their experience was shaped by heteronormativity, making it more difficult for gay men to be perceived as embodying dominant masculinity. Many had to endure overt or covert comments that they were homosexual, assuming that gay men were less manly in the first place and thus less ‘out-of-place’:

That I had a job in healthcare, it was immediately like: ‘oh, he must be gay’. (R1)

Similarly, experiences of racism gave less access to dominant masculinity for men of colour. Men who identified as brown or black were seen as less ‘out-of-place’ than white men.

Most people working in care are of colour. (R9)

On the relational level, respondents struggled with primarily having female colleagues. According to them, women would ‘overly criticize men’, take things ‘too personally’ and not tell directly if something was bothering them, which left the men feeling they had to be cautious and could not speak freely. They also stated that women would pass their duties onto others, as opposed to men, who would take on extra work. Interviewed men felt that women were preoccupied with social interactions amongst each other, leading to work delay, gossip and conflict. All assumed that having more men in the workplace would diminish this dynamic:

If there are men in the team, you just notice that it enhances the atmosphere. (R12)

This negative judgement of feminized work spaces, also served to obscure their responsibility as men. For example, some interviewees described how they felt singled out ‘unnecessarily’ to watch their (sexist) tongue, and one respondent was even asked to change his job because of offensive speech, implicitly placing blame on his female colleagues for this event:

But yes, when you work with women, things quickly turn into a #metoo story. [laughing] While it's unintentionally you know. One just makes a joke once in a while. But, yeah, then it's interpreted differently... (R5)

On the job-content level, men expressed difficulties with feminine-typed caring approaches to care work. For example, they struggled with the requirement for emotional involvement rather than business-like relationships with clients and found it tiresome to be 'supposed to be caring from the heart', while it is 'just one's job' (R3). We observed a class intersection, as men attributed this specifically to low paid care work, and expected this to be less of a predicament higher up the ladder:

One has to offer oneself and play nice and... And when you are a doctor or a surgeon, it is somewhat more from a business perspective, you know. Then it's not... It's all very much focused on the relations, in caring work. That's very tiring. (R3)

On the institutional level, men experienced a jeopardy of their socio-economic status. Their work in long-term care was low paid compared to other occupations at the same educational level. Plus, the sector had its difficulties in accommodating fulltime jobs and regular work schedules. This is a problematic issue for both men and women, but the men in our sample particularly described how it endangered their status as man and their social role as breadwinners. The words they used expressed their anger:

They came up with..., that we could only work six hours a day. And then ..., the manager told me: 'Yes,' she says, 'then you can go home nice and early.' I say: 'yes, but I'm unemployed for two hours a day. And how am I going to solve that? My payment is cut, hell with it.' (R1)

Re-claiming status by performing hegemonic masculinity

In reaction to the undermining of their status as men in long-term care, men employed strategies to perform their 'hegemonic masculinity'.

First, on the personal level, men presented themselves in interviews according to hegemonic norms. Words that came to pass when describing themselves and other men at work were for instance: strong, leading, advisory, hard workers, courageous, stress-resistant, stable, pragmatic, straight-to-the-point, easy, and independent. They felt strengthened in this view by colleagues and managers. They presented themselves as 'wanted', and some even explicitly found men more suitable, or at least more cost-effective, for care work:

Look ... We have some clients here, when... when I cannot come to work, two women have to go there. One did not venture (?) going alone, another felt like it was too heavy... So, I feel like, for the employer, well, maybe when I take a shift, it's less expensive than if two women do. (RA)

Second, on the relational level, heterosexual men re-directed attention to the benefits of

working primarily with women, as it granted them 'sexual power'. They emphasized how working in long-term care gave them plenty of dating opportunities, that female colleagues liked a 'caring man' and gave various example of female colleagues who fancied them. This explicit reference to their sexuality, may be understood as a response to the homophobic notion that men in care 'must be gay'. The interviewed men were often quite explicit in describing this privilege or 'sexual power' to the first author:

And I was the only man in the [nursing assistant] course. Well yeah, and there we went, with all those girls we went into town. And at a certain moment, well, bam, into the [lingerie shop]. And well, you know, like, I say: 'and, does it look good on you?' 'Well, yeah, take a look if you want' So there I went, taking a look. (R5)

Third, on the job-content level, men reframed their job in line with norms of hegemonic masculinity. They emphasized the required medical expertise, resilience, the many challenges and responsibilities, and the need of 'masculine' competences summed up earlier. One respondent even described care work as being 'all technic', because of his skills in applying medical circuits and drains. Others opted for self-employment, which allowed them to foreground a more masculine-typed entrepreneurial identity as care workers.

I can imagine, when one has children and a wife and a mortgage and that kind of stuff ... one thinks: I'm opting for self-employment for the next ten years, and from there we'll see. (R8)

Fourth, on the institutional level, behaving according to hegemonic masculinity resulted in privileges, such as better contract conditions and a higher salary. Some explained how they negotiated themselves a better salary. Others mentioned how they received larger contract (i.e. more working hours) than their female colleagues. They judged this as fair, referring to their role as breadwinners, in doing so re-producing the idea that women are not financially dependent upon their paid care work:

They often have a partner taking care of the main income ... In general women just work to keep themselves busy. (R5)

Although men of colour said to exhibit similar hegemonic behaviours, they generally did not gain similar privileges as white men. They had to work harder, proving their competence through education before gaining a better salary. One man of colour got paid a whole salary scale lower than his educational level allowed, which he and his colleagues interpreted as racism. A self-employed white man explicitly told how he learned to ask for more for the same job than his colleagues of colour.

Men who experienced discrimination (racism, homophobia or both) responded by opting for self-employment. Self-employment allowed control over education opportunities, financial rewards and emotional distance. Self-employment granted agency to avoid working environments in which they experienced discrimination:

Why? [...]How people treat each other. ... Oh no. Yes, often enough you think like: 'o, well, I will not come here again', being self-employed. You think like: 'oh no, not doing this again.' (R2)

Health as battlefield: displaying hegemonic masculinity at the expense of health

Although adhering to norms of hegemonic masculinity helped to gain access to privileges in low-paid care work, their behaviour backfired in relation to health. Care work is physically demanding, and although hegemonic norms of masculinity required men to be fully equipped for heavy work, their bodies were not. Men recurrently mentioned that they were asked by colleagues to lift a client who had fallen on the floor. Also, assistive instruments designed for heavy lifting of clients were left unused and seen as 'unnecessary for strong men'. However, their bodies did not keep up with their efforts. Physical injuries arose, including back problems, wrist injuries, tennis elbow and upper arm and shoulder strains:

And they said: 'yes you're a man, you can do this easily, because you are strong.' But, well, I got a tennis elbow and other hassle. So that didn't really go well. It was just too heavy. (R1)

Although self-employment provided distance from discrimination, it also allowed for risky health behaviour, due to the lack of managers or regulations guarding their health. Many self-employment men reported working many shifts in a row, resulting into tiredness and diminished self-care, but felt compelled by the financial rewards:

It really only had an impact on my self-care. Because you just say yes very easily, like, 'one more'. But after those eleven shifts, you are just tired and tired. (R2)

Mental health issues were also amplified because of hegemonic behaviours, according to the respondents. Being a breadwinner was considered a psychological burden, and even more so as a self-employed due to the lack of social security. Also, being put forward as a leader was said to increased job responsibilities, which weighted heavily on the men's shoulders. Men often obscured the impact of misery, illness and death they encountered in long-term care, and hegemonic masculinity required them to appear unaffected and deny help, as became visible in the story of this men after being involved in an incident where a client died:

R: Yes, it was a shock of course ... And at one point, you start to wonder, 'what if?' What if I had continued or something? [...] And I was allowed to go home after that event, but I didn't. After telling it to all your colleagues, you have something like: 'Well, now I know the story. It happened. And yes, it comes with the job' [...] I still remember that after it happened, I spoke to my supervisor, who said: 'We have a counsellor, etcetera, so if you want to use that, just say so.' ... Then I had something like 'dude, it still has to sink in' So I had something like: 'No, if I need it, I will let you know.' (R10)

Men of colour and sexually diverse men experienced an extra mental burden from

discrimination, coming from clients, colleagues and managers. Men who identified as homosexual described how they responded to homophobia by employing strategies to pass as straight. Men of colour had endless examples of racism, for example being refused by clients and being held excessively accountable for mistakes. These men had to put in energy to make their identity invisible or a non-issue, and dealing with (the risk of) discrimination took a lot of extra energy and created self-doubt, impacting their health and wellbeing:

...that pain [of a racist remark], what it does to me... now and then it makes me think that I'm less than another, and sometimes I forget I'm not. (R13)

Expressions of mental health issues were gendered and the men in our study tended to show more masculine-typed symptoms of burn-out such as apathy and depersonalisation. Interviewees talked rather casually about burdensome experiences or spoke about them as if it had not happened to them. Also, mental health issues were framed as more 'normal' for women according to the respondents, but appeared to be taboo among men, which became visible during interviews. One respondent spoke at length about 'all those women with burn-outs', only to admit that he himself suffered from a burnout in the very last minutes of the interview. Such distancing and depersonalisation are in line with hegemonic masculinity, which prescribes that vulnerability should be seen as weakness, and thus, inferior:

That (acting vulnerable) evokes the weak little boy in a man. That he shouldn't be vulnerable. Because you have to carry your family. You have to take your wife and children by the hand when things go wrong. II: And that is at the expense of your mental health? R: Exactly. Yes, because it has to... it is going somewhere. (R7)

Despite the silencing, denying and hiding of mental health issues, stress and burn-out appeared to be highly prevalent among the interviewees. About half of them had a (work-related) burn-out, and several others sought professional psychological help for problems developed in the workplace. Also, interviewees said to continue work while experiencing mental exhaustion.

The privilege to exit: leaving long-term care to repair status and health

As a result of the status loss and subsequent health risk, all men in our study had the intention to leave their current job in long-term care, either now or in the near future. Respondents entrusted the interviewer that they left to improve their health, their social status as man, and for financial reasons. Publicly, they predominantly showed the latter. As described in the first theme, some respondents already had exit plans on entry and never fully committed themselves to their current job. Many already held another job in the side, as a possible escape strategy:

That can indeed cause moments of stress. But yes, the nice thing is, of course, I'm also a bus driver. ...And that is actually a very good,

a good distribution. So, that makes it easier to let go. ... That's why I now have made the decision to work a little more in the bus. (R5)

Live events, such as becoming a parent, moving, a new partner or reaching a certain age, often fuelled their decision to leave:

And when I am older [now 31], from 45 or 40, and I have a family, I will choose a different career, a different job. Maybe I can..., at least, do something with IT or do something with management. That's why I went back to college. (R9)

Four exit strategies were mentioned: opting for self-employed care work, moving to a more masculine-typed care sector, moving up into a higher function, or leaving the care sector all together. Exiting low paid care work in long-term care was aided by hegemonic masculinities and male privilege. On a personal level, men felt entitled to have a better job. On an institutional level, it granted them opportunities to move up relatively easy compared to women. Many men were offered opportunities, such as being asked to go in training for a higher degree, sometimes even in a short track. These privileges felt fair 'win-win situations' (R10), being both profitable for the organization as well as for the interviewees:

Yes, a location manager, she said: 'you are going, you are going, just try.' 'Just start the training' they said. And I was allowed to do an internship at the time, and yes, after a few hours I actually already knew. Yes, and then I started the training for advanced nursing assistant.

And I completed it. And then, I was immediately hired for the training to become a nurse. (R6)

Again, these benefits were different for men of colour, especially black men, who did not share white men's privileges and felt more 'stuck' in long-term care. They did not have the same amount of privilege to protect their health and to enhance their financial situation, as white men had:

I have to say ... several times I've heard that as a native person one gets admissions more easily at caring organisations than as a foreigner. (R8)

Discussion

In this study, we analysed how the lived experiences and health of men working in low-paid caring occupations are shaped across social identities. Masculinity as a privilege is extensively discussed, especially in gender studies (Elwér et al., 2012; Evans, 1997; Fletcher, 2001; Kahn, 2009; Williams, 1992). Our study shows how men strategically negotiate hegemonic masculinity and caring masculinity to gain privilege through paid care work. They can draw upon caring masculinity to gain access to paid care work, and were encouraged to do so by their environment, but also have the privilege to abandon this masculinity once their status or health is at risk in the workplace. Academic debates resolve around the question whether caring or inclusive masculinities can be seen as men's investment in gender equality (Anderson, 2009; Elliott, 2016)

or not (Bridges, 2014; Bridges and Pascoe, 2014). Our empirical findings are in line with Elliott's later argument that the autonomy to shift between different expressions of masculinity perpetuates male privilege (Elliott, 2019), but not for all men alike, since especially white, heterosexual men can capitalize upon this negotiation act. Therefore, our findings show that this question requires a diversity perspective.

Our empirical findings also shed light on the different experiences of men and women in labor markets. Although both men and women suffer from the gendered devaluation of (paid) care work in our society and the impact this has on the long-term care sector (Fraser and Jaeggi, 2018), their experiences in labor markets are distinctly different. This devaluation of care work has been extensively theorized by social reproduction theorists (Fraser and Jaeggi, Vogel, cf. Bergeron, 2006). In the Netherlands, recent budget cuts and policy reforms further lowered the 'status' of the care sector (Maarse and Jeurissen, 2016). Our study shows how men resort to care work in times of limited labor market opportunities in male-dominated sectors, keeping one foot out of the door, being able to move up or move out when their health is at risk. Therefore, we argue that (some) men can be characterized as *passers-by* or *stopgappers* in low-paid care work (Simpson, 2009; Torre, 2018) and that their careers are shaped by both a '*glass-escalator*' and a '*glass-revolving-door*' (Williams, 1992). These findings can be understood by Joan Tronto's notion of men's 'privileged irresponsibility' in relation to care (Tronto, 2013). While men can and do care, they can more easily draw a 'get-out-card', due

to the privilege they acquire in the workplace, which makes it easier to leave when their health, status and finances are under pressure. This also implicates that catering to the needs of men in caring occupations does not necessarily translate in prolonged engagement in paid care work. This contrasts with women's experiences in the labor market (Verdonk et al., 2010; McGrath, 2006). Yet, the abovementioned experiences are not true for all men. The '*glass-escalator*' and the '*glass-revolving door*' are distinctly shaped by race and sexuality, as has been shown by other scholars (Wingfield, 2009).

Remarkably, several men turned to self-employment to repair their social and financial status. Yet, their experience contrasted with female self-employed care workers. While self-employment allows men to foreground an entrepreneurial identity, which allows for profit-making, often at the expense of their health, women tended to make financial sacrifices as a self-employed to foreground their caring identities and to protect their health (Duijs et al., 2022).

New to our study is the backlash of masculinities for health in male long-term care workers. These insights are especially relevant since the health-related experiences of low-paid men in long-term care are understudied. Nursing in long-term care comes with high physical job demands (Ernst and Young, 2020) and men's physical strength and muscularity could make men particularly suited. However, we found that norms of hegemonic masculinity rendered men vulnerable when their physical and mental strength was treated

as an inexhaustible resource, also by men themselves. Their 'privileged irresponsibility' towards informal care enables risky health behaviors, such as working ongoing shifts, illustrating how multiple social roles can also be protective in terms of health (Hyde, 2016).

These findings resonate with literature on men and health, showing that men associate masculinities with invulnerability and nonchalant attitudes towards health (Verdonk et al., 2010). Verdonk et al. describe that men as a consequence present themselves as invulnerable, which realistically they are not, and therefore at least they should keep silent about how vulnerable they really are. As such, masculinities can endanger health by '*celebration of heroism, physical strength, toughness and stoicism*' (Stergiou-Kita et al., 2015, p. 216), and that men, more than women, feel the need to endure and stifle health complaints. This invulnerability act has negative health consequences, leaving men working in health care in relatively poor health compared to women, as shown in studies among higher-educated male nurses (Watts, 2015). Our study shows that this gender dynamic also plays out among low-paid men in long-term care. This invulnerability act does not have to be performed, when caring masculinities are more embraced. As such, men's investment in caring masculinities might benefit their own health. Yet, more research is needed to understand caring masculinities' potential for health. In addition, we understand men's performance of hegemonic masculinity as a response to the lack of societal appreciation for long-term care work. More

political, societal and financial appreciation for paid care work, might give space for embracing caring masculinities at work.

Occupational health was not only shaped by gender, but important intersections occur with race and sexuality. Racialized and homosexual men encountered a lot of racism and homophobia in the workplace, which impacted their health. We know from literature that discrimination has a direct and indirect effect upon health (Priest and Williams, 2018). Discriminated men in our studies suffered from high stress levels, were offered lesser career opportunities, and had less access strategies to support, protect and maintain their health. Several of them resorted to precarious work to distance themselves from racism in the workplace, which is, in turn, a risk factor for poor health (Benach et al., 2014).

Conclusion

Our study shows that it is important to take an intersectional approach into account in the study of masculinities, men and care, both regarding respondents, since we found experiences to be different at various intersections, and regarding researchers, we could see their social locations influence the results.

In relation to the strive for gender equality, it is relevant to consider that new non-traditional forms of masculinity may perpetuate male privilege by allowing men to strategically shift between masculinities and opt for a more

beneficial mode of masculinity in a given situation. These privileges play out in labour markets, providing (some) men with more career opportunities than women and men of colour and non-heterosexual orientations.

In relation to occupational health in long term care, our study shows that increasing the status of residential long-term care work by society and politics is decisive to prevent and tackle health issues for men (and women) working in long-term care, and to prevent their turnover. Our current gender order should be targeted and revolutionized, as currently both men and women are victimized by it. And so should racism and sexual discrimination need to be targeted by institutions and policymakers, being both a human rights issue as well as a health issue.

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Negotiating health in the context of self-employment



More and more low paid care workers in long-term care opt for self-employment. Self-employment is not necessarily precarious work, but can be precarious for specific groups of workers.

In this section, I explore how female self-employed care workers experience precariousness in relation to health. I conclude that self-employment is both a health strategy and a health risk.

But not for all workers alike. Some workers find themselves in more precarious situations than others. Therefore, I unravel inequities among self-employed care workers (chapter 5) and describe how these were exacerbated during the COVID-19 pandemic (chapter 6).

CHAPTER 5

Squeezed out

Precariousness of self-employed care workers in long-term care

Abstract

Aim

To understand self-employed long-term-care workers' experiences of precariousness, and to unravel how their experiences are shaped at the intersection of gender, class, race, migration and age.

Background:

In the Netherlands, increasing numbers of nurses and nursing aides in long-term care (LTC) opt for self-employment. Societal organizations and policy makers express concerns about this development, as self-employment is seen as a risk factor for poor health. Self-employment is not necessarily precarious work but can contribute to the precariousness of specific groups. Knowledge about inequities among self-employed nurses and nursing aides in long-term care is lacking.

Design:

A participatory, qualitative interview study. The research team consisted of four academic researchers and five (un)paid care workers.

Methods:

Semi-structured interviews with 23 self-employed nurses and nursing aides in LTC (2019–2020). Data were analysed from an intersectional perspective.

Results:

First, we describe that feeling precarious as a hired employee—due to increasing workloads, health risks, poverty and discrimination—

shapes care workers' choice for self-employment. Second, we describe inequities between self-employed care workers who could (financially) afford to turn to self-employment as a health strategy and those who felt squeezed out of the organizations due to poverty or discrimination. They more often dealt with precarious work in the context of precarious lives, negatively impacting their health. Third, we describe how negotiating an entrepreneurial identity with a caring identity required material sacrifices and thus contributed to self-employed care workers' financial precariousness, particularly as women.

Conclusion:

Our findings indicate that working in LTC is becoming increasingly precarious for all care workers, both for hired and self-employed, with younger, lower-paid and racialized women with unpaid caring responsibilities seemingly most at risk for precariousness.

Keywords

Long-term-care, nurses, nursing aides, self-employment, entrepreneurship, precariousness, occupational health, intersectionality, gender, racism

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Introduction

Healthcare workers, such as nurses and nursing aides, care for the health and well-being of individuals, families and communities. Yet, while caring for others their own health might be compromised. In the Netherlands, a postwelfare state that deals with an ageing society, care workers have to attend to increasing care loads with decreasing financial means (Maarse & Jeurissen, 2016). The impact hereof is strongly felt in the long-term care (LTC) sector, which deals with the highest sickness-absence leave and turnover rates of the entire care sector (Ministry of Health, Welfare and Sport, 2020). The Dutch situation is comparable to other European countries that aim to constrain health care expenditures through health care reforms, particularly in LTC. In Western-European countries with an ageing society, tensions arise between the financial sustainability of LTC, the health of paid care workers, and societal support for the policy measures (WRR, 2021). The health of healthcare workers is under pressure, but not for all care workers alike. To understand inequities among LTC workers, we need to unravel the intersecting social determinants of health that shape the health and well-being of care workers in LTC.

In the slipstream of these policy transitions, more and more low-paid care workers in LTC opt for self-employment (Ministry of Health Welfare and Sports, 2020). In the health and social care sector, the number of self-employed workers has grown from 73,700 to 128,600 between 2007 and 2018 (Central

Bureau for Statistics, 2020). Numbers continue to grow. In 2022, the number of self-employed care workers further increased to 168.439 (The Netherlands Chamber of Commerce, 2022). Self-employment is used to predominantly attract higher-paid professionals, such as nurses and doctors (Conen & Schippers, 2019). Nowadays, lower-paid professionals, such as nursing aides, make up a large amount of self-employed care workers (Central Bureau for Statistics, 2020). As a consequence, sectors that employ mainly low-paid care workers, such as residential LTC for older people, are increasingly confronted with self-employed care workers. For them, this is a relatively new phenomenon and the LTC sector struggles with this development (Jakobsen et al., 2021).

What is happening in the LTC sector reflects labour market tendencies on a national level. Self-employment is increasingly becoming relatively common in the Netherlands, compared to other European countries (Central Bureau for Statistics, n.d.) and this growth affects almost all sectors of the labour market (CBS, 2020). The Dutch situation does not stand alone, as the flexibilization of labour markets is a worldwide phenomenon (Kalleberg & Vallas, 2017), but particularly profound in countries that have fostered neoliberal policies in the last decades (Stanford, 2017).

On a societal level, politicians and policy makers debate the desirability of self-employed care work (Ministry of Health Welfare and Sports, 2020). Societal organizations and public health researchers express concerns about the precariousness of self-employed care

workers in the Netherlands (Bodin et al., 2020; Julià et al., 2017; Ministry of Health Welfare and Sports, 2020). Most self-employed care workers do not have social insurance such as retirement pensions and only a small minority (17.8%) has disability insurance (Ministry of Health, Welfare and Sport, 2020). Overall, self-employed workers face a relatively high risk to fall below the poverty line, and this risk appears to be substantially higher for women and racialized groups when self-employed (CBS, 2019). Lorey (2015) conceptualizes precariousness as the lived and subjective experience of being in a socially vulnerable or precarious position. Thus, self-employment is not necessarily precarious but can be experienced as precarious by specific groups of care workers (Conen & Schippers, 2019; Wall, 2015). Yet, little is known about the experiences of self-employed care workers in LTC: who experiences self-employment as precariousness and who does not – and why (Wall, 2015).

Background

In the field of health research, much scholarship revolves around precarious employment and whether or not self-employment is precarious work (Conen & Schippers, 2019; Kalleberg & Vallas, 2017; Kreshpaj et al., 2020). Precarious employment is defined as a combination of employment insecurity, income (in)adequacy and lack of rights and protection (Kreshpaj et al., 2020). From a public health perspective, scholars increasingly recognize precarious work as a risk factor for health, impacting the physical

and mental health of workers and their families (i.e. causation) (Bodin et al., 2020; Julià et al., 2017). And vice versa, people with health problems more often work under precarious conditions (i.e., selection). Generally, scholars identify three links between precarious work and health (Bodin et al., 2020; Julià et al., 2017). First, experiences of uncertainty, unfairness and powerlessness impact workers psychological and physical health. Second, workers in precarious work disproportionately face detrimental physical and psychosocial working conditions; more often deal with discrimination and stigmatization at the workplace, and; lack access to occupational health care. Third, the material deprivation and lack of access to social security contribute to socioeconomic health inequities.

Other scholars argue that the (health) impact of precarious work cannot be understood in isolation from societal context, foregrounding the concept of precarization (Porta et al., 2015; Syed, 2020; Berg, 2021; Lorey, 2015). Precarization refers to the governmental policies by which increasing numbers of people are confronted with precariousness, not only in the labour market but also in all aspects in their lives, including housing and social security. This perspective helps to understand why some workers can mitigate the impact of precarious work in their lives, while others cannot.

Yet, societal debates tend to discuss self-employed care workers as a homogeneous group (Ministry of Health Welfare and Sports, 2020; Commissie Reguleren van Werk, 2020).

This is re-produced by studies among self-employed care workers that do not take intragroup diversity into account (Jakobsen et al., 2021; Burke, 2015). As a consequence, policymakers respond to increasing numbers of self-employed care workers with one-size-fits-all policy measures (Burke, 2015; Commissie Reguleren van Werk, 2020; Ministry of Health Welfare and Sports, 2020). In general, such policies bear the risk of exacerbating inequities, as they tend to underserve those who are most at risk for marginalization (Hankivsky, 2012).

Therefore, we are in need of more diversity responsive research on self-employment of care workers (Burke, 2015; Karatas-Ozkan, 2018). To date, much insightful academic work on self-employment, mostly across employment sectors, has been done from a gender-first or gender-only perspective (McAdam, 2013; Vosko & Zukewich, 2006). Researchers are increasingly adopting an intersectional approach to understand inequities among (self-employed) women (Knight, 2016; Ozasir-Kacar & Essers, 2019; Tao et al., 2021). Also, in the field of occupational health, scholars describe the need for intersectional analytical approaches to understand the complexities of precarious employment, particularly its relation to health (Bodin et al., 2020).

Intersectionality is grounded in a rich tradition of black, queer feminist thought (The Combahee River Collective, 1977). An intersectional perspective aims to understand interactions between social determinants of health, such as gender, class, racialization and age, rather than focusing on single-axis

analyses that fail to account for intragroup diversity (Crenshaw, 1990; Hankivsky, 2012). Intersectionality aims to unravel how people's lived experiences are shaped by the interaction of social determinants of health—and also addresses interconnected systems of power that produce privilege or oppression, such as patriarchy, racism, ableism, homophobia or colonialism (Hankivsky, 2012). Intersectionality helps to understand health and labour market inequities, within and between groups (McCall, 2005). Such a perspective also enables scholars to understand which groups do not profit from current policies, because their experience is shaped at a specific, overlooked, intersection (Purdie-Vaughns & Eibach, 2008).

The study

Aim

To understand self-employed care workers' experiences of precariousness in relation to health, we conducted a qualitative inter-view study (Green & Thorogood, 2018). Our qualitative interview study is in line with a qualitative descriptive study as described by Sandelowski (2000, 2010). This study was conducted with a team of academic researchers and nursing aides, who participated in all phases of the research process (Abma et al., 2019; Wright et al., 2018). We employed an intersectional perspective to understand which (groups of) self-employed care workers are specifically at risk for precarization and why. Such knowledge enables policy makers and health care

organizations to develop diversity-sensitive policies for self-employed care workers who are currently underserved by existing policy measures. We formulated the following research question:

How do self-employed care workers in the residential LTC sector for older people experience precariousness, in relation to health and how is their experience shaped by intersecting factors of gender, class, migration, racialization and age/life phase?

Design

This qualitative interview study was part of a broader participatory health research (PHR) project 'Negotiating Health' (2018–2022) into the health of care workers in residential LTC. The aim of this parent study was to explore how the health and well-being of paid care workers were shaped by gender in intersection with class, race age/life phase, sexuality and (dis)ability, particularly in the light of recent policy transitions and women's overrepresentation in paid care work.

PHR is part of the family of transformative and action-oriented research practices, such as action research or community-based participatory research (Abma et al., 2019; Mertens, 2008; Wallerstein & Duran, 2017). PHR is conducted in the field of health research and aims to 'maximize participation of those whose life or work is subject to the study in all phases of the research process' (Wright et al., 2018). Therefore, this PHR project was conducted by a team of four academic researchers (Duijs, Bourik, Abma and Verdonk) and five community

researchers (Plak, Jhingoeri, Senoussi, Abena-Jaspers and Mazurel) who are experiential experts as paid and unpaid care workers in LTC. Three community researchers worked as (advanced) nursing aide, one as a nurse assistant and one as unpaid caregiver in LTC. PHR is characterized by moral dilemmas and power imbalances. A methodological reflection of our participatory research process is described elsewhere (Duijs et al., 2022).

In the parent study, we conducted several qualitative interview (sub-) studies among hired employees, and among men and women working in LTC, before and during the COVID-19 pandemic. This sub-study particularly focusses on the experiences of self-employed women and was conducted in 2019–2020. The consolidated criteria for reporting qualitative research (COREQ) guided the reporting of the study (Tong et al., 2007). Findings from other sub-studies are published elsewhere (Duijs et al., 2021; Duijs et al., submitted; Wees et al., 2023).

Theory of Science

The parent study 'Negotiating Health' was informed by a transformative and participatory research design (Abma et al., 2019; Mertens, 2008; Wallerstein & Duran, 2017), embracing experiential knowledge as essential for academic knowledge production and by doing so fostering epistemic justice in research (Fricker, 2007). PHR and intersectionality are both social-justice-oriented research approaches, grounded in critical theory (Verdonk et al., 2019; Wallerstein & Duran, 2017). In PHR, knowledge is produced in a

hermeneutic dialogue between different types of knowledge, including academic theories (such as intersectionality) and experiential knowledge (Duijs et al., 2022; Gadamer, 1960).

In the qualitative interview-study presented in this article, we studied participants’ lived and subjective experiences with precariousness, inspired by phenomenology (Denzin & Lincoln, 2011), while not overlooking the material and social circumstances of their’ lives. In our intersectional analysis of their experiences, the academic research team drew upon critical theory to unravel the societal inequities that shaped their lived experiences.

We understand intersectionality as a normative, methodological and theoretical approach to health research (Hancock, 2007). Intersectionality guided our research question, recruitment, data generation and analysis (Duijs et al., 2022; Hunting, 2014; Stuij et al., 2020).

Sample/Participants

Participants of this interview study (Table 1) were recruited through organizations (such as the professional associations for nurses and nursing aides, unions, LTC organizations, support organizations for informal caregivers, migrant organizations and the professional association for self-employed care workers), via social media and via the personal network of community researchers. Initially, we focused on self-employed care workers in residential LTC (i.e. nursing homes), but rapidly realized that many worked across different sectors (domiciliary and residential care) and home-

dwelling clients. Following our intersectional approach, self-employed care workers (N = 23) were purposively sampled across genders, age, occupational level and cultural background/ migrant status (Hunting, 2014). Occupational systems in LTC differ across countries. In the Netherlands, nursing aides (level 2) and advanced nursing aides (level 3, also: certified nursing aides) make up the majority of the LTC workforce and are both low-paid occupations (Tuinman, 2021; cf. van Wieringen et al., 2022). Based on our first analysis of 10 interviews, we initiated a theoretical sampling (based on intersectionality) to specifically include and explore the perspectives of care workers of colour, single mothers and older women in more depth, as their experiences appeared to be distinctly shaped. In Table 1, we present care workers self-identified cultural identity. In the interviews, their cultural identity did not emerge as a theme, but participants did emphasize the importance of racialization as a consequence of their skin colour (being seen as ‘white’ or ‘black’), which we describe in our findings.

We included participants until we had sufficient evidence to describe the diversity and inequities among female self-employed care workers and how these played out according to gender, class, ability, age, sexuality and race (i.e., data saturation). Experiences of nursing aides (level 2) remain relatively underrepresented in our sample, due to time constraints (i.e. data saturation did not occur in relation to their experiences).

Table 1: Participant Characteristics

R	Age	Household	Minority/Majority	Profession ****	Domiciliary Residential	Unpaid caring responsibilities	Location Interview	Interviewer
R1	42	Married*	Dutch Majority	NA (2)	R	Children (2)	Home	SD
R2	50+	Divorced, partner*	Dutch Majority	ANA (3)	D	Children*** (2)	Work	SD
R3	37	Married*	Antillean-Dutch	ANA (3) + MSc.	R/D	Children (3), mother (Curacao)	Public location	SD
R4	58	Divorced*, Single	Dutch Majority	ANA (3)	R/D	Father**	Home	SD
R5	52	Married*	Dutch Majority	ANA (3)	R/D	Children*** (4)	Home	ZB + YJ
R6	50+	Married*	Dutch Majority	ANA (3)	R	Children*** (4), mother	Home	SD + YJ
R7	58	Married*	Dutch Majority	ANA (3)	R	Mother, grandchildren (2)	Home	ZB
R8	40	Married*	Moroccan-Dutch	NA (2)	R/D	Children (3), 2 with disability	Telephone	ZB
R9	61	Divorced*	Dutch Majority	N (4)	R	Children***, father	Home	SD + OP
R10	60	Single	Surinamese-Dutch	NA (2)	R	Parents	Public location	SD
R11	36	Single	Antillean-Dutch	ANA (3)	R/D	Children (2), 1 with disability	Home	SD
R12	+/- 30	Single	Cameroon-Dutch	ANA (3)	R/D	Child (1)	Telephone	SD
R13	39	Unknown	Surinamese-Antillean-Dutch	ANA (3)	R	(undisclosed)	Telephone	SD
R14	60	Divorced *	Antillean-Dutch	ANA (3)	R	Children***, parents	Telephone	SD
R15	70	Married*	Dutch Majority	ANA (3)	R/D	Grandchildren	Home	SD
R16	55+	Divorced, re-Married*	Dutch Majority	N (5)	R/D	Children***, mother**	Public location	SD
R17	37	Married*	Dutch Majority	N (4)	R/D	Children (2)	Home	ZB
R18	64	Married*	Surinamese-Dutch	N (6)	R/D	No	Telephone	SD
R19	33	Single	Surinamese-Dutch	NA (2)	R	Children (2)	Telephone	ZB
R20	30	Married*	Moroccan-Dutch	ANA (3)	R	Parents in law, child (1)	Telephone	ZB
R21	50	Partner*	Dutch Majority	ANA (3)	R	Parents in law**	Telephone	SD
R22	28	Single	Moroccan-Dutch	ANA (3)	R/D	No	Telephone	ZB
R23	58	Single	German-Dutch	NA (2)	R	Children*** (4)	Telephone	ZB

* Heterosexual

** Passed away

*** Mature children

**** NA: nurse assistant, ANA: advanced nurse assistant, N: nurse.

Data-collection

Semi-structured interviews were conducted by an academic researcher, sometimes accompanied by a community researcher. The community researchers were could not always join the interviews, due to time constraints or changing work schedules, and later on, due to the COVID-19 pandemic that severely impact their work and lives. In line with our PHR approach, the topic-list for this study was developed with and by the community researchers who identified themes and topics that were relevant to them during a 6-month photovoice project that was conducted prior to this qualitative study (Duijs et al., 2022; Wang & Burris, 1997). Topics included balancing paid and unpaid care work, financial concerns, age-related health issues, such as menopause, and health strategies of care workers while working in LTC. During the photovoice process, the community researchers made a poster displaying these themes, supported by their own photographs. This poster was used during the interviews as a conversation tool and to allow participants to set the agenda using the following question: 'If you look at this poster, is there a theme that resonates with you? What do you think is important to talk about during this interview?' A topic list with open questions was developed to probe on different sub-themes on the poster. The interviewers were trained in intersectionality and probed on participants' intersectional experiences during the interview (Hunting, 2014).

Face-to-face interviews were conducted across the Netherlands, between May 2019 and March 2020, and by telephone from

March 2020 to May 2020 when the COVID-19 pandemic set in. Interviews lasted between 54 and 118 min, most of them lasted approximately an hour. Interviews were recorded and transcribed ad verbatim. Data was securely stored at the internal drive of Amsterdam University Medical Centre. This study focuses on experiences of self-employed care workers before the pandemic. Interviews were conducted in Dutch and translated by the first author. Member checks were conducted by feeding back summaries of the interviews when participants indicated that they would appreciate that, which was done by one participant. Most participants indicated that they rather received a summary of our study findings, which was presented to them in a factsheet.

Ethical considerations

This study was evaluated by a Medical Ethical Review Committee which confirmed that the Dutch Medical Research Involving Human Subject Act did not apply. Transcripts were anonymized and audio-tapes and transcripts are stored anonymously and will be archived until 5 years after the completion of the study. Informed consent forms were explained orally and a copy was handed to the participants. Participants signed informed consent forms which are securely stored at Amsterdam University Medical Centre.

Data Analysis

Data generation and data analysis were done iteratively and collectively. First, data was discussed in monthly— audio recorded and transcribed verbatim—dialogue meetings

with the research team, including the community researchers. Newly emerging topics, such as experiences of racism, were added to the topic list. Second, the first author conducted an inductive thematic analysis using MAXQDA, guided by the last author, following a process of open, axial and selective coding (Braun & Clarke, 2006). This coding process yielded several descriptive themes but lacked sensitivity to diversity and inequities among participants. Therefore, third, after the thematic analysis, we (Duijs and Verdonk) applied an intersectional perspective to deepen our understanding of the ways these experiences were shaped at the intersections of gender, class, race, migration status, disability and age (Crenshaw, 1990; Hankivsky, 2012). This intersectional coding process was informed by two practical guides on (secondary) intersectional analysis in qualitative research (Hunting, 2014; Stuij et al., 2020). This analysis enabled a more in-depth understanding about the societal inequalities that became visible in interviewees' experiences. An overview of the themes with intersecting aspects that shaped workers' experience is presented in Table 2. Findings were discussed with the academic research team until we agreed on the themes that are presented in this article. The outcomes from this second and third round of analysis were discussed with the community researchers, who validated our findings. We discussed our analysis with the community researchers, but their participation in this analytical phase was relatively limited when compared to earlier phases of the research process. The community researchers were not involved in the writing of this article, as writing and reading

academic articles in English provided too big a barrier for them to participate. However, the findings were discussed with them and they agreed with the content of this article.

Rigour

We employed the following strategies to enhance the quality and rigour of our study (Frambach et al., 2013; Green & Thorogood, 2018). The study was conducted with a team of multiple academic and community researchers. Intensive dialogue about the findings contributed to the credibility of our study. At the request of our participants, we conducted member checks on our study findings by sending a summary of preliminary findings and requesting feedback. The maximum variation sampling strategy enhanced the transferability of the findings and supported our aim to do justice to the diversity among our participants. Data generation and analysis were done iteratively and impacted following interviews. We continued until we reached data saturation, which supports the dependability of our findings. Findings were discussed with societal organizations in steering group meetings and in individual conversations with a representative of a professional association for self-employed care workers. Their reflections validated our findings as well, which contributed to the confirmability of our study. But most of all, the input and reflections of the community researchers have contributed greatly to the quality of our study, as their lived experiences guided our attention to themes that otherwise would have remained brushed under the carpet, such as racism, poverty and menopause.

TABLE 2. Themes and intersections

		Sub-subtheme	Intersections:	
Opting out	A care sector under pressure	devaluation of care work	gender	
		a sense of alienation	age	
		re-allocation of care responsibilities to lower professional levels	class	
	Health risks	burn-out	(dis)ability	
		lack of access to disability insurance	age class (dis)ability	
		exploitation of one's health	gender age class (dis)ability	
	Poverty and fear of debts	financial precariousness	gender age class marital status	
		financial risks of flexibility	gender age class marital status	
		child benefit scandal	race	
	Informal care responsibilities	combining paid and unpaid care work	gender	
		motherhood	gender age	
		informal care giving to children with a disability	gender age disability	
	Menopausal transition	transition into a more masculine identity	gender age	
		becoming older	gender age	
	Ageism in the workplace	work-related health issues	age (dis)ability	
		less access to career opportunities	age class (dis)ability	
		everyday racism within care teams	race	
		institutional racism	race	
	Inequities among self-employed care workers	Shortages of staff	labor market privileges for ANA (level 3) c/t to NA (level 2)	class
		Privileged lives	pre-pensions	age class
low housing costs / paid off mortgages			age	
heterosexual marriages			gender marital status sexuality	
opting out of disability insurances			gender age class (dis)ability marital status sexuality	
impact of divorce			gender class marital status race	
Precarious lives		precariousness of being a breadwinner on paid care work / poverty	gender age class marital status race	
		unaffordable housing	class age	
		working while sick	gender class (dis)ability marital status	
		racialized inequities	race class marital status	
Gendered negotiation acts	Framing work	distancing from masculine-typed entrepreneurial values 'not doing it for the money'	gender class	
	Investing own resources into one's care work	time	gender class	
		money	gender class	
		expertise	gender class	
	Caring identities as a privilege	silencing and condoning financial motives	gender class race	

Findings

Participants in this study worked as self-employed nursing aides (N = 5), advanced nursing aides (N = 14) and nurses (N = 4). They ranged from 37 to 70 years of age and consisted of individuals from Dutch majority groups (that is, white women with a Dutch nationality) and Dutch minority groups (that is, who self-identified as bi-cultural and/or as a women of colour). Participant characteristics are described in Table 1.

We describe our empirical findings in four parts. First, we describe how experiences of precariousness as a hired employee within LTC organizations shape care workers' choice for self-employment. Second, we describe how opting for self-employment is shaped by gender, class, race and life phase, illuminating differences among self-employed care workers. In the third section, we describe how self-employed care workers negotiate a 'masculine-typed' entrepreneurial identity with their caring identity as women, which contributes to precariousness, particularly as female self-employed care workers.

Opting out: The precariousness of being a hired employee

Participants foregrounded their experience of the precariousness of working within LTC organizations. Many participants experienced working as a hired employee as riskier in terms of health, finances or well-being, compared to being a self-employed care worker. Others experienced a lack of a healthy psychosocial working environment as a consequence of

gender, race and age-related discrimination in LTC organizations. They opted for self-employment to deal with these experiences of discrimination and exclusion. We will illuminate these experiences in more detail below.

A care sector under pressure

All participants framed their choice for self-employment against the backdrop of a care sector under pressure. Older participants expressed a sense of alienation as they witnessed their work change over the years, with increased bureaucratic loads and decreasing time for clients. Some participants even felt increasingly unable to live up to their own professional and/or personal standards of care as a hired employee, due to recent budget cuts and shortages of staff. Witnessing incidents in which quality of care was compromised urged them to take action:

Right there and then, I decided that I didn't want to be belong to that club anymore. I mean, you can go to a different organization, but it is the same story everywhere. The problem is bigger. So, I literally stepped into my car and drove away. (...) That same afternoon I registered myself as a self-employed. (R21)

Health risks of being a hired employee

Many participants experienced precariousness in terms of health as a hired employee. For many participants, working in residential LTC came at the expense of their own health and well-being. Several participants opted for self-employment after experiencing a burn-out, or to prevent one. The increased

autonomy of self-employment allowed care workers to employ health strategies that were unavailable to them as hired employees. Self-employment also enabled them to disconnect from institutional moral appeals, as it provided the 'emotional distance' necessary to set boundaries.

I: Is it easier to say no as a self-employed? R1: Yes, sometimes. If you are a hired employee then you are constantly asked to fill in shifts. (...) As a self-employed, I just check a (digital) schedule and choose shifts whenever I can, at a location like. I: So, the pressure is less, because you are in charge? R1: Yes, definitely. (R1)

Self-employment was a health strategy, not so much of a choice, rather a necessary evil to sustain, protect and maintain their health. A participant described how she could not afford a disability insurance as the costs were relatively high due to her age and medical history. Yet, she emphasized that the risk of financial adversity as a self-employed felt less precarious compared to the risk of getting ill (again) as a hired employee.

I am convinced I would get sick. In my opinion, the problem is bigger. It feels as if I have no other options left. It is not even a choice to become self-employed. It is a survival strategy. (...) Being self-employed is the best disability insurance I can imagine. (R16)

In addition, several, particularly younger, participants expressed anger and frustration about how austerity measures and budget cuts came at the expense of their health and

well-being. Self-employment can thus also be understood as a protest against these health risks:

You don't earn much and your health is ruined. (...) While at the other hand, there are care organizations making money (...). So, when I think about the future, I know that I cannot do this job for another 20 years; it is just too hard. And if do, I do it for myself. As a self-employed, at least I am the one making some money out of it. (R22)

Poverty and fear of debts

Many, younger and single women, particularly single mothers, pointed out that they felt at risk of ending up in (financially) precarious situations as a hired employee. They could not make ends meet as a hired employee and used self-employed care work to earn more money. Others described the financial risks of having to be 'flexible' as a hired employee:

A as single mother I am responsible for all our finances. As a self-employed, I can make sure that the costs for my children's daycare are stable. That is a big difference with the time when I was a hired employee. My employer often changed my shifts, required me to work an extra day or cancelled a shift. Then you are confronted with retrospective repayments. (R11)

Her fear for retrospective payments has to be understood in the context of the Dutch tax system in which people receiving childcare allowance are confronted with retrospective repayments if they have worked irregularly,

which puts them at risk for indebtment. This fear was amplified by the recent child benefits scandal in the Netherlands, that unjustly indebted 10,000 of families, particularly those of colour, receiving childcare allowance (House of Representatives, 2020).

Informal caring responsibilities

Several female participants opted for self-employment to attend to their informal caring responsibilities, for their parents or grandchildren, for their children or for both. Several younger women experienced troubles combining work and motherhood as hired employee, and turned to self-employment as a solution. Often, human resource policies in LTC organizations require flexibility from hired employees, especially in the context of shortages of staff. As a consequence, many felt pressured to be available for work 24/7, without adequate support to organize paid work around informal caring responsibilities:

I have three children and two of them have special needs. Care organizations are simply unable to organize my shifts around their care needs. They would schedule my shifts day and night. I cannot go and request for an exception every time. As a self-employed, I have control over my schedule. (R8)

Attending to unpaid caring responsibility was uniquely challenging for care workers with a migration background. Transnational caring responsibilities required them to travel for longer periods abroad, yet they were not always granted their right for longer holidays as a hired employee:

I've always known, I might be born here, but I am not seen like that. I know I am entitled to six consecutive weeks of holiday, but then my colleagues look at me like: 'the summer is the most difficult time in the care sector. What is she thinking? Going on a holiday, not just for three weeks like the most of us, but for four of five.' As a self-employed I can just decide how long I go. (R3)

The role of menopausal transition

Several mid-aged participants connected their choice for self-employment to their experiences as (post-) menopausal women. Menopause-related physical complaints such as fatigue, burn-out or increased weight made their health concerns more pressing. More importantly, several women narrated how menopause induced a more spiritual and psychological process which made them reflect on their lives and work. Some participants described menopausal transition as becoming more 'masculine' as they started to question their caring identities as women that required unlimited attention to other people's needs, and they increasingly allowed themselves to foreground their own needs.

You become a little more indifferent. (...) You become a little bit more like a man, they have said to me. Well, maybe it is true. I think at least I started to be more relaxed and confident. I: It was the time you started to address issues at work and decided to opt for self-employment. (...) R: Yes, but still, you can never really tell if it was menopause or just all the negative stuff that happened. (R4)

Others linked this process with getting older, and increased trust in their own knowledge and expertise as an experienced care worker. As a consequence, they found it more difficult to fit into hierarchical LTC organizations which appealed to their caring identities, while lacking participation and voice over their working conditions:

Forty was my turning point. At that point I said: I'm done. I want my life to be different. (...) I see that happening around me very often. You are more or less at halfway your lifetime. That's how it feels. And then you look back and think: am I content? Am I enjoying my life? Am I happy? In my case, the answer was: no, no, no. At that point, I realized that things needed to change. And yes, the hormones definitely played a role in that process. (R2)

Ageism in the workplace

Older participants, in their 60s and, with work-related health issues, shared how they felt treated as a financial risk by their employers, felt pushed into unemployment benefits or early retirement by their superiors, or were denied career opportunities. They turned to self-employment to continue their career as a paid care worker.

I was more or less kicked out because of my age. That's kind of how things started. I really loved my job and I cried because I had to go. And then I found myself sitting at home, knowing that there were shortages of staff. It just tugged at me. And then they asked, why don't you join our team as a self-employed. (R15)

Racism in the workplace

Participants of colour mentioned experiences of racism in LTC institutions as a key factor that pushed them out of the institutions into self-employment. Remarks, jokes, lack of support or trust from colleagues and managers were experienced as most painful, and played a big role in their decision to opt for self-employment:

The work in itself is hard enough, you know. And then you add colleagues who ... Well, no, I would not go back to being a hired employee, because of this racism thing (R13)

Some participants were hesitant to frame their experiences as experiences of racism and several initially framed it as 'fuzz within the teams' (R12) to the white interviewer of this study (first author). Other participants were very outspoken about the racism that they experienced at the workplace and how it informed their decision. Self-employment provided emotional and practical distance from racism within organizations:

It was the way my colleagues treated me (...) Look, as a self-employed you just do your work, and you don't like it there, you just never go again. (R3)

Lower-educated care workers of colour mentioned how they lacked access to career opportunities as a hired employee. One participant, for example, shared how her white colleagues obstructed her education, which caused her to leave hired employment straight after graduation. Self-employment enabled

renewed access to career opportunities, as they could invest in their own education enabled by tax rulings for freelancers.

The organization was all white and they just gave people of color a hard time. Afterwards, one colleague said to me: I am surprised that you managed to get so far. Most people of color don't make it here. (...) The moment I graduated, I literally ran to the chamber of commerce. I was so tired of it all. (R13)

In the light of institutional racism in care organizations, for example in organizations where higher-paid managers are predominantly white and lower-paid workers are more often of colour, some participants also expressed how institutional demands for 'flexibility' and 'availability' were laden with colonial history:

In my head the dynamic resonated with colonial history and slavery. There is the master, and here is the slave. I was thinking that I should just create my own job, and bring it to work. To make all of that black-and-white stuff stop. (R10)

Inequities between self-employed care workers in terms of precariousness

The experiences of precariousness, particularly in terms of financial security, differed strongly among self-employed care workers. In this section, we describe if, and if so, how participants in our study experienced privilege or precariousness as a consequence of being self-employed. We describe how self-employment can translate into taking health care risks for those without financial buffers.

Experiencing privilege in the context of shortages of staff

Most participants did not opt for self-employment lightly, and carefully considered the potential precariousness of self-employed work. They referred to current shortages of staff in the sector that would ensure them access to sufficient work. This privilege was felt slightly more strongly by the higher-educated care workers but expressed across different levels. Although some participants referred to major budget-cuts and lay-offs in the (recent) past, they did not expect that this would happen again in the near future.

If you don't have work for a week, then you are in trouble. Well, a week without work? That might have happened a few years back, but that is not happening anymore. Right now, people are waiting in line for you. I am sure I am able to continue like this until my retirement age. (R7)

Negotiating 'precarious work' with 'privileged lives'

The older (60+), often white, participants in our study did not perceive self-employment as precarious work. In relation to the first theme, these women were mainly pulled to self-employment to enhance their work pleasure or as a health strategy and could afford to do so. They could fall back on the pre-pensions they built up as a hired employee, or had paid off mortgages over the course of their working lives. Others, relatively younger (40–50), also often white women in a heterosexual marriage, emphasized how they were privileged as they were married to men who held secure jobs.

In several occasions, it was these men that motivated them to opt for self-employment in the first place.

I have my husband. He was the one who pushed me into self-employment in the first place. Because, well, he had everything on track, of course (R5)

They perceived self-employment as low-risk, as they could ‘afford to get ill’. Their perception of being in a privileged position as women, materialized in opting out for unemployment insurances:

We don’t rely on my income for our mortgage. My husband takes care of that. So, in case I would get sick or anything, we don’t have to worry a bit. (R7)

Although this was experienced as a privilege, their financial dependency as women was under threat. This was felt by self-employed care workers who opted for self-employment during marriage or a relationship, but lost privilege when they divorced or separated. For them, self-employment became more precarious.

Negotiating ‘precarious work’ with ‘precarious lives’

Experiences of precariousness were mainly expressed by single self-employed care workers who were breadwinners for themselves or their families. In relation to the first theme, these women were squeezed out of the organizations due to poverty, informal caring responsibilities or experiences

of racism. Several younger participants expressed how they negotiated precarious work with precarious lives, for example by pointing towards increasingly unaffordable housing. For single women, being financially responsible as a self-employed care worker translated into health risks. Several participants indicated that they overburdened themselves to save up for difficult times. This participant for example indicated that she continued to work while sick to save up for a period of recovery after an operation:

As self-employed you do feel like to have to work a lot, to make sure that you have a buffer to fall back on. Because, you never know what might happen tomorrow. (R9)

Single mothers who were financially responsible for their families described how they regularly continued to work while sick, and also described how they sacrificed their health for financial reasons:

Only If I have no other option left, then I will call in sick. That is really hard for me. Sometimes at work I do feel like ‘I shouldn’t have done this’. But usually, when I am working, I just keep going so you don’t feel anything. But when I have a day off, I find myself lying on bed all day doing nothing. That’s when I feel it. I can just sleep all day. (R11)

Other self-employed care workers pointed to the structural aspect of this inequality and pointed out that white women were more often in the position to ‘afford to get ill’, while women of colour less often had access to this privilege:

Well, many white women, they consciously choose for self-employment. Many of them have a husband at home that takes care of everything, and they can just free-wheel as an entrepreneur. They sometimes say to me, I am happy if I can make around 1000 euros a month as a self-employed. Then I am like, that is a privilege. Because, single women with two children, they do not make it with 1000 euros a month. You have your children to feed and maybe even family abroad that you need to sustain. That is a different story. (R3).

Gendered negotiation acts contributing to precariousness

Many participants struggled to negotiate a ‘feminine-typed’ caring identity with a ‘masculine-typed’ entrepreneurial identity. This negotiation act required framing work, and manifested as making financial sacrifices to foreground their caring identity. This negotiating act thus contributed to their precariousness, particularly as female self-employed care workers.

Framing work: Distancing yourself from entrepreneurial values and foregrounding a caring identity

Self-employed care workers in our study expressed frustration over the way they have been framed in policy documents and mainstream media. In response, several of them explicitly distanced themselves from the idea that care workers choose self-employment for ‘economic’ or ‘selfish’ reasons. In doing so, they distanced themselves from a more ‘masculine-typed’, profit-oriented, entrepreneurial identity, by foregrounding their caring identity:

‘Believe me. I have spoken to a lot of self-employed, and no one says that they are doing it for the money’. (R3)

Investing own time, money and expertise
A caring identity is performed through making financial sacrifices, such as doing unpaid care work for clients:

Well, if I earn less, then I earn less. If I stay an extra hour, then it is my own time and my own decision. Who cares? It is not costing anybody anything. So, what am I worrying about? It is fine by me. (R2)

Some women invested expertise that exceeded their job description, providing higher quality care for lower tariffs. Others lowered their tariffs, or did not bill all their working hours, out of loyalty to LTC institutions:

I know how it works. So, if I would say, I want to earn a lot of money, I know that someone is paying the price for it. I mean, if a care organization does not want to go bankrupt, it needs to break even. (...) Yes, I feel responsible. I don’t need to be paid a high tariff at the expense of someone else. (R16)

As a consequence, participants ended up trading an exploitative institution for a system of self-exploitation. They opted for self-employment to disconnect from institutional moral appeals, but quickly realized that they were unable to escape their own caring identity.

Foregrounding a caring identity is a privilege

This was mainly done by self-employed care workers who negotiated precarious work with privileged lives, they could afford to foreground their caring identity. Within this frame, financial motives to opt for self-employment were (implicitly) silenced and sometimes even condoned, reproducing the stigma on those self-employed care workers who opted for self-employment due to poverty or experiences of racism:

There are a few bad seeds who are in it for the money, but they are ruining it for the rest of us. (R5)

Discussion

In our empirical findings, we have described self-employed care workers experiences with precariousness in three themes. In the first theme, we describe how self-employed care workers experience precariousness as a hired employee due to increasing workloads, health risks, poverty and experiences of (gender, race and age-based) discrimination, and that they negotiate the precariousness of being a hired employee with the precariousness of being self-employed. In the second theme, we describe inequities in precariousness between self-employed care workers who could (financially) afford to turn to self-employment as a health strategy, and those who felt squeezed out of the organizations due to poverty or discrimination and had to deal with precarious work in the context of precarious lives. In the third theme, we describe how

self-employed care workers negotiate their feminine-typed caring identity with their masculine-typed entrepreneurial identity. For women, this negotiation act translates into making financial sacrifices to foreground a caring identity, contributing to their precariousness, particularly as female self-employed care workers. This gendered ideal of 'not doing it for the money' was not equally attainable for women who were financially dependent upon their care work.

Precarization

Our empirical findings resonate with theoretical perspectives on precarization. The mere fact that participants in our study experienced being a hired employee as precarious, and sometimes even more precarious than being self-employed, illustrates that precarization impacts all spheres of the labour market, including the work of hired employees in permanent contracts (van den Berg, 2021; Porta et al., 2015). Our empirical findings show precarious work is to be understood in the context of increasingly precarious lives, resonating with Porta (2015, p.2) who describes that: 'precarization is not (...) limited to the labour market but can penetrate entire lifeworlds of individuals and groups of people'. Our empirical findings illuminate the inequities among self-employed care workers.

Our empirical findings particularly illustrate inequities between self-employed care workers who can afford to turn to self-employment to enhance their work pleasure and health, and those who feel

squeezed out of the organizations due to poverty and discrimination. The relatively low financial reward for care work shaped at the intersection of gender and class (Bhattacharya, 2016; SER, 2021) and the fact that care workers opt for self-employment due to poverty is a classed inequity. Experiences with poverty and financial precariousness were more pressing among nursing aides in our study sample, in comparison to the nurses. This might explain why most studies on entrepreneurial nurses pay little attention to financial precariousness (Jakobsen et al., 2021; Neergård, 2020; Wall, 2015). Experiences with financial insecurity also intersected with age. Older care workers described health issues for instance menopausal complaints, age discrimination and lack of career opportunities, which contributed to their precarization as older women in the labour market. In relation to housing, older women more often described that they had the security of paid-off mortgages, while the younger generation struggled with unaffordable housing due to governmental housing market policies (Hochstenbach, 2022).

Studies on women entrepreneurs also describe that those pushed into self-employment tend to be more economically precarious than those pulled into it (Ahl & Marlow, 2021; Vosko & Zukewich, 2006; Wall, 2015). Yet, literature on the so-called 'push' and 'pull' hypothesis show that such individual choices for self-employment have to be understood in the context of political and organizational policies, because: 'Some pull factors, such as such as independence

and flexible working hours may, in fact, reflect the push posed by eroding working conditions and job quality as well as work-family considerations. For example, waged work might be unsuitable because of the lack of child-care, flexible hours or the absence of workplace policies that take into account the responsibilities of workers outside the labor force' (Vosko & Zukewich, 2006, p. 70).

The role of gendered policies

In the Netherlands, the LTC sector was confronted with major budget cuts and health policy reforms in 2015. Budget cuts were enacted through two policy acts that aimed to re-allocate caring responsibilities from higher to lower professional levels, and from formal caregivers to informal caregivers (Maarse & Jeurissen, 2016). In the Netherlands, societal organizations have voiced critique on these policy measures, as they would increase gender inequity (Schenk, 2013). These policy measures form the backdrop of our empirical findings, as it impacted care workers paid and unpaid care work. Paid care workers had to attend to more and more complex caring responsibilities at work. These policy measures also impacted their unpaid care work, as female care workers carry a disproportional large amount of informal caring responsibilities at home compared to the entire working population (De Boer, 2017; Schenk, 2013).

In our empirical findings, we recognize that care workers struggle to combine their paid care work with unpaid caring responsibilities as a family caregivers or mother. This resonates with other recent studies that describe how

women turn to self-employment as a strategy to resolve their work/life conflict (Bari et al., 2021; Neergård, 2020). Our empirical findings illustrate that these policies indeed contribute to the precariousness of care workers, particularly for those with informal caring responsibilities, such as young mothers and older women who take care of their parents.

Gendered ideologies of women's caring identities contribute to precariousness

So, while these policies contribute to women's precarious position on labour market, our empirical findings also show that women are at risk for precarization due to gendered ideologies. Our findings on gendered negotiation acts of self-employed care workers (theme 3) resonate with other studies among self-employed care workers (Anderson & Hughes, 2010; Jakobsen et al., 2021; Nadin, 2007; Neergård, 2020). These studies describe how self-employed care workers, particularly low-paid nurses and nursing aides, are guilty for profit-making, implicating that 'doing it for the money' threatens their caring profession. Nadin (2007) refers to the 'moral precariousness' of building a business on caring, as through the commodification of the caring needs of vulnerable others, they thus risk betraying their own gendered values that construct caring as 'natural and willingly given' (2007, p. 465).

Our study adds to these insights by showing how these 'moral' tensions materialize into making financial sacrifices to foreground their caring identities, exposing how these 'gendered ideologies of care' contribute to the

precarization of self-employed women working in the (long-term) care sector. So, while poverty is a classed/gendered issue squeezing paid care workers into self-employment, gendered ideologies consequently reproduce gender/classed inequity among self-employed care workers.

Racism and racialized inequities

In our empirical findings, we illuminate the distinct experiences of women with a migration background, who face specific challenges in regards to transnational caregiving, and those of racialized women who opt for self-employment to escape racism in LTC institutions. We described how younger, single and racialized care workers are more likely to experience precariousness as a self-employed care worker, and self-employed care workers themselves emphasized that there is a racialized inequality at play here.

Their analysis is backed up by statistics. In the LTC sector, also in the Netherlands, lower-educated care work is often done by racialized women (Syed, 2020). So, throughout our empirical findings, there is a strong, but often implicit, class/race intersection at play. This class/race intersection often remains hidden as gendered dynamics tend to be more explicit and visible. The fact that racialized women are pushed into self-employment by experiences of racism, is a novel insight from this study. Racialized dynamics tend to stay hidden for white researchers and white policy makers. They are hardly mentioned in political debates and policy papers on labour-market challenges in the LTC sector (Commissie

Reguleren van Werk, 2020; Ministry of Health, Welfare and Sport, 2020). None of these analysis mention racism as an important issue. Recently, The Black Lives Matter movement in the Netherlands succeeded in getting racism, also in healthcare, on the public and political agenda. Since then, studies have been initiated into care workers experiences with racism. Yet, awareness on racism has yet to trickle down into debates on labour-market dynamics and self-employment.

The added value of an intersectional perspective

In our findings, we illuminate self-employed care workers experiences with precariousness. We illuminate the inequities between self-employed care workers, particularly raising attention for the pivotal role informal caring responsibilities, poverty and racism play in precarization of particular care workers. These are novel findings of our study. While most studies and policy reports regard self-employed care workers as a homogenous group, our empirical findings stress that they are not. And popular conclusions about self-employed care work, namely that they are pulled to the freedom of self-employment and are 'not doing it for the money' are obscuring the harsh reality that some do, and have to do so in order to sustain themselves and their families. Employing an intersectional perspective helped us to unravel inequities among self-employed care workers and fosters a thorough understanding how their choices are shaped at the intersection of gender, class and race. This enabled us to pay attention to 'intersectional invisible' groups among self-

employed care workers who are overlooked by researchers and policy makers (Purdie-Vaughns & Eibach, 2008).

Strengths and Limitations

In this study, we included a diverse population that allowed us to understand inequities between self-employed women in LTC. This study did not address the experiences of men working as self-employed care workers, which were distinctly different and were thus described elsewhere (Wees et al., forthcoming). Our findings cannot be transferred to all care workers in LTC, as we explicitly aimed to pay attention to particular groups of self-employed care workers that are currently overlooked in studies or policy papers. Our study aimed to explore experiences of low-paid care workers, but our sample consisted for a large part of advanced nursing aides and nurses. This might have caused an underestimation of the inequities among self-employed care workers and the role poverty plays in the choice for self-employment. The experiences of nursing aides and lower-paid colleagues in LTC require more attention, as experiences of poverty among paid care workers is a pressing societal issue in the Netherlands and elsewhere, that has been exacerbated by the COVID-19 pandemic and by increased costs for living due to the current inflation (Duijs et al., 2021).

Conclusion

We conclude our discussion by offering suggestions for diversity-sensitive policies that specifically serve self-employed care

workers that suffer from this ‘intersectional invisibility’. Our findings indicate that self-employed women working within the LTC sector, and especially the single, younger, lower educated and racialized women with unpaid caring responsibilities, are at risk of precarization. Healthcare institutions should therefore include anti-racism as a strategy to foster ‘sustainable employability’ of care workers. Governmental policy makers have to reflect upon conflicting policy aims, that bear the danger of squeezing women between having to be available as a paid caregiver (in long-term-care institutions) and having to attend to growing moral appeals on unpaid care (for older people). Our findings urge policy makers to develop policy responses that especially serve the younger, lower educated and racialized care workers in our LTC institutions by creating jobs that allow for financial independence, to particularly support single mothers to sustain their families while working in LTC.

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CHAPTER 6

Pushed to the margins and stretched to the limit

Experiences of self-employed care workers during the COVID-19 pandemic

Abstract

Introduction

Eldercare professionals engaged in precarious work in the Netherlands faced shortages in personal protective equipment (PPE), testing, and staffing during the COVID-19 pandemic. This qualitative study of the health, financial situations, and paid and unpaid caring responsibilities of freelance eldercare workers illustrates how labor market inequalities have been (re)produced and exacerbated during the pandemic.

Design

A qualitative interview study was conducted with self-employed care workers (N=23) during the pandemic.

Data was initially analyzed using thematic analysis. In the second step, we applied an intersectional perspective to understand how the initial topics were shaped by gender, class, ethnicity, disability and age.

Results

Freelancers were pushed toward the margins of the labor market, working risky shifts and compromising their own interests, while unprotected by organizations, social security, or political efforts. Consequently, these workers were stretched to limits where they could no longer attend to their own health or to their paid and unpaid care responsibilities.

Discussion

The study places these empirical findings within Nancy Fraser and Rahel Jaeggi's

theoretical work on capitalism, illustrating how eldercare workers found themselves at the center of boundary struggles during the pandemic.

Keywords

Precarious work, COVID-19, intersectionality, capitalism, labor market inequality, elderly care

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Introduction

In the Netherlands, just one month after the first COVID-19 patient was identified, 13,884 paid healthcare workers had tested positive for SARS-CoV-2, of which 458 were admitted to the hospital (National Institute for Public Health and the Environment [RIVM] 2020). People with migration backgrounds, those living in nursing homes, and healthcare workers were overrepresented (Kunst et al. 2020). Studies show severe physical and psychological impacts on health professionals caring for COVID-19 patients (Lai et al. 2020). The impacts are particularly severe for women, who comprise the vast majority of paid and unpaid caregivers, and as a consequence face considerable unprecedented dilemmas in

balancing health, work, and family care (Li et al. 2020; Beroepsvereniging Verpleegkundigen & Verzorgenden Nederland [V&VN 2020]).

These are not ‘just’ personal dilemmas. Structural inequalities of gender, class, age, and race have been exacerbated during the pandemic and the following corona crisis and illuminate existing labor market inequalities (Bhala et al. 2020; Kabeer 2020; Wenham, Smith, and Morgan 2020). Social disadvantages at the intersection of gender, race, age, and class mutually constitute each other, and to understand the experiences of different people during the COVID-19 pandemic, an intersectional perspective is essential (Verdonk et al. 2019; Hankivsky and Kapilashrami 2020). Intersectionality urges scholars to analyze how individual experiences are shaped at the nexus of race/ethnicity, gender, class, age, and disability/ability, and it aims to foster an understanding of how these intersections occur within connected systems of oppression, such as racism, ageism, patriarchy, and capitalism (Fraser and Jaeggi 2018).

Theoretical analyses made in the slipstreams of previous pandemics show how in the heat of a pandemic structural inequalities shift out of focus in favor of urgent biomedical needs. This disproportional focus on ‘urgent’ and ‘essential’ care needs has been called ‘the tyranny of the urgent’ (Smith 2019), and ‘urgency’ is shaped by existing power differences and hierarchies within the healthcare sector (Watts 2015). For instance, the gendered, classed, and racialized hierarchy between ‘cure’ and ‘care’ became prominent during the corona crisis. One example

of this hierarchy is how intensive care units were favored in terms of finances and personal protective equipment (PPE), whereas the long-term care sector suffered from shortages of PPE and lack of access to testing (V&VN 2020). 218

In the Netherlands, the COVID-19 pandemic occurred against the backdrop of existing problems in the eldercare sector. In the aftermath of the global financial crisis of 2008, the Dutch government fostered austerity measures that included major budget cuts that were enacted through two new acts that aimed to reallocate caring responsibilities from higher professional levels to lower professional levels, and from paid to unpaid caregivers (Maarse and Jeurissen 2016). In addition, years of neoliberal policies had fostered precarious and flexible employment in eldercare, for example, through on-call contracts or temporary employment (Conen and Schipper 2019). As a consequence, paid care workers were increasingly stretched, as they had to conduct more complex care-related tasks at work, while also having more unpaid care responsibilities at home, under more precarious working arrangements. The Dutch experience of commodification, privatization, flexibilization, and devaluation of care work is comparable to that of other European countries, such as the UK.

Recently, the Netherlands has seen a rise in eldercare workers opting for self-employment, as an alternative to flexible temporary employment as a hired employee. The number of freelancers in health and social care has increased from 61,000 in 2010 to 91,000 in 2018 (Ministry of Health, Welfare, and Sport

[VWS 2020]). In public debates and mainstream media, the rise in the number of freelancers is often framed as problematic from the perspectives of politicians, policymakers, and healthcare institutions. Freelancers are thought to disproportionately burden healthcare budgets, compromise continuity of care for clients, and fail to contribute equally to the social security system, as they pay lower income taxes. Unions have expressed concerns that freelancers undermine solidarity among care workers, and pension funds or interest groups have warned about their precarious employment conditions and lack of social insurance (VWS 2020). Although freelance care work is considered to be precarious work, it is important to note that its precariousness differs from that of other care workers in the Netherlands, such as live-in migrant workers (Bruquetas– Callejo 2019) or migrant domestic workers (Federation of Dutch Trade Unions [FNV] 2020), who suffered severely from the COVID-19 pandemic due to their migrant status and lack of access to social security.

In our ongoing, four-year research study, ‘Negotiating Health,’ we have explored freelancers’ reasons to opt for self-employment and their experiences as freelance eldercare workers. Increasing time spent on accountability, decreased professional autonomy, increased care loads, increasing demands to be ‘flexible’ and available at the expense of private life, health, finances and, especially for racialized care workers, experiencing racism in the workplace, were among factors that squeezed them out

of the organizations and pushed them into self-employment. Since they felt changing the system would be impossible, their opting for self-employment can be understood both as a coping strategy as well as an individualized act of protest against an exploitative system.

As the pandemic profoundly impacts their lives and work, we initiated this qualitative study to inquire into how the corona crisis affects freelance eldercare workers, particularly in terms of their health, financial situations, and paid and unpaid caring responsibilities. We aimed to understand from an intersectional perspective the mechanisms that (re)produced social inequalities within the COVID-19 pandemic and the subsequent corona crisis. In the discussion that follows we relate these mechanisms to Nancy Fraser and Rahel Jaeggi’s (2018) theoretical work on capitalism and the concept of boundary struggles.

Methods

As noted, this study is part of a large research project, ‘Negotiating Health,’ on the health and well-being of paid care workers, informal caregivers, and volunteers in eldercare, funded by the Netherlands Organization of Health Research and Development. This sub-study followed a qualitative interview design, and we place our work within the interpretative epistemological tradition (Green and Thorogood 2018).

Data were collected through semi-structured interviews conducted by three interviewers (Duijs, Haremaker and Bourik). Respondents

were recruited via the professional organization for freelance healthcare workers, social media, and snowball sampling. Some respondents (R16– R23) included in this study were previously interviewed before the pandemic in the context of the broader study. We interviewed freelancers working in residential care (that is, nursing homes) and/or in domiciliary care (that is, home care). Respondents (N = 23) were purposively sampled across gender, age, occupational level, and migration status (Table 1).

Our topic list focused on the lived experiences of freelancers during the pandemic, including health concerns about COVID-19, balancing paid and unpaid caring responsibilities, concerns and dilemmas concerning others' health, financial concerns, (governmental) support, and experiences of marginalization and racism. Interviews were conducted by telephone, as government measures to reduce physical distancing did not allow face-to-face interviews. Interviews were conducted between March and May 2020, audio recorded and transcribed verbatim. Member checks were sent to the respondents to validate interpretations of the interviews.

In the first step of data analysis, we used thematic analysis (Braun and Clarke 2006) by identifying relevant themes and topics from the respondents' perspectives. Analysis was conducted manually by two authors (Duijs, Haremaker). In the second step, we (Duijs, Verdonk) applied an intersectional perspective to understand how the initial themes and topics were shaped by gender,

class, ethnicity, disability, and age, which enabled a more in-depth understanding of the societal inequalities that were reproduced and how (Verdonk et al. 2019; Hankivsky and Kapilashrami 2020). Data saturation did not occur in relation to racialized inequalities, nor have we been able to include men in our study. These themes required further exploration, which was hindered by time constraints.

This study was evaluated by the Medical Ethical Review Committee of the Amsterdam University Medical Center (UMC), location VUmc, Netherlands, which confirmed that the Dutch Medical Research Involving Human Subjects Act did not apply. Data was stored anonymously at the internal network of Amsterdam UMC and will be archived until five years after the study. 'Negotiating Health,' has been completed. Informed consent was expressed orally over the telephone and was audio recorded. Informed consent forms were sent via email to ensure access to important information that was mentioned on the form.

Results

To illustrate the pandemic's disruptive effects and deepening of inequalities, we first describe how the COVID-19 pandemic impacted freelance workers by pushing them to the margins of the labor market. Second, we present how inequalities subsequently play out in the freelancers' morally stressful navigation between paid and unpaid care responsibilities, which stretch them to the limit.

Pushed to the margins of the labor market; unprotected care work during the COVID-19 pandemic

For many respondents, self-employment symbolized the freedom to attend to their own health, informal caring responsibilities, and financial obligations, free from unhealthy organizational practices, such as unlimited demands for flexibility or having to endure racism in the workplace. Opting for self-employment in times of staff shortage strengthened care workers' perceptions of earning secure incomes as freelance care workers, while creating more meaningful work. The COVID-19 pandemic disrupted these conceptions of freedom and laid bare the precariousness of freelance care work. **A confrontation with precariousness of work**

All respondents experienced their flexible care work being framed as a health risk, and institutions and individual clients feared that freelancers would form a vector for infection. As a result, many freelancers were actively kept out of workplaces, or clients required exclusivity, which compromised freelancers' income, as tax rules required them to have at least three clients per year. Those with a financial buffer could actively choose to withdraw or minimize their client base to protect their own health as well as their clients. Those in financially precarious situations expressed how this made them feel vulnerable, exploited, or pushed aside:

You think you've got a lot of freedom, but it isn't that much. It's five days since the coronavirus is here, and I have lost most of

my work. And then there's nothing you can rely on. It's not only a financial hit, but also an emotional one. (R11)

Other respondents mentioned how they were immediately confronted with the risk of being crowded out of the labor market:

My problem is this. On the one hand, you're being pushed out as a temp or self-employed, but on the other hand, there is a massive demand for everyone with a healthcare background who, for example, are now suddenly allowed to work in healthcare. (R5)

Respondents of color shared how they were excluded from care teams while their white colleagues were not, suggesting that these decisions are also shaped by racism. Respondents with limited financial means sometimes had to withdraw involuntarily as they were dependent upon public transportation and were unable to get to work due to adjusted timetables, or were afraid to travel by train as they feared infecting their clients. They often chose to prioritize the health of their clients over their financial situations, but as a consequence, their already-limited financial means were depleted further. This problem was especially impactful for single mothers who were sole breadwinners:

We can't really afford to stay home for a day. A day without work is a day without money. (R1)

The financial consequences of being kept out of the workplace hit them hard, while the

older, white, single, and/or higher-educated respondents often expected to be able to fall back either on financial buffers, partners' incomes, or early retirement, or did not worry as much about financial adversity as they had to take care of 'only' themselves. They did not immediately experience the situation as precarious.

Working the risky shifts

While on the one hand freelancers were kept out of the workplace, on the other hand several respondents received increasing requests to work in institutions with COVID-19 patients, while lacking access to adequate personal protective equipment (PPE):

Yes, the requests are far more frequent – 'Would you like to work with us? Oh, by the way, we do have COVID-19. (R12)

Respondents explained these requests in terms of the sharp increase in hired (non-freelance) employees going on sick leave to protect their own health, supported in this strategy by trade unions, professional organizations, and their employers (V&VN 2020). Freelancers were not always informed about the presence of COVID-19 patients, which made an informed decision whether or not to accept a certain shift impossible. Freelancers who provided noncontracted care (that is, caregivers not contracted by insurance companies, who often provide care directly purchased by clients) faced different challenges. Some were requested to co-quarantine with clients to avoid the risk of transmission to clients by caregivers, and some even ended up in involuntary co-quarantine:

I just got called from a befriended freelancer who takes care of a corona patient. She's been covering several twenty-four-hour shifts now, but no one is willing to take over. A burnout is about to happen. For me, it's too far away, otherwise I would have helped her. Noncontracted care workers, they can't withdraw. They have a duty to provide care; they're the only ones responsible. The dynamics are very different. (R15)

Unprotected work

Freelancers lacked access to social protection. They felt they would not be covered by social protection measures for freelancers who lost their work due to the COVID-19, as they expected that these would not be granted to freelancers in the care sector:

As a self-employed care worker, you can't really say, 'There is no work to do.' There is plenty. Care work didn't stop. If you're not working, well, that's your own choice. (R17)

They were also not served by governmental efforts to redistribute PPE. Eldercare was at the bottom of the care-cure hierarchy, to the great frustration and anger of respondents:

From the start, I was irritated by the fact that all attention went to the hospital. True, on intensive care, people's lives are saved. But the nursing homes are completely left to themselves. It's not just shortages, because, let's be fair, it's also just indifference. (R7)

After public debates, the regulation was revised a few weeks into the pandemic,

which gave more priority to nursing homes: 'but not for self-employed and neither for the small homecare organizations. So, well, we missed the boat anyway' (R23). Freelancers with shifts in nursing homes could benefit from PPE in the institutions, but freelancers providing noncontracted homecare had to pay extortionate prices for PPE in the free market. Simultaneously, some care workers' financial situations were compromised by outstanding payments from health insurance companies and/or care organizations for work done in the past months, which now became an acute problem:

Some just don't have the money to buy this expensive protective equipment. (R15)

The lack of sufficient PPE for caregivers on the frontlines was also a source of great frustration and anger:

We're being sent to the front without weapons. This really irritates me. I have to care for my clients without protective equipment, but when I have to go to the team leader, I must hold a six-feet distance. Yeah right, you feel safe and we have to care with the risk of sacrificing our own health. (R12)

Political and societal disregard for freelancers in eldercare became especially painful for freelancers during the COVID-19 pandemic:

So much has been said about the self-employed, they want to push us aside, but now they need us badly. (R12)

Stretched to the limit: Navigating moral minefields during the COVID-19 pandemic

As freelancers were pushed toward the margins of the labor market, their health, unpaid caring responsibilities, and financial situations were increasingly put at risk. Freelancers in pandemic areas, who also had informal care responsibilities but did not have financial buffers, felt stretched to the limit and found themselves having to make harsh choices. They were no longer able to negotiate looking after their own health while caring for the health needs of others. In a landscape of gendered, classed, and racialized inequalities, they entered moral minefields in which they tiptoed between their own health, the health of others, and their financial situations.

Harsh choices

The intense dilemmas caused by this moral minefield of care become tangible in the story of an Antillean-Dutch mother who carried out informal caring responsibilities at home for her son who had asthma, and who was able to protect the health of her son by relying on the income of her partner:

We're care providers, we're also mothers, we're also someone's daughters, we're also aunts, someone's cousin or niece. You do this work from your heart, but not at the cost of your private life and putting your own life at risk. I am devoted to my work, but my child needs me too. Get it? It's so contradictory. From whatever perspective, you want to do your job, assist your colleagues, but you're being restrained because there's no safety. It's hard, so then you decide to stay home.

But then you feel guilty, too. There are people out there who need help and there are shortages of staff. I want to be there. But if I'm there, I might infect my son. And then I wonder: is this worth doing? My thoughts are going both sides all the time. (R13)

Several other respondents shared how they felt 'stuck in the middle, having to make harsh choices,' such as the 52-year-old freelancer who migrated from Surinam and who felt forced to protect the health of her partner by withdrawing from paid work, which not only compromised her own financial situation, but also her ability to (financially) support her family abroad. She expressed guilt and shame and felt alienated from herself, as she was no longer able to attend to her caring responsibilities:

I've got brothers in Surinam with families . . . I used to support them monthly, but I can't do that anymore, at least not as much as I used to . . . That's the mean thing about this whole situation, you're thinking increasingly in terms of 'I.' Yes, and I hate myself for this, because that's not how I am. I just can't afford to give everything away right now. (R7)

The caring identity and the ideology of self-sacrifice

The moral values expressed by care workers, such as protecting the health of intimate others, expressing solidarity with colleagues, and the responsibility to care for clients are characteristic of their caring identities as women. This identity puts care workers in a bind. Even if refusing to work shifts was financially possible and necessary to protect

their own health and the health of others, choosing not to care for clients meant they had to compromise their caring identities, as voiced by this older freelancer who stopped working to protect her own health:

You feel guilty. You know that you have good reasons not to go. But it just sticks in your mind. When I watch television, I see people grab their uniforms out of their wardrobes after many years. And then I look at myself, sitting home, being the experienced one. I'm 60 already. I had to reassure myself over and over again. (R17)

Pushed in a corner: How money trumps everything

Moral considerations (moral minefields) are overshadowed by financial struggles, as was expressed by this 32-year-old single mother of three, who worked in the epicenter of the pandemic:

At the moment, it's just the financial part that's causing me stress, because the bills need to be paid, otherwise you'll risk falling into severe debt. If I had to choose between my own health and my financial situation, I think I'd go for the latter. Ill health or good health, I would just go out working. (R1)

Her story illustrates how the experiences of freelancers are largely shaped by class; being able to attend to your own health and the health of others became the preserve of those with the financial means to do so. Not everyone could afford a moral dilemma. For some, working in the pandemic was plain survival.

Discussion

In this study, we show the mechanisms behind the exacerbation of existing inequalities in the corona crisis. Using two themes, we illustrate the pathways through which gendered, classed, and aged inequalities are perpetuated and reinforced. First, in the COVID-19 pandemic and the following corona crisis, freelancers were 'pushed to the margins,' as the precariousness of freelance care work was exposed at multiple levels. Second, freelance elder care workers endured and had to navigate moral minefields as their paid and unpaid caring responsibilities were 'stretched to the limit.'

We position our empirical findings within Fraser and Jaeggi's (2018) theoretical work on capitalism. They theorize that interconnected systems of oppression, such as class, patriarchy, racism, and environmental injustice, are deeply rooted in the institutional structure of capitalism. Fraser and Jaeggi (2018) conceptualize four background/foreground divisions in capitalism: structurally separating economic production from social reproduction (that is, a gendered division of 'work' and 'care'), economy from polity, human from nonhuman nature, and exploitation from expropriation (a classed and racialized division). Capitalist economies do not exist in the absence of public power, social reproduction, expropriation at the (non-Western) 'periphery,' and inputs from nature. Yet, simultaneously, capitalism disavows the value of these realms for economic production, as well as their intrinsic value. Viewed as infinite free gifts to the economy,

capitalism does not recognize the need to replenish them.

These background conditions are not infinitely elastic, and therefore struggles occur in each of these four realms, conceptualized as 'boundary struggles' (Fraser and Jaeggi 2018). We understand the dilemmas, emotions, and acts of resistance of freelance eldercare workers as markers of these boundary struggles, expressing anxiety as they feel stretched too far and as they make (implicit) moral judgments over unjust structures. The gendered, classed, and racialized hierarchy of the health system is laid bare before their eyes, as those working in higher-educated, white, medical, technical, and male-dominated sectors are better protected than those working in the eldercare sector, where care work is performed relatively often by the bodies of less-educated women of color (Watts 2015; Fraser and Jaeggi 2018).

First, we turn to the production/reproduction division, which has been extensively theorized by Marxist feminists as a source of gendered oppression of women in capitalism, as production is traditionally associated with men and reproduction with women (Fraser and Jaeggi 2018). Social reproduction refers to forms of paid and unpaid provisioning, caregiving, and interacting that produce and maintain social bonds, called 'care' or 'affective labor,' which take place in households, neighborhoods, and families, but also in public institutions such as schools and eldercare centers. Before the pandemic, austerity measures relegated paid

care work in the welfare state to the sphere of unpaid care in the community. The reason for this shift was that eldercare was not 'productive enough,' not profitable, and too costly for the welfare state. These measures have increased gender inequalities in the Netherlands, and rendered social reproduction invisible again (Duijs, Verdonk, and Abma 2019). The corona crisis painfully illuminated how the world's formal economies and the maintenance of our daily lives are built upon invisible, devalued, and (in)formal care work mostly done by women. Our study shows how the pandemic exhausted freelancers' paid and unpaid reproductive work, as they had to make harsh choices between their paid and unpaid caring responsibilities. Their unpaid reproductive work threatened their paid reproductive work and vice versa. The corona crisis thus exhausted the reproductive work of these freelancers up to a breaking point, which can both be understood as a broader 'crisis of social reproduction.' The fact that the recent austerity measures in the Netherlands indirectly caused the dilemmas that care workers faced during the pandemic did not lead to societal discontent or political debate. The feelings of shame and guilt displayed by respondents in our studies illustrated how their dilemmas were strongly individualized; they felt personally responsible for being unable to attend to both their paid and unpaid caring responsibilities, rather than blaming life in a system that set them up for these dilemmas and ultimate 'failures.'

Second, our study illustrates boundary struggles at the economy/polity division.

Eldercare workers who were squeezed out of the organizations of the welfare state and into self-employment had shifted from the public domain (polity) to the domain of the free market (economy). Our study shows how the corona crisis plunged them into precariousness, and as a result, boundaries started to be questioned. During the COVID-19 pandemic, the Dutch government showcased an unprecedented intervention in the healthcare sector, yet freelancers were not served by these political efforts, as, according to politicians, they had to take care of themselves in the 'free market.' While freelancers in other sectors could rely on governmental support, as could hired employees within the eldercare sector, freelancers in the eldercare sector appeared to be falling through the cracks. This 'intersectional policy failure' (Hankivsky and Kapilashrami 2020) led to debates in mainstream media and advocacy by professional organizations to shift the boundary toward including freelancers in public and political efforts to protect and support eldercare workers. These boundary struggles are ongoing, as the role and position of freelancers in eldercare is on the political agenda (VWS 2020).

Third, Fraser and Jaeggi (2018) address boundary struggles between human nature and nonhuman nature. This boundary struggle is more difficult to pinpoint directly within the context of our study, although both scholars and public organizations such as the World Wildlife Fund International, World Health Organization, and United Nations

have pointed toward the link between the COVID-19 pandemic and the destruction of nature (Carrington 2020; Lambert et al. 2020). Recently, health scholars have articulated more fiercely that climate change is a major public health issue (Watts et al. 2018). While the boundary struggles of production/reproduction and economy/polity were defensive, trying to shift the boundary back, this particular boundary struggle, of human/nonhuman nature, is transformative, as the very existence of the boundary was questioned. The pandemic shows how human and nonhuman nature are deeply intertwined, impacting the bodies, lives, and work of those working in healthcare.

Last, we turn to the boundary struggle at the exploitation/expropriation axis. Fraser and Jaeggi argue that in current financialized capitalism expropriation is becoming universalized:

'... where low-waged precarious service work is replacing unionized industrial labor and governments are cutting public goods and social services at the behest of investors, capital is now routinely paying the vast majority of workers less than the socially necessary costs of reproduction' (p. 107).

(2018: p.107). As one result, people become dependent on debt to sustain themselves. In the present case, while the push into self-employment was a response to exploitation, the COVID-19 pandemic caused freelancers to fear indebtedness or dependence on their partners' incomes, thus increasingly fearing

expropriation. For many, their very financial independence was under threat.

In past years, healthcare workers' salaries have been hotly debated in the Netherlands. These boundary struggles intensified during the corona crisis, with outcries over 'underpayment' of care workers in the media and with unions using the pandemic to advocate for higher salaries. Furthermore, Fraser and Jaeggi (2018) understand expropriation as historically shaped by racialized inequalities. In the Netherlands as elsewhere, the corona crisis collided with an uprising of the Black Lives Matter movement and the growing acknowledgment of racism as a public health issue (Devakumar et al. 2020). In this study we observed how the experiences of freelancers were shaped by institutional racism, as respondents of color were overrepresented in lower-educated sectors, and by cultural racism, as respondents of color were pushed toward freelance work due to experiences of everyday racism in the workplace.

Conclusion

In conclusion, our study shows how freelance eldercare workers' experiences are shaped at the nexus of all four of capitalism's divisions, and how boundary struggles occur at all levels. It is no surprise that these struggles erupt so acutely in eldercare, as neoliberal policies and austerity measures in the aftermath of the financial crisis have left the sector overstretched and underserved and, thus, crisis prone. A failure by those in power to understand how the gendered, classed, and racialized

dynamics that disadvantage eldercare workers are interwoven into capitalism's broader social order will push freelancers further into precariousness. Governmental organizations, politicians, unions, professional organizations, pension funds, and other parties in the Netherlands hold conflicting views concerning freelancers in eldercare. These conflicting views stand in the way of building a broad alliance that can enhance the situations of those working in the sector. In this paper, we provide inputs for a dialogue that requires shared actions among diverse parties. Because as Fraser and Jaeggi note,

'Only by joining a robustly egalitarian politics of distribution to a substantively inclusive, class-sensitive politics of recognition can we build a counterhegemonic bloc that could lead us beyond the current crisis to a better world' (2018: 223).

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Unraveling intersectional inequities through participatory health research



As a PHR researcher, I wanted to understand how researchers can address health inequities together with those whose life or work are subject to the study. Health inequities are shaped by structural and intersecting systems of oppression, such as class, race, gender, age and sexuality.

I experienced how PHR can become a disempowering endeavor when these structural inequities remain unaddressed (chapter 7). Therefore, I wanted to explore how critical perspectives on these structural inequities can be developed in dialogue *with* participants, rather than *about* participants, and particularly how intersectionality can strengthen this process of critical reflection in PHR (chapter 8).

CHAPTER 7

Why action needs compassion

Responding to experiences of powerlessness and
suffering in participatory action research

Abstract

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Duijs, S. E., Baur, V. E., & Abma, T. A. (2021). Why action needs compassion: Creating space for experiences of powerlessness and suffering in participatory action research. *Action research*, 19(3), 498–517.

Background:

Participatory action research is often informed by strength-based approaches such as appreciative inquiry. However, when social change and collective action appear to be difficult, feelings of powerlessness and suffering can arise. There is an ongoing debate on the place and importance of these so-called negative emotions within strength-based approaches. In a participatory action research project on citizen participation in the Netherlands we encountered a social and political context that was beyond our ability to change.

Methods

This article presents a first, second and third-level reflection on the researchers' moral dilemmas within a participatory action research project, using the reflective logbook of the first-researcher, field-notes and transcripts from the PAR project and notes of collective team meetings.

Findings

We came to realize that change or action is not always possible in participatory action research and that 'pushing' for action can become a disempowering experience for those

involved. In this article we share the moral dilemmas that we encountered and reflect on our own learning experiences as academic researchers.

Discussion:

We argue that researchers need to anticipate upon these moral challenges by reflecting upon their personal position towards powerlessness and suffering. Nussbaum's notion of compassion can help researchers to create space for these experiences and to acknowledge these experiences as sources of generative knowledge.

Conclusion:

Researchers should carefully navigate between fostering action and expressing compassion in participatory action research. With this article we aim to contribute to a care ethical perspective on participatory action research that acknowledges vulnerabilities and precariousness in research practices.

Keywords

Participatory action research, appreciative inquiry, action, empowerment, compassion, ethics

Introduction

Fostering collective action and social change is at the heart of participatory action research (PAR) and related transformative action-oriented research, such as community-based participatory research, participatory health research, action research and transformative

evaluation (Mertens, 2009; Reason & Bradbury, 2008). These approaches strive for democratization of knowledge, human flourish- ing and social justice. These values drive the research and social change process, and include a critical awareness of unequal power relations and structures. Participatory approaches aim to ‘maximize the participation of those whose life or work is the subject of the research in all stages of the research process’ (ICPHR, 2013).

Empowerment of those involved in the research process is considered key (Jacobs, 2006). Wallerstein (1992) defined empowerment as

‘a multilevel construct that involves people assuming control and mastery over their lives in the context of their social and political environment; they gain a sense of control and purpose- fulness to exert power as they participate in the democratic life of their community for social change’.

Another fundamental aspect in transformative research is a strength-based approach: ‘the belief in the strength that is often overlooked in communities’ (Mertens, 2009, p. 18). Researchers who position themselves within the transformative research paradigm distance themselves from a deficit perspective that focus- es on the problems in a community (2009). In doing so transformative research is closely related to appreciative inquiry (AI) (Ludema, Cooperrider, & Barrett, 2001; Zandee & Cooperrider, 2008). This strength-based or generative approach to organizational change is future oriented as it

invites people to imagine ‘what could be’ by focussing on the following questions: ‘What gives life?’, ‘What are our strengths?’ and ‘Who are we at our best?’. These elements from AI are often used within PAR (Boyd & Bright, 2007; Zandee & Cooperrider, 2008).

Fostering social change and collective action are thus core values of PAR. Yet, in the messiness of daily practice, fostering collective action and social change is not always possible. Complexity theory teaches us that change is often a messy rather than a linear and orderly process, because parts and system mutually influence each other while the whole is much greater than the sum of its parts (Cook, 2009; Davis & Sumara, 2005). This is especially relevant for the social and health care sector due to its multiplicity of actors, as health and social problems are strongly intertwined and vulnerable people often deal with multiple care professionals from different care domains.

This idea that control over the process is limited became particularly urgent and morally challenging in a PAR process on citizen participation in a neighborhood of a Dutch city with women in a marginalized position. This PAR process was conducted within a transformative (Mertens, 2009) and participatory (ICPHR, 2013) research paradigm and our approach was strongly informed by AI. During the research process it gradually became clear that our project was con- ducted within a disempowering social and political context that was beyond our ability to change. Fostering collective action and social change appeared to be complex and even disempowering for those involved

in the research process. While we (academic researchers) were passionate to give these marginalized women a voice in the public domain and change their situation, it felt as if our attempts did not do justice to the tragic impossibilities of the situation. By focus- sing solely on the strengths and possibilities of these women, we unintentionally participated in a silencing act in which their powerlessness and suffering were not acknowledged. We got stuck in a paralyzing impasse and began to question whether compassion with the tragic impossibility would be a better (ethically informed) answer than ‘pushing’ for action. Our key dilemma centered around the question: *How to deal with powerlessness and suffering of research participants from a strength-based approach?*

Although action research is concerned with challenging the unjust social structures or practices that cause human suffering (Reason & Bradbury, 2008), dilemmas on how to deal with powerlessness and suffering of research participants exist in both PAR and AI (Bushe, 2011). Within the tradition of AI there is an ongoing debate on AI’s affinity with positive psychology and the place and importance of so-called negative emotions within a strength-based approach (Bushe, 2011). Central to this debate is the question which sources of knowledge can be valued as ‘generative’ or have ‘generative capacity’ (Zandee, 2015)?

In this article we share our learning experiences, and will argue that in PAR researchers need to anticipate upon these moral challenges by reflecting upon their

personal position towards powerlessness and suffering. This reflective process can enable them to more carefully balance action and compassion within their research process. With this article we aim to contribute to a (care) ethical perspective on PAR, which is concerned with expressing care towards research participants in a way that acknowledges vulnerability and precariousness (Banks et al., 2013; Banks & Brydon-Miller, 2018; Groot et al., 2018).

Short description of our PAR project

PAR follows an iterative process of action and reflection, and practice and theory. Our PAR project followed such logic, but was not structured along the phases of analysis, planning, doing, acting and evaluation. Our prime focus was to maximize participation and to create a ‘communicative space’ (Wicks & Reason, 2009) in which all of those involved, including ourselves, felt mutually encouraged, respected, and supported to join the process. Much of our work was person-centered, relational and geared to facilitating an open and safe space to tell and share stories, building relationships of trust and handling complicated group dynamics and unplanned shifts and needs. This way of working was very much influenced by the context and the social position of the people involved.

Our PAR was established in a relatively poor and culturally diverse urban neighborhood in The Netherlands to study and support citizen participation through collective action and reflection. The project was funded by a local elderly care organization and carried out by

an all-white Dutch academic research team comprising a doctoral researcher (Duijs), a post-doctoral researcher (Baur) and a professor (Abma, also the PhD supervisor). The local elderly care organization was part of a neighborhood platform of professional care organizations, established by the local government at the time of our research, to support citizen participation in the neighborhood. They funded our research to express their support for this platform, but played little role in doing the research. Moreover, the organization that commissioned the study did not have much control over the processes in the neighborhood; many other actors played a role, and the power relations were diffuse. One of the key actors was the local government. The neighborhood where our PAR took place was chosen by this local government because of its high level of citizens receiving professional care and low level of citizen participation.

Our PAR project was part of a bigger research project on citizen participation in the neighbourhood (2013–2015). This research project was set up within a transformative (Mertens, 2009) and participatory research paradigm (ICPHR, 2013). Its aim was to responsively evaluate the multidisciplinary neighbourhood platform from multiple stakeholder perspectives. The PAR project emerged from this more comprehensive evaluation study (June 2013–May 2014; Duijs, Baur & Abma, 2014). We followed the systematic steps of a responsive evaluation for the broader study which included an exploration, consultation and integration phase (see Table

1 for an overview of phases and activities). The theoretical foundations and systematic steps of responsive evaluation are described in more detail elsewhere (Abma, 2005). Methods of data collection included observing community meetings, formal and informal interviews and homogeneous focus groups.

During the responsive evaluation we came into contact with several women who expressed a wish to get more involved in the neighbourhood. We invited nine women to form a PAR group to share their experiences, dreams and collaboratively develop ideas and actions for social change. This PAR group was facilitated using the PARTNER approach which is a dialogical, action-oriented method to create partnership relations between diverse groups of people who work together to improve practices based on mutual understanding and collective action (Baur & Abma, 2012; Duijs, Baur & Abma, 2016). The principles and systematic steps of the PARTNER approach are also described in detail elsewhere (Baur, 2012). We chose methods for data generation that maximized participation and fitted with the communication styles of the women, including storytelling through in-depth inter-views, brainstorm and dialogue sessions. An overview of the methods and data generated are presented in Table 2.

Two women resigned before the project started, but a group of five to seven women regularly met – with eight meetings between March and September 2014. These women came from diverse cultural and religious backgrounds: three were born in Turkey, two

Phase	Methods	Data collected	Number	Period
Meetings of the action group (N=6 meetings)	Participant observation of the meetings of the action group	Field notes of the researchers (junior and senior researcher)	N= 18 h observation	March–September 2014
		Ad verbatim transcripts of the meetings with the action group	N= 6 transcripts	
		Reflexive journal of the junior researcher, including reflections from senior researcher	N= 48 h	
		Transcripts of open interviews	N= 4 transcripts	May 2014
Reflection with participants	Open interviews with 4 participants of the action group	Narrative of the action group written by first researcher	(N=12 pages)	August 2014
Reflection by academic researchers	Critical creative hermeneutic analysis*	Transcript of the meeting	N=1 transcript	

fled from Rwanda and Iraq and two were born and raised within this particular neighbourhood (one Dutch woman who spoke the local dialect and one Indonesian woman). They were aged between 35 and 60. A few had previously been active in their neighbourhood. Yet, most lived very isolated lives, some hardly spoke Dutch and several were struggling to find work. They had few local contacts.

Reflection on the process was an ongoing activity during and in between the meetings. Research participants received minutes from the meetings. Joint reflection on the process took place during the meetings and in open interviews that were conducted with participants during the research process.

Due to the difficulties described in the reflections below the women refrained from participating in the meetings and collective analysis appeared to be impossible at the end of the project (September 2014). Therefore, data generated from this study were mainly analysed by the academic research team.

Levels of reflection

Within PAR we distinguish first, second and third-level reflection (Reason & Bradbury, 2008; Zandee, 2015). First level concerns a reflection on inner experiences and feelings, which can be used for a broadening of the inquiry within a social group at second level. This can also be related to third-level reflection which includes insights the broader socio-

political context and structural disadvantages and injustices. Our aim was to develop a critical subjectivity: personal experiences became the subject of inquiry, reflection, and discussion. These personal issues were related to structural processes of inclusion and exclusion (third level) which helped us to understand the dynamic within our PAR project. Second-level reflection created a deeper understanding of how our own identity and biography as researchers were 'embodied' within the research process (Todres, 2008).

Our reflections are based on the following sources of data: (1) the reflective journals of the first author that were made during the PAR-research project (some of which were written retrospectively), (2) data from the PAR-research project such as field notes, transcripts of interviews and meetings of the PAR group, and (3) notes of meetings of the academic research team. We focus on moments in the research process that were emotionally laden, i.e. moral dilemmas, as Nussbaum (2001) argued that emotions are 'values embodied'. Mertens (2009, p. 80) also urges researchers to '*pay attention to . . . dilemmas and key phrases that are charged with energy or that seem to hold multiple meanings.*'

Although participatory action researchers would ideally reflect on moral dilemmas in the research with research participants (cf. Montesano Montessori & Ponte, 2012), participant voices are lacking in our reflective process afterwards due to the issues that are described in this article. The voices of participants are embedded within the first-level

reflections using quotes from the participants that were collected during the meetings of the PAR group and during interviews with participants. These quotes were the starting point of the reflexive process within the academic research team. This article focuses on the methodological dilemmas of the academic researchers who facilitated the PAR process. We believe that these reflections can be of value for fellow participatory action researchers.

Reflections

Moral dilemmas of the first researcher (first-level reflection)

As a novice participatory action researcher, I (Duijs) was highly motivated to support citizen participation and democratic participation in a neighbourhood and at municipal level. Yet, I soon was confronted with several moral dilemmas. The first dilemma concerned balancing between connecting to people where they are now and imagining how it could be. The second dilemma centred around the tension between acknowledging structural inequalities while fostering collective action of the PAR group.

Balancing between connecting to people where they are now and imagining how it could be.

During the responsive evaluation I met nine women who shared their concerns and ideals about this neighbourhood with me. They expressed their wish to take action. I had several informal conversations with these women and they spoke about their life to me.

I was touched by their stories and invited them to be part of a PAR process. Eventually, seven of them decided to participate. The first few meetings of the group were facilitated by both me and a senior researcher (Baur). In our perspective the project started wonderfully. The women, from diverse backgrounds, quickly shared intimate experiences of loneliness, exclusion and discrimination with each other. We were touched by the women's stories and felt as if they connected heart to heart. In the meetings that followed the woman occasionally brought up ideas to promote social contact with or informal gatherings for other woman in the neighborhoods.

After the first two or three meetings, participation in the group became complicated. Conflicting views and agendas became apparent and personal struggles concerning job employment, (transnational) family care, depression, loneliness, conflicts or language barriers greatly impacted the lives of these women and there- fore the dynamic of the group. As facilitators we considered these experiences crucial to the process and hoped that the sharing of these experiences could contribute to the relational empowerment of the group (reference blinded). This would possibly foster political empowerment and collective action (Melucci, 1996). Yet, this turned out to be more complex than we thought.

After several meetings we (Duijs, Baur) still felt that there was a lack of focus, confidence and shared responsibility to actually take action. We both felt as if we arrived at a dead end in the process. In preparation of

the next meeting, we hoped that the women could define a common dream and decide on an agenda for action. Together with the supervisor (Abma) we decided to take on an appreciative approach, bearing the words of Mertens (2009) in mind:

'One of the major principles underlying transformative research and evaluation is the belief in the strength that is often overlooked in communities' (p. 18).

We decided to focus on the strengths and possibilities of this group of women, inviting them to think of 'How it could be' (Ludema et al., 2001), hoping this could breathe new life into the group.

Yet, at the end of this meeting we (Duijs, Baur) were both feeling exhausted. Travelling back from the meeting I suddenly remembered a specific moment in the meeting which made my heart sink. One of the women shared her desire for encounters and informal gatherings with other women. We asked her, bearing in mind the role of the appreciative inquirer: '*What does your dream look like? What is the first step you can take to make this dream possible? What possibilities are already in your reach?*' But while we started asking these and other questions, she bow her head and remained quiet. Another woman quietly said: '*We don't know anyone around here.*' One of the other women referred to her neighbours when she noticed: '*No one is ever here, they are always at work or busy doing other things.*' We continued to press for possibilities: '*Okay, so they are away for the day. What else*

could you do? You could approach them in the evening? Or focus on the people who are at home during the day?' Again, the women shared their frustrations and doubts. This time more forcefully: *'Listen, we don't even know their language.'* Some of the women expressed shame toward their neighbours and referred to their cultural background and inability to speak the language: *'I cannot imagine myself ... going up there ringing their doorbell? What will they think of me?'* The harder we tried to uncover 'hidden strengths' (Mertens, 2009) or invite them to *'imagine how it could be'* (Ludema et al., 2001) the more the women started to express their frustration and powerlessness. They did not see any possibilities to connect with the neighbourhood residents and I even sensed that they felt ashamed in even considering trying to reach out.

A short while after the meeting we shared our disillusionment about the meeting with each other. What did we do wrong? In a way this situation made me feel uncertain about my role as a novice PAR researcher: was I getting this AI thing right? Did I just need to study it more, practice it more often and learn how to ask better questions? Of course, that might have been the case. But that was not the question that was confusing me most. Mostly, I looked back with a sense of sadness about this meeting: as if the connection between me and the women was lost.

Although the group dynamic wasn't easy, I had interviewed all of these women separately and we often had spoken informally about their lives, dreams and worries. I felt a strong

connection with these women and I was touched by the stories they told me and the struggles they faced in their daily live. I felt as if we were able to connect on an intimate level as they shared their hardships, pain or loneliness. Some of this connection was tangible during the first few meetings, in which the women shared bits and pieces of their stories. During this last meeting I felt as if there was no room for these stories anymore and we somehow compromised our relationship by mainly focusing on the strengths, rational solutions and possibilities for getting from a to b in a linear fashion. Yet, I also acknowledged that at this moment in the process merely sharing stories was not enough to foster confidence in their own ability to make a change (personal and relational empowerment) and to encourage collective action (political empowerment).

It felt as if I had to balance between connecting to the participants where they were now and invite them to 'imagine how it could be' as a strategy to foster change. What would have been the right thing for me to do as a PAR researcher during this meeting? Persist in taking on an appreciative approach that could foster collective action and change, while feeling as if I was ignoring the pain and struggles that form their daily reality? Would I, by doing so, participate in a silencing act in which their lived experiences of pain and struggle were denied? Or should I settle for creating space in which their stories could be shared as they are, not as they should be, and in which I could express my compassion with their pain and struggles, with the risk of

never getting anything done? I felt as if I had to navigate between fostering action and expressing compassion and I wondered: 'Can I, and if so how, take on a strength-based approach, while also acknowledging pain and suffering?'

Acknowledging structural inequalities while fostering collective action of the action group.

At the same time the women also expressed little confidence in their ability to make a change on their own and shared their need for financial, moral and practical support. They decided to invite a policy maker from the local government. As a facilitator I encouraged this course of action. Maybe this could shake things up? The policy maker, who had previously expressed his enthusiasm for our project, accepted the invitation.

During the introductions the women immediately started to express their vulnerabilities and were explicitly searching for a helping hand. One of the women referred to her inability to make contact due to language problems. Others mentioned their unemployment and their search for work. They mentioned the barriers they experienced to organize community activities by themselves. These barriers were financial as most of these women were living on social security or had irregular, insecure work. Others also mentioned their inability to organize activities as they were struggling with depressions. One of the women concluded by saying: *'Yes, I love it. But we also know that we can't do it alone. We need help from someone.'* Then the

women introduced the key issue they wanted to address: their wish to organize activities in their neighbourhood, and the hampering issue of the high rent to use the local community building. The policy maker immediately responded by defending governmental policy. Current policy focused on self-management of community houses, in which the municipality *'only rented the place'* (quote policy maker) and neighbourhood citizens were responsible for developing social activities in these community houses.

The women attempted to create a dialogue about this governmental policy on self-management of community houses from their perspective, but this appeared to be difficult. The policy maker persisted in explaining the rationale behind the governmental policies and he consistently told the group that they should be inventive and look for possibilities themselves, without asking for governmental support. This kind of response did not match with the needs of the group, and the women became more and more defensive. After the local policy maker had left the meeting, the women expressed disappointment: *'I actually find that he didn't really listen to us by saying all these things.'* They felt as if they were no further than were they were before and, moreover, as if they were left on their own. Yet some of them seemed to be able to stay positive: *'Like he says, no one will help me. I don't like it, but still, I have a good feeling, a positive feeling. We should work together.'*

I was frustrated: how could it be that there was so little room for dialogue? Here we had

five (two did not attend this meeting because of other care or work related responsibilities) women who responded to the 'affective appeal' (Verhoeven & Tonkens, 2013) of policy makers to organize activities for other (vulnerable) citizens in their neighbourhood and yet their voices and concerns were granted little attention. Both me and the women understood that governmental finances were limited, but I was rather frustrated that even within these limits there seemed to be so little room for dialogue. There was hardly room for democratic participation and shared decision making on the level of the municipal thus possibilities for organizational empowerment appeared to be limited. Not long after this meeting the women refrained from participation in our PAR process. They felt disappointed and disempowered by the research process. One of the women concluded: *'It is just too much stress. I already have too much stress in my head.'* Another woman decided that she had to *'prioritize taking care of my family over taking care of my neighbourhood.'*

At the start of this research project, I thought we (i.e. first author and the policy makers and professionals I spoke to at the start of this project) all had the same ideals in mind: supporting the voice, participation and empowerment of vulnerable citizens. Then why did I feel as if we were miles apart? Later on I realised that my position towards these women had shifted during this project. At first I took on the same position as the policy makers, trying to foster empowerment and citizen participation in the neighbourhood through our PAR project. Yet, I realized that

my role shifted gradually toward advocacy on behalf of these women and focussing on political empowerment. When I look back at this moment in our research I'm fascinated that both me and the policy makers actually did the same thing: we, unintentionally, denied the structural inabilities these women experienced by adopting an appreciative approach in which we mainly focussed on whatever possibilities they could create for themselves.

I realised that our academic research team also focussed on hidden strengths as a way to enable personal empowerment and collective action. By doing so, we failed to pay sufficient attention to the structural mechanisms of exclusion and disempowerment the women faced in daily life, as their responses pointed out to us. Solely focussing on strengths clearly did not create the new openings that we hoped for. Pushing for collective action seemed to confront the group of women even stronger with the structural mechanisms of exclusion and marginalization (such as unemployment, gender, discrimination) that were beyond their ability to address. By focussing on individual responsibilities rather than on structural inequalities, we did not foster collective action but rather confronted them with their own vulnerability which even led to shame.

Exploring the broader context of our PAR process (third-level reflection)

We turned to theories of empowerment from care ethics, community psychology and critical sociology to better understand this dynamic. Several scholars have criticized the notion that empowerment can be situated at

the level of the individual (Jacobs, 2006; Van Regenmortel, 2009). Focussing on personal empowerment without addressing structural mechanisms of exclusion or oppression (political empowerment) bears the danger of individualizing structural problems and so contribute to blaming the victim. This dynamic can also be seen in the responses of the women. Their shame can be explained by their experience of unemployment, exclusion, loneliness or depression as a personal failure, especially in a meritocratic society where one is believed to be responsible for one's success, and thus also failure. Jacobs (2006) and Van Regenmortel (2009) therefore have argued that striving for personal empowerment in a disempowering context can become a disempowering experience for those involved.

I began to understand that our project indeed took place in a disempowering context. This insight was further supported by other scholars who studied the recent developments in social policy on citizen participation. They described how the recent welfare retrenchment was framed by a strong top-down policy discourse on active citizenship and citizen participation in the neighbourhood as alternative to governmental welfare regime (Verhoeven & Tonkens, 2013). Local policy measures were aimed at the participation of citizens in their neighbourhood, but did not grant citizens voice or co-determination in the creation or execution of these local policy measures. These policy measures were beyond negotiation, as became apparent in the meeting with the local policy maker. Tonkens (2016) therefore pointed towards the

'democratic deficit' of this policy transition. Other scholars criticized the governmental discourse of co-creation as a technique to exercise power by local governments (Grootegoed, Van Barneveld, & Duyvendak, 2015). Citizens are allowed to have a voice, but only within the margins that are top-down determined.

Moral dilemmas of the first researcher (first-level reflection)

So, if there was no room for the voice of these women within the given political context, should I keep on motivating the participants to be part of our project that was – one could say: against all odds – aimed at organizational or political empowerment and collective action of these women? To what degree was it my responsibility to protect these women for participating in a project which appeared to become a rather disempowering enterprise? Again, I felt as if I had to navigate between action (i.e. continue to work for collective action and political empowerment) and compassion (i.e. acknowledging the impossibility for political empowerment and thus the reality of exclusion). Could I express my compassion, with the danger of thereby contributing to the disempowering context? Could I give up hope? Or should I, as a strength-based researcher, hold on to *'the belief in the strength that is often overlooked in communities?'* In summary, can we, and if so how, as participatory action researchers foster collective action in a disempowering research context?

Embodied knowledge (second-level reflection)

Exploring these moral dilemmas led to a new layer of reflection within the research team. We all felt some unease with the moral dilemmas as we felt as if we had created a dichotomy between fostering action and expressing compassion. This unease led us to probe further into our biographies and how these were embodied through our roles within the research process.

(Baur): I wonder what framed our roles and experiences? I realize that, at that time, I was strongly influenced by the skills and experiences I had gained from recently being trained as a professional Consciousness Coach. Also, in prior research projects during my PhD research, I had experienced that the appreciative approach that I took led to beautiful results of relational empowerment and collective action of residents of elderly care organizations. I was thus very optimistic about the possibilities of participative research projects and, as a life coach, my focus lay on the potential of people to create new possibilities. This is also how I dealt with my own emotions: instead of compassionately 'being with' my own feelings of unease, sadness, anger, disappointment, I would rather look for ways to transform them into something 'positive.'

(Duijs): My father died when I was young. The grieve that I observed growing up made me realize that there is suffering that you cannot undo. Yet, that there is beauty and love in being able to share this grieve with

one another. And, on the other hand: not being able to share this pain is an utterly lonely experience. The people in my life to whom I feel connected the most, are the ones that understand this sense of intimacy in the midst of pain and suffering. At the time of this research project, I was, among others, inspired by care ethics that emphasises vulnerability and interconnectedness of human beings and Christian spirituality of vulnerability and presence. This strongly guided the way I looked at the dynamic and how I related to the women in our group.

As researchers we represented two seemingly contradictory movements within our research team in how we positioned ourselves in relation to powerlessness and suffering: almost like the two extremes of a scale.

Concluding remarks

Exploring the moral boundaries of striving for change

While fostering collective action and social change is key to PAR, our project showed that this is not always possible when a project is conducted in a disempowering social and political context. Solely focussing on action and change in this context can even be unethical, as it can lead to silencing acts in which powerless-ness and suffering are denied and structural problems are individualized (i.e. blaming the victim). When participants in a PAR project experience powerlessness and a lack of hope, to focus solely on 'hidden strengths' (Mertens, 2009)

and inviting participants to 'imagine what could be' (Ludema et al., 2001) does not always seem to be the right response. In this article we reflected on how we navigated between fostering action and change and expressing our compassion about the experiences of powerlessness and suffering that appeared to be beyond our control. Yet, acknowledging this powerlessness, suffering and disempowerment is not easily done in a research culture that focuses on the strengths, action and change. It is thus critical that we create spaces to reflect on the moral boundaries of fostering action and social change and acknowledge that change is not always makeable within trans-formative research and AI. With this plea we place ourselves in line with other PAR scholars who have described the complexity (Davis & Sumara, 2005) and messiness (Cook, 2009) of action research. We aim to contribute to a more (care) ethical research practice by making the dilemmas that derive from this complexity and messiness visible.

Compassion in PAR

When working toward an inclusive and sustainable world for all, action researchers should be very careful not to reproduce societal dynamics of inclusion and exclusion within their research practice. We argue that the notion of compassion could contribute to a more ethical and inclusive research practice by creating space to share stories of powerlessness and suffering (of all participants, including academic researchers). The notion of compassion has a central place within a (relational) care ethical perspective (Olsman, Willems, & Leget, 2016)

that acknowledges the interrelatedness, vulnerability and precariousness of those in a marginalized position (Banks et al., 2013; Leget, van Nistelrooij, & Visse, 2019; van Heijst, 2005). Care ethics provides a critique on the neo-liberal discourse of self-sufficiency and self-determination that dominated in the political context of our PAR process (Leget et al., 2019; Vosman & Niemeijer, 2017). Nussbaum (2001) defined the ethical concept of compassion as 'a painful emotion occasioned by the awareness of another person's undeserved misfortune' (p. 306). According to her, compassion is thus the acknowledgement of the suffering, vulnerability and dignity of people through the judgement of undeserved suffering: 'this person did not bring the suffering on himself or herself' (p. 321). Compassion helps to see the structural mechanisms that could lead to suffering. It also acknowledges that there are vulnerabilities, suffering and structural mechanisms that cannot be easily undone. PAR and related transformative research practices could also benefit from researchers fully acknowledging pain and suffering (their own and that of others involved) through Nussbaum's understanding of compassion.

Carefully navigating compassion and action

Yet, in describing our moral dilemmas in this research, we felt as if we created a false dichotomy between fostering action and expressing compassion. Through our reflections we were able to move beyond this dichotomy, which actually aligns with debates within the field of AI. In recent years, AI scholars have argued

against these polarities and urged other scholars to avoid simplistic notions of positive and negative (Bushe, 2011; Zandee & Cooperrider, 2008). The dichotomy we created and embodied as we described in the second-level reflection is thus exemplary for this debate. The importance of moving beyond this dichotomy is increasingly emphasized within the field of AI, as has always been the intent of Cooperrider and Srivastava (1987). Our reflections very much resonate with the following quote from Cooperrider, one of the founding fathers of AI:

‘The more I move towards AI, the more I personally feel a need to also face the ugly. And yes, then I do embrace the appreciative stance’ (Cooperrider, 1997 in Zandee, 2017).

A central notion within AI is ‘generativity’ (Zandee, 2015). In this PAR process we came to understand that pain and suffering, when heard and acknowledged by others, can also be important sources of generative knowledge.

Actionable points

In retrospective we have formulated several learning point from this research. First, unconditional support for the outcomes of a PAR process from those in power is of utmost importance to avoid a PAR process to become set up to fail. Yet, it is important to note that this is fairly complicated in a bottom-up process in a context with many stakeholders. It is not always possible to identify strategic partners before setting out the PAR process as the important themes and dreams of those involved are still to be explored.

Secondly, as PAR processes are messy, complex and above all relational, PAR facilitators have a responsibility to take care of the participants within their research (Groot et al., 2018). Being able to attend to the emotions that arise within a PAR process, both negative and positive, might not always lead to action, but is crucial to attain ‘epistemic justice’ within the research process (Fricker, 2007). Epistemic injustice refers to a situation in which someone is wronged in their capability as a reliable knower. Acknowledging the value and truth of the full story of those involved in the research process (i.e. epistemic justice) is therefore the counterpart of a silencing act, in which parts of one’s experience are silenced, which is an unethical exhortation of power. Thirdly, reflection of PAR facilitators concerning their position towards powerlessness and suffering before setting out and during their research is essential to create a more (care) ethical research process. We conclude that when hope for change is diminished and experiences of suffering and hopelessness are expressed by individuals, professionals, such as PAR facilitators, need to create space and sensitivity to carefully balance action and compassion. In order to do so, space is needed for PAR facilitators themselves as well, to share and reflect on their own emotions and moral intuitions concerning suffering and feelings of powerlessness.

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CHAPTER 8

Navigating voice, vocabulary and silence

Developing critical consciousness in a photovoice project with (un)paid care workers in long-term care

Abstract

Background:

Photovoice is a widely used approach for community participation in health promotion and health promotion research. However, its popularity has a flip-side. Scholars raise concerns that photovoice drifts away from its emancipatory roots, neglecting photovoice's aim to develop critical consciousness together with communities. Our four-year photovoice project aimed to unravel how the health of (un)paid care workers was shaped at the intersection of gender, class and race.

Design:

This article springs from first, second and third-person inquiry within our research team of (un)paid care workers, academic researchers and a photographer.

Findings:

We observed that critical consciousness emerged from an iterative process between silence, voice and vocabulary. We learned that photovoice scholars need to be sensitive to silence in photovoice projects, as silence can be the starting point for finding voice, but also a result of silencing acts. Social movements and critical theories, such as intersectionality, provide a vocabulary for participants to voice their critical perspectives to change agents and to support collective action.

Discussion:

We discuss our experiences using Frickers' concept of 'epistemic justice', arguing that critical consciousness not only requires that communities are acknowledged as reliable

knowers, but that they need access to interpretative tropes to voice their personal experiences as structural.

Keywords

participatory health research; photovoice; critical consciousness; community participation; intersectionality; epistemic justice; long-term care; unpaid care workers; paid care workers; occupational health

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Introduction

Photovoice is a widely used approach for community participation in health promotion and health promotion research (Catalani and Minkler, 2010). Photovoice is a visual methodology that aims to foster collective action and social change (Wang and Burris, 1997; Liebenberg, 2018). It is often conducted within participative and action-oriented research approaches, such as Participatory Health Research (Wright, Springett and Kongats, 2018), Participatory Action Research (Reason & Bradbury, 2012), Community Based Participatory Research (Wallerstein et al., 2017) and Transformative Research (Mertens, 2008).

The goal of photovoice is threefold (Wang and Burris, 1997). First, photovoice allows participants (or: community members) to express their lived experiences by using photography. Second, photovoice aims to create a dialogical space to understand how personal experiences are shaped by broader structural inequalities. Third, it enables participants to challenge these experiences of marginalization together with researchers and other stakeholders ('change agents') such as professionals and policy makers.

Photovoice, as developed by Wang and Burris, is grounded in critical social theory, including feminism, postcolonialism, social justice theory and Paulo Freire's work on the pedagogy of the oppressed (Wang and Burris, 1997; Liebenberg, 2018; Freire, 1968). In the last decades, photovoice became increasingly popular among health scholars (Golden, 2020). Currently, photovoice is often seen as a 'fun', 'quick' and 'easy' way to gain access to participants' lived experiences and share these in an accessible manner with policy makers (Liebenberg, 2018). However, its popularity also has a flip-side. Scholars raise concerns that photovoice drifts away from its critical and emancipatory roots, neglecting photovoice's aim to critically reflect upon broader societal structures of oppression together with participants (Gubrium and Harper, 2013; Sanon, Evans-Agnew and Boutain, 2014; Coemans et al., 2019; Derr and Simons, 2020).

Liebenberg (2018) (p. 1) brings into remembrance how Wang and Burris aimed photovoice to be an '*analytical, pro-active*

and empowering' endeavor that honored participants' expertise and wisdom. She argues that

'part of honoring this wisdom and experience requires us to facilitate critical reflection on structurally embedded experiences, and that the knowledge emerging from this reflection is both given a platform from which to be voiced, and equally important, amplified in ways that are heard'.

In other words, photovoice is not solely meant to voice participants' lived experiences to policy makers. Photovoice should also amplify participants' perspectives on structural systems of oppression to these policy makers. Failing to address these structural issues could—unintentionally—turn photovoice projects into a disempowering experience (Duijs, Baur and Abma, 2019).

However, knowledge about developing critical perspectives on structural systems of oppression is underrepresented in photovoice literature (Liebenberg, 2018; Sanon, Evans-Agnew and Boutain, 2014; Coemans et al., 2019; Derr and Simons, 2020). Multiple (scoping) reviews—in diverse fields—focus on scholars' difficulties to reach policy makers with outcomes of their photovoice project, but they pay little attention to the critical reflection of participants (Dassah et al., 2017; Mysyuk and Huisman, 2020; Han and Oliffe, 2016; Fountain et al., 2021; Suprpto and Sunarti, 2020; Ilagan et al., 2020; Halvorsrud et al., 2021; Lofton and Grant, 2021). Articles that focus on developing critical consciousness with participants remain

scarce (Carlson, Engbretson and Chamberlain, 2006).

In this article, we describe how critical perspectives on structural embedded experiences can be developed in dialogue with participants rather than about participants. We draw from our experiences in a four-year photovoice process with paid and unpaid caregivers in residential long-term care. These paid and unpaid caregivers are members of the health workforce in long-term care and, thus, a part of the community (they are not representatives of this community, as no citizen can ever represent its' entire community) of (un)paid care givers. In this project we critically reflected upon community researchers' experiences with care work, informal caregiving and health and collectively unraveled how these were shaped by structural inequalities, including gender, class, ethnicity and age.

This photovoice project was part of a bigger PHR study into the health and wellbeing of (un)paid care workers. Our photovoice project was informed by critical gender and intersectionality theory. We will elaborate on intersectionality in more detail below (theoretical framework). We reflected upon our four-year project with the entire research team, consisting of academic researchers, a scholarly artist (photographer) and five (unpaid) care workers who participated in the photovoice process, to whom we will refer to as community researchers.

In our photovoice project, we collectively unraveled the complex interplay between

gendered (theme 1), classed (theme 2) and racialized (theme 3) inequities. Reflecting upon this process, we came to understand that the critical consciousness of these structural inequities emerged from an iterative process between silence, voice and vocabulary. Based on our reflections, we argue that photovoice scholars need sensitivity to recognize many meanings silence can have in photovoice projects, as these as the starting point for findings voice. We also stress the importance of engaging with critical theories, such as intersectionality, as these provide a vocabulary that enables participants to voice their critical perspectives to themselves and to others.

We conclude that critical consciousness on structural inequities is an essential aspect of epistemic justice (Fricker, 2007). Facilitators of photovoice can contribute to epistemic justice by creating spaces in which participants are acknowledged as reliable knowers (witnessing justice). However, Fricker's (2007) notion of epistemic justice urges facilitators to introduce interpretative tropes that are necessary for critical consciousness (hermeneutic justice).

With this article, we aim to address current concerns about photovoice by illustrating how critical consciousness can be fostered in photovoice processes together with participants. In addition, we aim to contribute to the growing body of literature that aims to combine emancipatory research approaches, such as PHR and photovoice with intersectionality (Fine et al., 2021; Fine and Torre, 2019; Teti et al., 2021; Kapilashrami and Marsden, 2018; Ferlatte and Oliffe,

2019; Verdonk et al., 2019), as we think that intersectionality offers a valuable framework for critical reflection on the specific nature of these societal structures of oppression.

Theoretical framework

Intersectionality

In the last decades, intersectionality has emerged as such an ‘interpretive trope’ to understand lived experiences in their socio-political context. Grounded in queer women of color’s experiences and academic reflections, intersectionality has emerged as an ideological, theoretical and methodological approach (Verdonk et al., 2019; Combahee River Collective, 1997; Hancock, 2007; Collins and Bilge, 2020). It aims to understand how multiple aspects of identity and/or multiple systems of oppression interact with each other to shape peoples lived experiences. The term intersectionality was coined by legal scholar and critical race theorist Kimberlé Crenshaw (1990). Embraced by activist movements, intersectionality builds upon the premise that ‘all oppression is connected’ which provides a shared narrative that allows for alliances between social movements.

In the last decade, intersectionality receives growing attention from scholars studying (health) inequities (Hankivsky, 2021; Hankivsky et al., 2017; Hengelaar et al., 2021). For health scholars, intersectionality provides a framework to (1) understand health inequities within and between groups (McCall, 2005), (2) identify groups who are specifically at risk, but remain

invisible in single-axe analysis (Purdie-Vaughns and Eibach, 2008), and (3) understand how these health inequities are shaped in their broader societal context, taking into account societal systems of oppression, including but not limited to patriarchy, class, racism, ableism or environmental injustice (Hankivsky et al., 2017).

Setting

Societal Context of Our Photovoice Project ‘Negotiating Health’

In the Netherlands, the health of paid and unpaid caregivers is under pressure. Due to an ageing population and austerity measures in long term care (LTC) both paid and unpaid caregivers have to deal with higher care loads. Studies show how their health and wellbeing is increasingly under pressure, but not for all care workers in a similar manner (Duijs, Verdonk and Abma, 2019).

In response, scholars and societal organizations expressed concerns about growing societal inequalities due to these policy transitions. Care organizations wonder how they can provide diversity-sensitive HRM policies to their employees, to address their specific care needs. They advocated for diversity responsive and intersectional perspectives on the health of healthcare workers.

Therefore, authors of this paper worked together in a (PHR) study called Negotiating Health (2018–2022). This study aimed to understand how the health and wellbeing of (un)paid care workers in elderly care (45–67 years of age) was shaped at the nexus

of gender, class, race and disability, thus: from an intersectional perspective. This study was funded by the Netherlands Organization of Health Research and Development (grant number 849200012). The research team consisted of academic researchers (Duijs, 36 years old; Abma, 58 years old; Bourik, 50 years old; Verdonk, 57 years old), a professional photographer (Schrijver, 50 years old) and five community researchers who have experiential knowledge as an (un)paid caregiver in residential long-term care (Senoussi, 55 years old; Abena-Jaspers, 55 years old; Plak, 63 years old; Jhingoeri, 54 years old; anonymous, 55 years old).

The findings in this paper derive from the (photovoice) process that took place in advance (phase 1), parallel to (phase 3) and after (phase 4) several interview studies that were conducted as part of Negotiating Health (phase 2). The findings from these qualitative sub-studies are published elsewhere (Duijs, Verdonk and Abma, 2019; Mazurel and Abma, 2019; Duijs et al., 2021; 2022; Wees et al., 2023).

Methodology

Research Approach

We position ourselves in the critical and feminist strands of PHR (Wallerstein et al., 2017; Fine et al., 2021, Fine and Torre, 2019; Reid & Frisby, 2008). We conducted our photovoice project, following Wang and Burris’ (1997) approach, who employed photovoice as a means to foster critical reflection, collective action and social change (Liebenberg, 2018).

We opted for photovoice from our own positive experience with arts-based research (Gergen and Gergen, 2016). The long-term care sector is characterized by dominant narratives and recurring societal debates around the health and wellbeing of care workers, often focusing on psychosocial working conditions. We aspired to move beyond such well-known narratives and capture new realities, literally, that would spark collective action. Photography has the potential for emotive and moral appeals on change agents (Wang and Burris, 1997; Gergen and Gergen, 2016).

Phases of Our Research Process

The photovoice process consisted of (roughly) six-weekly, 2 h long meetings between 2018 and 2021. Roughly, four phases can be identified (see Table 1). In the first phase, ten paid and unpaid caregivers in long-term care participated in the photovoice process to set the research agenda for the broader PHR study. In the second phase, five out of ten participants continued to participate as community researchers. Together, we conducted three qualitative interview studies into the experiences of men and women, hired employees and self-employed care workers in long-term care (phase 2). Parallel to these qualitative studies, we continued our own reflexive process through photovoice and aimed to deepen our understanding of the societal and intersecting systems that shaped our own and others’ lived experiences in long-term care (phase 3). In the last phase (phase 4), we co-created four portraits, included in a book, to communicate our main findings to change-agents.

Phase	Year	Activities	Participants	Results	Typology of Hermeneutic Understanding	Critical Lens
1	2018–2019	Photovoice (n = 10 meetings)	10 (un)paid caregivers	Article in journal for professionals in the health and social care domain	Academic researchers reflecting about participants' photographs and narratives	Gender
2	2019–2021	Photovoice	5 co-researchers	Op-ed in national newspaper	Dialogue between co-researchers, photographer and academic researchers	Gender/Class
3	2019–2021	PHR projects	5 co-researchers	Scientific article #1 Scientific article #2 Scientific article #3 Scientific article #4	Academic researchers and co-researchers reflecting about respondents in the qualitative sub-studies of Negotiating Health	Gender/Class/ Race/Disability/ Sexuality
4	2019–2021	Photovoice	5 co-researchers	Portraits and Book	Co-creation of portraits and book	Gender/Class/ Race/Disability/ Sexuality
5	2021–2022	Dialogue and Action	4 co-researchers	Dialogue meetings with change agents Book presentation	Dialogue with change agents	Gender/Class/ Race/Disability/ Sexuality

Table 1. Phases of PHR project Negotiating Health (2018–2022)

Our six weekly photovoice meetings were facilitated by the academic researchers and the professional photographer. Data in this photovoice process consisted of the photographs, made by and of participants in co-creation with the professional photographer. Other sources of data are audio-tapes and transcripts of monthly meetings and field-notes of the academic researchers/photographer. In addition, in crucial moments semi-structured interviews and numerous informal conversations took place between researchers, photographer and community researchers.

First, Second and Third-Person Reflection
PHR scholars stress the importance of first-, second- and third-person inquiry (Reason and Torbert, 2001). First person research centers around the reflections of one's own practices, dilemmas and emotions (I-perspective). Second person inquiry focusses on reflection between people, such as the reflection that takes places within a PHR research team (we-perspective). Third person reflection refers to the reflection that takes place within broader communities, such as a community of practice or academic debates. This article springs from

the first, second and third-person inquiry that took place within our PHR research team. We extensively reflected upon our photovoice project during and after the photovoice process, continuously moving back and forth from individual perspectives (first-person), collaborative reflections (second-person) and connecting these to academic theories such as Fricker's (2007) epistemic justice or intersectionality (Combahee River Collective, 1997; Hancock, 2007; Collins and Bilge, 2020; Crenshaw, 1990; Hankivsky, 2021; Hankivsky et al., 2017; McCall, 2005; Purdie-Vaughns and Eibach, 2008) (third-person). The academic researchers took the lead in writing this article, yet the voices of the photographer and community researchers have a prominent place. The consolidated criteria for reporting qualitative research (COREQ) guided the reporting of this study (Tong et al., 2007). In addition, the article was re-written until everybody felt that conflicting and shared perspectives were adequately described. This study was evaluated by the VUMC Medical Ethical Review Committee which confirmed that the Dutch Medical Research Involving Human Subject Act did not apply (dd. 17 April 2018). All community researchers consented to including their pictures in this article.

Results

In this section, we present the dynamic between silence, voice and vocabulary in four themes, which reflect the chronological process of our research project:

- In the first theme, '*What on earth am I doing?*', we described how we developed critical consciousness on gendered inequities. This process took place in phase 1 of our photovoice project.
- In the second theme '*We should all be wearing yellow vests*', we describe how critical consciousness led to us speaking out about inequities that were shaped at the intersection of gender and class. This process took place at the beginning of phase 2 of our photovoice project.
- In the third theme, '*You'd rather not see it*', we not only describe how we broke the silence on racial inequities but also how we were consequently silenced by each other and by change agents. This process took place at the end of phase 2 of our photovoice project.
- In the fourth theme, '*What you don't see*', we present the portraits and booklet that we created and used in dialogue with change agents. These portraits and booklet describe how the health and wellbeing of paid care workers in long-term care is shaped at the intersection of gender, class and race. This process takes place in phase 4 of our photovoice project.

Each theme will reflect how critical consciousness came about in this iterative process of silence, voice and vocabulary.

‘What on Earth Am I Doing?’ Developing Critical Consciousness on Gendered Inequities

At the beginning, our photovoice project was experienced as a preluding silence: ‘a process that allows one to go within before one has to speak or act’ (Malhotra and Rowe, 2013) (p. 2). This silence was enabled by photography.

If you make a photo, you literally have to stand still and look at your live. And then it also becomes visible for others. When I looked at my own pictures, I realized: what on earth am I doing? That made me think about my life. (community researcher)

We immediately observed a gendered difference in the photographs. Whereas the women’s photographs were personal and intimate, the male community researcher voiced political concerns about working in long-term care, being initially silent about the impact on his own life and work. The

photographs sparked a dialogue among the participants in which they started questioning experiences that were normalized.

You start talking and recognize things from each other. That’s when you start thinking: ‘this is not normal’. (community researcher)

Participants could draw upon unconscious, embodied and affective methods of knowing in the silence that photography enabled. The professional photographer described this process as follows.

Directing the camera towards your own life starts a reflective process. It urges you to think about what you see in the picture. To attribute meaning to it. You often start by what is unconsciously captured in the picture, by what is ‘inside’ you. It’s like soil. You start digging, shuffle and wield the ground, and allow for the air to come in’. (photographer)



Figure 1. (a–d) Portrait of community researchers with chosen photographs

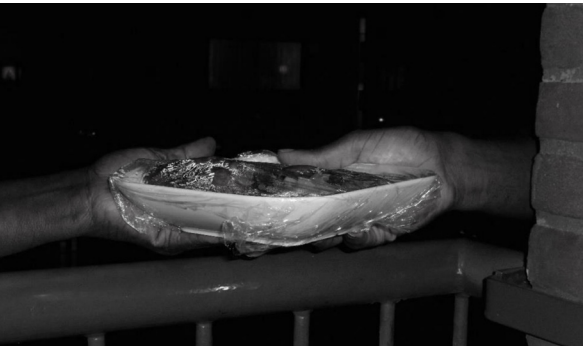


Figure 2. Photograph of community researcher handing over food to her son, titled: ‘my duty, unconditional love and care, thankful’.

Participants started voicing their experiences to each other (Figure 1a–d). They felt literally seen and acknowledged by each other. This experience contrasted with their experiences as care workers, which they characterized as, ‘Being invisible, doing hidden work’. They voiced this insight through a poster we co-created at the end of phase 1.

For academic researchers, participants’ photographs and lived experiences with ‘being invisible, doing hidden work’ resonated with academic theories on women’s caring identities (Skeggs, 1997; Forssén, Carlstedt and Mörtberg, 2005) and women’s care responsibilities as a source of gender inequity (Bhattacharya, 2017; Fraser and Jaeggi, 2018; Vogel, 1983; Tronto, 2013). The academic researchers shared these reflections with the participants but noticed that these were not (yet) engaging for participants. Feeling pressured to publish about our project, the first author published an article in which she theorized about the participants, rather than with the participants (Duijs, Verdonk and Abma, 2019). Opening up a conversation about which theories did resonate, and which did not, enabled us to search for a vocabulary that enabled participants to understand their experiences. Participants emphasized the meaningfulness of caregiving [Figure 2] and the pain of not being able to care (Figure 3).

Their experiences did resonate with a care ethical perspective (Gilligan, 1982; Tronto, 2013) that emphasized the importance of caregiving for our societies. Looking back,

community researchers appreciated that theoretical concepts were brought into the conversation, even when they did not all resonate with (all of) them: Theories provided had the potential to break the silence also in one’s self.

For me, these moments were really eye-opening. You just realize, wow, what happened to me (pregnancy discrimination) was not just an incident. I started to look back at certain life events, and started to see them in a new light.’ (community researcher)

If you don’t have the words to describe what happened to you, then how can you speak about it? If it’s something that is never spoken about, you don’t hear the experiences of others, and you are the first to put it into words, that is just so hard. It’s not likely that it will surface, or that you will speak out. (academic researcher)

Figure 3. Photograph of a community researcher whose hands are tied while looking at a picture from her mother who lives in Surinam, titled: ‘missing out/the loss’.



Engaging with theories (vocabularies) did result in tensions and dilemmas also within the research team. The academic researchers and the photographer struggled with the following question:

When and what is an ethically and relationally sound way to engage with complex concepts in a photovoice process?

While some believed that engaging with theories was essential for fostering critical consciousness, others feared that adding theoretical perspectives by academic scholars might endanger participants own process of finding voice. We concluded that engaging with theories requires courage, sensitivity and timing from facilitators to bring this this knowledge to the table in a horizontal manner.

It's a process of trial and error, and that's no problem as long as you stay connected with each other throughout this tension. If participants don't respond to our input, we can reflect on it, maybe they need time to process, maybe they cannot relate. Either way, it requires courage to stay close to 'what is', that is the hardest thing to do. (photographer)

**'We Should Be Wearing Yellow Vests!'
Speaking out about Inequity at the
Intersection of Gender and Class**

In the second phase, community researchers' (from here onwards, we speak of community researchers rather than of participants to emphasize the changing nature of our collaboration. See Table 1) experiences as low-paid workers in residential long-term care were discussed more elaborately. The community researchers began to understand some of their experiences with (paid) care work as a form of gendered and classed-based exploitation. Obviously, it was not the gendered caring responsibilities per se but rather the fact that care work was structurally devalued, also economically, by society, political policies and healthcare institutions, putting their health, wellbeing and financial situation under pressure (Bhattacharya, 2017; Fraser and Jaeggi, 2018; Vogel, 1983). This understanding sparked anger in the group and immediately evolved into collective action. The community researchers found their voice. What happened?

At this time, the French 'Yellow Vests' movement' was prominently covered in newspapers and television. People protested against low wages in combination with



Figure 4. Picture of community researchers with protest signs and yellow vests.



Figure 5. Picture of community researchers with yellow vests.

increasingly high costs of living. In a meeting, we discussed the impact of paid and unpaid care work on community researchers' health and livelihood. This issue was of particular importance, as we observed that many of care workers deal with poverty and/or debt in our interview studies. One of the community researchers repeatedly started saying, 'You know, we should also be wearing Yellow Vests.' The others agreed—the vocabulary of class-based inequities resonated with them. Two community researchers had formerly been active in the labor union and/or in local politics, and they took 'ownership', as they thoroughly understood what was at stake and embraced class in particular as an 'interpretive trope' (vocabulary).

An academic researcher (first author) responded by asking what the Yellow Vests should look like and what slogans would fit. Slogans emerged at the interaction of gender and classed-based exploitation,

I provide care with love, but not at the expense of my income, pension and health.

The vests were printed, and in the next meeting, the community researchers' picture was made as an official 'protest' (Figure 4 and Figure 5).



Figure 6. Pictures of community researcher doing paid care work with protest sign.

Figure 7. Picture of community researcher doing unpaid care work wearing yellow vest.

As critical consciousness on gender/class-based inequities grew, the community researchers wanted to voice their message to a broader public. Collaboratively, we translated our insights and righteous anger into an op-ed to be published in a national newspaper. In the op-ed, the community researchers stated that quality of care came at the expense of their health, income, free-time and pensions (Mazurel and Abma, 2019).

In addition to the op-ed and the ‘protest’ pictures, the community researchers also wanted to be photographed by the professional photographer with their Yellow Vests and with their protest signs (Figure 6 and Figure 7). Photography became an act of protest in itself, and an act of making the invisible—literally—visible. This illustrated the pivotal role of photography, and other arts-based methods in this project. Photovoice allowed for both ‘verbal’ and ‘non-verbal’ vocabularies and speaking up was supported by a variety of ways to express voice, including art. By ‘commissioning’ these portraits, they took control over how they wanted to be photographed, which reflected their empowerment process.

Although the op-ed was written collectively, several community researchers did fear for the consequences at their workplace by speaking up (silence). Eventually, the op-ed was signed by the only male participant. Although he was just as anxious as the other community researchers, he felt backed up by the union, his manager and the fact he recently exited LTC to work in psychiatric care. His sent his

reflections on his individual decision-making process on whether to co-sign the op-ed to us and to his manager.

And suddenly I was very ashamed, that in these peaceful times, I am afraid to put my name under a newspaper op-ed. Notably, the resistance newspaper that my father risked his life for many years ago.
(Community researcher)

His letter illustrates how the ability to speak out (voice) was shaped at the intersection of gender and class, in this case professional status. Expressing criticism on the ‘system’ without fearing consequences or backlashes was an issue for everyone, including the academic researchers. By supporting the community researchers’ op-ed, the latter put their position as ‘neutral’ and ‘objective’ researchers on the line. This concern was explicitly voiced by a member of the project’s steering group. In the end, the op-ed was signed by the full professor (author) and by the male community researcher; those with the most privileges.

Amplifying the community researchers’ critical perspectives to places outside of the direct research process was challenging. The op-ed received support from care workers and unions (Westerlaken, 2019; Haalboom-Schram, 2019), but it was critically appraised by our own steering group. Several members fed back that our op-ed focused ‘solely on what was negative’, that it was not representative for the entire long term care sector, that it reinforced negative stereotypes about working in long-

term care and that it was not solution-oriented and failed to offer practical recommendations or clear-cut policy directions. Their responses communicated to the community researchers that there was limited space for their authentic ‘rough-edged’ narratives, although they also understood that this response came from a place of concern and worry for the sector. Throughout the project, we have not succeeded in organizing a dialogue between the steering group and the community researchers. Fear of being silenced was an obstacle for the community researchers to take a seat at the table.

This project enables to voice my concerns, speak out about the things that need to be heard. Our group makes me feel safe, and this safety helps you to articulate your experiences and voice them to others. I cannot always deal with the confrontation with managers or policy makers. They make you feel so small, so powerless. You don’t expect any support. They will downplay your story: ‘It’s not representative for the entire sector. It’s not happening. It’s not true.’ And then you start believing, maybe you are right.
(Community researcher)

‘You’d Rather Not See It’ Breaking the Silence on Racism

In the third phase, racism and its impact on (occupational) health emerged from interviews with other care workers. These interviewees’ stories uncovered (community) researchers’ own experiences, experiences that had thus far remained unspoken (silence). We spoke of experiences with race in general, but particularly

with racism shaping their daily care work and labor market experiences in the care sector. Our photovoice project did not ‘educate’ the community researcher on matters of ‘race’. Obviously, and unknown by the academic researchers, most community researchers had already been racially aware, and they were urged by their children to speak out.

We have learned to stay silent. Be modest. Listen to your boss. My children are not like that. They would say to me: mom, speak out! The younger generation doesn’t stay silent, like we have learned to be. (Community-researcher)

Rather, we reached a level of trust that allowed community researchers (and academic researchers) to express these vocabularies. The community researchers entered our photovoice project with a fair dose of ‘healthy mistrust’, as to them, it was not to be expected that white academic researchers would acknowledge their knowledge on racism as trustworthy or would support them in speaking out about these issues.

Too often you are asked to participate in a research project that turns out to be about someone else’s agenda. They say it’s about us, but in the end, it is not about us at all. (...) Our stories are often just erased. (Community researcher)

Many stated that they were urged by their children to speak out, *The younger generation doesn’t stay silent, like we have learned to be* (community researcher). Moreover, in our project, community researchers and academic

researchers started to voice their experiences. Speaking out was supported by arts-based methods. Together, we watched a video ‘Variations on White’ on racism in healthcare, developed in an earlier project at our department, which supported the conversation.

Meanwhile, in the outside world, the Black Lives Matter movement placed racism front and center in the nation’s attention. BLM provided an opportunity for white academic researchers to openly identify themselves as an ally, by supporting the protests and speaking out in public (Muntinga and Verdonk, 2020). In our app group, countless articles and experiences were shared about racial inequities, reflecting the group’s critical consciousness of racism.

However, while class-based inequities united the group and created collective action, the racialized discussion caused friction, especially in relation to the white male community researcher. Racism was a contested vocabulary, and as the women in the group started sharing feminist and anti-racist outings in the group app, the white male community researcher distanced himself from the group.

I decided to quit with our project. I realized that I was very angry about something (...) Now, I realize that I feel attacked as a ‘white man’. It is very unpleasant to be held accountable as a member of a group, when this group is seen as something that is very different from who I am and how I see myself. (Community researcher)

Critical consciousness about gender/class moved our focus to broader societal structures, enabling a conversation without blaming specific individuals. However, the opposite happened with racism. The discussion immediately became ‘personal’. Conversations did not lead to collective action, but they were experienced as divisive by the male community researcher. He felt misunderstood and excluded. We were not able to collectively speak of racism as a system that hurts us all; the system was exclusive and the vocabulary used to expose the system was not. The other community researchers did not respond to him leaving the group. Again, silence entered our joint space.

Silence on racism entered our photovoice process multiple times hereafter. For example, in a session that aimed to visualize the main findings of our study, the photographer—who had not been part of all our conversations about racism and aimed to explore participants’ experiences in the midst of the COVID-19 pandemic—glanced over the main themes, stumbled upon the word ‘racism’ and, in a split second, discarded the theme, ‘hmm, that might be a little too abstract for now’. None of us intervened. Only later, we began to understand this dynamic as result of whiteness. Racism can only be ‘too abstract’ from the perspective of those who do not have to live the experience of racism. Fortunately, we had built enough trust to reflect on this moment and, in a humbling process, we broke our white silencing and brought racism back to the table.



Figure 8. (a–d) Portraits of community researchers in book ‘What You Don’t See’.

Silence also happened in dialogue meetings with change agents as part of our photovoice process. For example, in a meeting with managers, one manager expressed her love for the photograph of a community researcher that expressed the necessity to root out racism. After the manager listened to the corresponding narrative and became aware of the message, she stated the following.

Now I know the story behind the photograph, it is not as pretty to look at anymore. You’d rather not see it.

For the community researchers, such reactions reflected their positions within many LTC organizations.

Our stories have a rough edge. You can consider it a bad thing, but it is what it is. It’s not like social media, where everything is covered up under a nice filter. This is reality. Our reality. A lot of people live in a different reality. Then our stories might be too rough

and confronting. Not everybody is willing to look at it. (Community researcher)

‘What You Don’t See’ a Book Voicing Critical Perspectives on Gender, Class and Race

In this paper, we describe the critical perspectives on gender, class and race that emerged from the iterative process of silence, voice and vocabulary. This process resulted in four portraits of the community researchers, each communicating a critical perspective on how their health and wellbeing as paid care workers in long-term care is shaped by structural inequities (Figure 8a–d). These portraits are used in dialogue meetings with change agents, such as managers in LTC, policy makers, HRM managers and occupational health professionals and will be published in a book that is co-created by the community researchers, academic researcher and photographer. Our book presents the iterative process between silence, voice and vocabulary in an artful and conceptual



Figure 9. Images in book
'What You Don't See'.

manner. This book invites readers to break the silence as they have to actively uncover the four portraits (Figure 9). The portraits capture the broader structural issues, and the reader can listen to the narratives of the community researchers speaking out about these injustices (Figure 9).

In doing so, we aimed to fulfill photovoice' ambition, which requires 'that the knowledge emerging from this reflection [on structural embedded experiences] is both given a platform from which to be voiced, and equally important, amplified in ways that are heard' (Liebenberg, 2018). We hope and expect that

this book will continue its journey among change agents, where it will continue the dialogical process between silence, voice and vocabulary.

Discussion

Summary of Empirical Findings

In our photovoice project, that was part of a broader PHR process, we collectively unraveled the complex interplay between gendered (theme 1), classed (theme 2) and racialized (theme 3) inequities in relation to the health and wellbeing of paid care workers in

long-term care. Living up to photovoice's and PHR's emancipatory intentions, we particularly aimed to foster critical consciousness about these structural embedded experiences in dialogue with community researchers.

Collectively reflecting upon our process, we came to understand that critical consciousness emerged from an iterative and dynamic process between silence, voice and vocabulary. This has implications for PHR scholars in general and for photovoice facilitators in particular. Our reflections illustrate that facilitators need to be sensitive to the different meanings silence can have in photovoice projects. Silence can be the starting point for finding voice, but it can also signal unsafety as the result of silencing acts. Engaging with critical theories, such as intersectionality, played a pivotal role in developing critical consciousness. Theories provide a vocabulary that enabled participants in understanding their experiences as structural and allowed them to voice their critical perspectives to each other, to the researchers and to change agents. Intersectionality, in particular, enabled the unraveling of the complexity and intersecting nature of these inequalities, and this understanding sparked collective action. We learned that engaging with theories requires relational and ethical sensitivity from photovoice facilitators in a horizontal and dialogical manner, which includes being responsive to the vocabularies of community researchers/participants and more. We will discuss our findings in relation to literature on silence, voice and vocabulary below.

Vocabularies Are Essential for Epistemic Justice

In our reflections, we illuminate the importance of theories as they support the critical consciousness of community researchers in particular. The importance of these vocabularies resonates with the work of philosopher Miranda Fricker on epistemic injustice (2007). PHR scholars, including photovoice scholars, are increasingly recognizing epistemic justice as an important aspect of social justice (Carel and Kidd, 2017). Fricker (2007) argues that epistemic injustice can occur in two different ways.

First, testimonial (or: witnessing) injustice occurs when someone is not acknowledged as a reliable knower; their knowledge is ignored, made irrelevant, or judged as untrustworthy because of who they are. This happens, for example, when clients' experiential knowledge is seen as less credible than professional knowledge (Carel and Kidd, 2017). Second, hermeneutic injustice occurs when marginalized groups do not have access to a vocabulary that enables them to interpret their experiences and/or to describe them these as unjust, oppressive or illegal practice. Hermeneutic injustice happens when certain groups do not have equal access to institutions that provide such vocabularies, including academia, political parties, governmental institutions, literature or mainstream media. As a consequence, group members are

'more likely than others in a position (...) where they do not have the concepts or interpretative tropes to render their experiences intelligible to others, possibly even to themselves' (Fricker, 2007) (p. 257).

In our photovoice project, we realized that making photographs and organizing a dialogue is not enough to foster hermeneutic justice. We need access to interpretative tropes, as Fricker has argued.

Engaging with 'Interpretative Tropes' Requires Relational Sensitivity

Therefore, in this project, we learned that as facilitators we also needed to take up space for our own expertise and knowledge in dialogue with community researchers, granting them access to these interpretative tropes. In our project, the academic researchers actively provided knowledge on gender, class, race and intersectionality theory. At the same time, facilitators need to stay attuned to interpretative tropes that are introduced by the community researchers themselves or by societal discourses. In our project, such narratives were provided by the yellow-vest and BLM movements. We conclude that photovoice facilitators should not shy away from engaging with these vocabularies, as these are necessary for hermeneutic justice. However, at the same time, engaging with theories requires reflexivity and relational sensitivity from facilitators to not compromise participants' witnessing justice. Fricker (2007) (p. 84) describes this virtue as 'testimonial sensibility' which 'enables the hearer to the word of another with the sort of critical openness that is required for a thoroughly effortless sharing of knowledge'. In other words, developing critical consciousness is a reciprocal learning process.

Intersectionality Provides Essential 'Interpretative Tropes' for Hermeneutic Justice

Another lesson learned from this project is that intersectionality provided essential interpretative tropes to foster hermeneutic justice. The empirical findings from our photovoice process captured in the portraits and book 'What You Don't See' show how the health of care workers was shaped at the intersection of gender, class and race. Intersectionality enabled us to unravel these multiple and interlocking inequities within our photovoice process, and it gave us a vocabulary to talk about these inequities. Moreover, we observed that some single-axe analyses such as a 'gender perspective' did not resonate with participants, as has been described by other intersectionality scholars (Hankivsky, 2014). Seeing oppression at an intersection of gender and class sparked activism and collective action among the participants, as it became visible in the op-ed. Over the course of our project, we unraveled how care workers' health was shaped at the intersections of gender, class and race. Intersectionality helped to reveal these intersections and fostered critical consciousness about complex social inequalities.

Learning to Listen to Silence

In addition, we paid attention to the many meanings of silence in our research project. Our reflections resonate with the literature on silence in the research process. Scholars have critiqued simplistic (or 'thin') conceptions of voice that are 'focused on explicit utterances

and their intelligibility to others' and plea for a 'thick' conception of voice that includes 'a *thick interpretative discernment of utterances, silences and bodily expressions*' (Carnevale, 2020) (p. 2). Carnivale and others redirect our attention to the importance of silences in relation to voice (Ryan-Flood and Gill, 2010; Gatwiri and Mumbi, 2016; Van Den Berg, 2021). Silences, gaps and omissions can lead the way to untold stories, conceptualized as 'shadow stories', which remain hidden behind the spoken narrative (De Medeiros and Rubinstein, 2015; Blix, 2016). Others challenge the assumed equation between voice and power and between silence and oppression (Malhotra and Rowe, 2013). Such an equation is theoretically problematic and empirically untrue and obscures the many possibly empowering meanings that silence can hold (Malhotra and Rowe, 2013; Ryan-Flood and Gill, 2010; Gatwiri and Mumbi, 2016; Van den Berg, 2021; De Medeiros and Rubinstein, 2015; Blix, 2016). In addition, Malhotra and Rowe (2013) particularly problematize the equation between voice and power because '*the burden of social change is placed upon those least empowered to intervene in the conditions of their oppression*' and state that such an equation shifts '*the focus away from the labor that might be demanded of those in positions of power to learn to listen to subaltern inscriptions—those modes of expression that are often interpreted as 'silence''*' (pp. 1–2).

In relation to our own research project, we recognize how silence could be a starting point for finding voice and could, thus, be empowering. However, the community researchers also experienced how they were

silenced by the researchers and by change agents. Although they felt empowered by developing critical consciousness in our project, they often felt silenced at their workplace and in dialogue with change agents. Empowerment within the research team, which became a community in itself, does not necessarily translate to other life domains. In line with Malhotra and heeding the call of our community researchers, our project should also be understood as an invitation for change agents to listen to the things that are not (easily) said when we speak about the health and wellbeing of care workers, such as their experiences of poverty and racism.

Speaking about Oppression Is Painful and Not 'Positive' but Is Essential for Hermeneutic Justice

In our photovoice project, rendering social experiences understandable to ourselves was not the biggest bottleneck. However, we did experience how speaking about (multiple and interlocking) systems of oppression was in particular a painful 'interpretative trope' to others. This became tangible in tensions within our own research team (in relation to gender and race) as well as in relation to the steering group (in relation to gender/class/race). Interpretative tropes such as gender, class and race are often contested and can be hard to acknowledge in particular by those in a privileged position. This has since long been described by critical race scholars, such as political philosopher Charles Mills (2014). His concept of 'epistemic ignorance' describes white people's epistemological inability to see and acknowledge racism. In addition, with the

inability to see inequality, we also observed that norms of ‘positivity’ can turn into silencing discourses when raising your voice about injustice is not listened to because it is not ‘constructive’ (Ahmed, 2010; Arts and Van Den Berg, 2019). We recognized this dynamic in the reactions to our op-ed in specific in response to the project findings as presented in the photographs of the community-researchers at the end of the project, as well as in the community researchers’ experiences in the workplace in general.

Strengths and Limitations of Our Study

In this article, we reflected upon a photovoice project as a team of academic researchers, community researchers and a professional photographer. In doing so, we have been able to capture a wide array of voices and perspectives. Fostering reflection together with all participants contributes to the quality of the study and to ethical research practice. However, we also described how the white, male community researcher withdrew from the study, as he felt his perspective was not sufficiently addressed. As a consequence, the reflections in this paper mainly focused on women’s experiences, while we know that men’s experiences are differently shaped by norms around masculinity (Wees et al., 2023). Photovoice is highly local and contextual. However, dynamics within our photovoice project resonate with empirical findings in our broader PHR project ‘Negotiating Health’ (Duijs et al., 2021; 2022a; 2022b; Wees et al., 2023) which suggest that findings can be transferable in the Dutch context.

Conclusion

In this paper, we have described how critical consciousness in photovoice, as part of a broader PHR project, springs from an iterative process between silence, voice and vocabulary. This has several implications for participatory health scholars in general and for photovoice scholars in particular. First, we conclude that facilitators need the courage and sensitivity to engage with ‘vocabularies’ from academic theories or emancipatory movements. These vocabularies support critical consciousness and are essential for epistemic justice in photovoice. Second, we conclude that intersectionality is a useful interpretative framework within PHR and photovoice. Intersectionality enables critical consciousness about complex and intersecting inequities and supports collective action. Third, we conclude that PHR and photovoice should go beyond fostering voice to those whose experiences are marginalized. The responsibility for social change lies with those in power who can learn to listen to care workers’ silences, particularly on issues that are not easily said in relation to their health and wellbeing, such as gendered poverty and racism.

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general discussion

In this final section, I will reflect on the main findings in two ways. In Chapter 9 'What you don't see', I present four portraits. These portraits are the result of our photovoice process in Negotiating Health. Each portrait is co-created by professional photographer Janine Schrijver, a co-researcher and the academic researchers.

These portraits capture and address the main findings in an arts-based way. You can listen to the stories of Yvonne, Naziha, Olivia and Usha by scanning the QR codes.

In Chapter 10 'Precarization of paid care workers from an intersectional perspective' I will present an answer to my research questions and offer a theoretical reflection on my main findings using Fraser & Jaeggi's theory on capitalism. In this chapter, I



aim to provoke thought about the larger societal, political and economic structures which contribute to the precarization of paid care workers and shapes their health.

Protecting, maintaining and restoring the health of paid care workers in long termcare is not just an issue of individual workers or employers. It is a societal issue and shaped by political choices, as I will argue in this section.

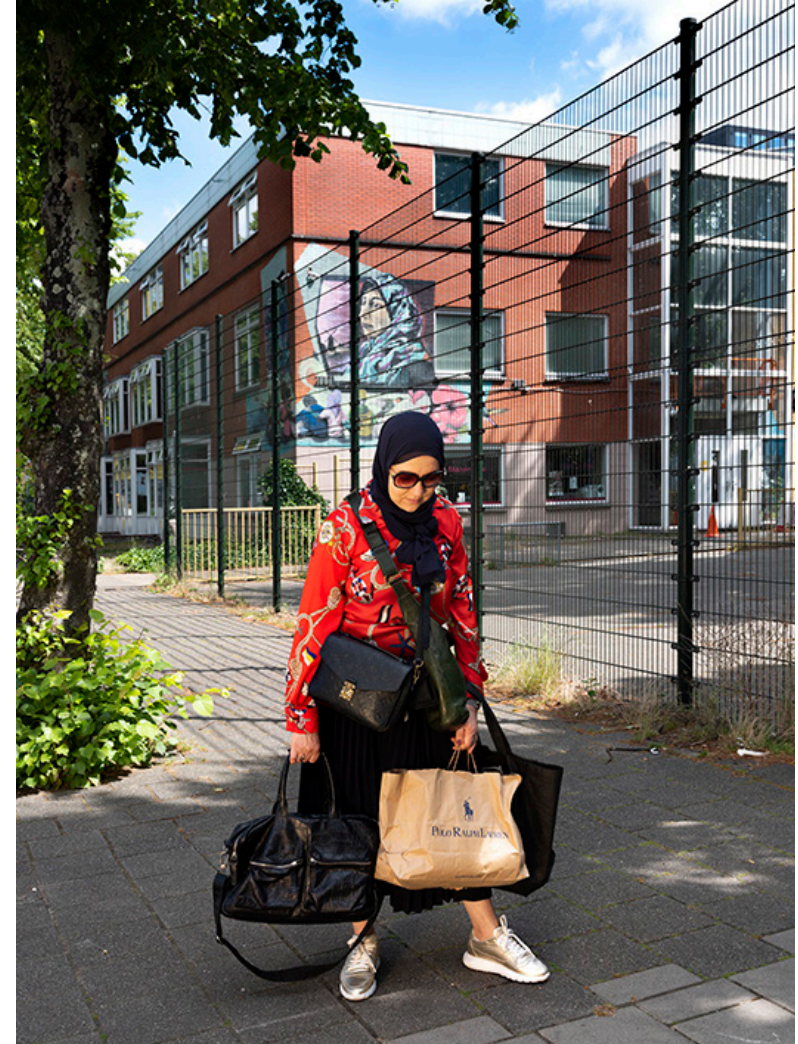
CHAPTER 9

What you don't see

A reflection on the main findings in
four portraits

Wat je niet aan mij ziet

Het verhaal van Naziha





Deze kant van
mijzelf kan ik niet
vaak laten zien

Het verhaal van Usha



Je bent
onzichtbaar

*Het verhaal van
Yvonne*



(On)zichtbaar racisme ontwortelen

Het verhaal van Olivia



CHAPTER 10

Precarization of paid care workers from an intersectional perspective

Introduction

Aim of this thesis

This thesis aimed to understand the health and wellbeing of (un)paid care workers in residential long-term care for older people, from an intersectional perspective. In this thesis, I describe how societal inequities permeate labor markets and workplaces, leading to precarization of paid care workers and impacting their health. But not for all workers alike. Not for all *bodies* alike.

To understand these health inequities, I answer the following research questions:

- How is the health and wellbeing of nursing paid care workers in long-term care shaped by gender in intersection with class, race, sexuality and (dis)ability?
- How is paid care workers' health and wellbeing shaped by gender, across its intersections, particularly in the context of self-employment?

As a PHR researcher, I wanted to understand how those working in academia can address these health inequities together with *'those whose life or work are subject to the study'*. Therefore, this thesis also includes a methodological and epistemological research question:

- How can intersectionality strengthen participatory health research?

Outline of this chapter

In this final chapter, I will formulate an answer to these research questions. In the first section, I will present the main findings from the empirical studies which I conducted together with paid care workers. These empirical studies provide an answer to the first two research questions. This section also includes a methodological reflection, focusing on the added value of intersectionality for participatory health research, in response to my third research question.

Next, I will reflect upon the main findings in the context of capitalism (Fraser & Jaeggi, 2018). By taking on a critical political outlook on the health of paid care workers, I aim to provoke thought about the larger societal and economic structure that contribute to precarization of paid care workers and shapes their health. Protecting, maintaining and restoring the health of paid care workers in long term care is not just an issue of individual workers or employers. It is a societal issue and shaped by political choices, as I will argue in this section.

Finally, I will formulate recommendations for future research and practice, small and grand, personal and political. In the hope that this thesis can support gender and diversity sensitive measures which are needed to tackle growing health inequities among paid care workers in LTC.

Main findings

Shared experiences with the gendered devaluation of paid care work in LTC

There is one theme that permeates all chapters of this thesis, and that is the lack of societal, political and financial appreciation for long-term care work (Chapter 3–8). The lack of appreciation for long-term care was the landscape of care workers' stories; sometimes implicitly present and oftentimes forcefully voiced. This is a persistent societal issue and critique concerns have been raised by multiple political advisory boards in the Netherlands, together with unions and professional associations (RVS, 2021; WRR, 2021, SER, 2021). So, if we want to understand how the health of paid care workers in long-term care is shaped by *gender*, we cannot ignore the *gendered* devaluation of paid care work.

The devaluation of paid and unpaid care work has been subject of debate for decades within feminist movements (Fraser and Jaeggi, 2018; Bhattacharya, 2016; Vogel, 1983; 2000; Bergeron, 2016). With women being the default caregivers, devaluing feminine-typed work such as working in long-term care, is a source of gender oppression, so they argue. This gender oppression is distinctly classed and racialized. In the Netherlands, as globally, *'high-touch-low-tech'* care work is particularly low-paid and disproportionately often done by racialized care workers. The empirical findings of our studies are done in the aftermath of the 2015 long-term care reforms, as we have described in the introduction of this thesis (Maarse and Jeurissen, 2016). Care workers

in LTC often pointed to these measures, to indicate how the lack of financial and political appreciation has grown over the last years.

Gendered health strategies of men and women working in LTC

The empirical findings of this thesis show how all care workers – men and women – struggle with the lack of appreciation (Chapter 3–6,8). In this thesis, we describe how the lack of appreciation has implications for health in several ways. Including – but not limited to – the following aspects. First, psychologically, by feeling uncared for (Chapter 3–8) or experiencing status loss (Chapter 4) while working in LTC. Second, financially, as the low salaries cause financial stress and poverty, which is a risk factor for ill health (Chapter 3–6,8). Third, by squeezing people into precarious employment, which is a risk factor for health (Chapter 5 and 6). And last, through risky working conditions, which became particularly evident during the COVID-19 pandemic, where LTC received insufficient political attention and had to struggle to gain access to personal protective equipment (Chapter 6).

Yet, our studies among men and women indicate that they responded differently to this political context. We describe (Chapter 3 and 4) how individual health strategies differed among women and men, and that these health strategies were distinctly shaped by normative expectations around femininity and masculinity. But not for all women and all men alike, as these normative expectations were shaped by class, race, sexuality and (dis)ability.

Women's' relational health strategies as mechanisms of in- and exclusion

Being socialized into a caring identity (that is, prioritizing caring for others even at the expense of one's own health, cf. Forssen, 2005), many female LTC workers employed *relational health strategies*. In response to the lack of care from LTC organizations, in combination with a taboo on self-care, they often depended upon each other to protect, maintain and repair their health. In this thesis, we have characterized these relational health strategies as a care-ethical response to the given political context (Chapter 3). Supporting these *relational health strategies*, could support the health of female nurses and nursing aides in long-term care, rather than focusing solely on individualistic strategies such as learning to set boundaries.

Yet, these *relational health strategies* have a flip side. A novel finding of this thesis is that women's relational health strategies can (re-) produce mechanism of in and exclusion at the workplace. The interdependency of paid care workers often required a level of sameness. If you are dependent upon your colleagues to protect your health, it can be straining to dependent on a colleague that does not, or cannot, adhere to the normative expectation of self-sacrifice. Our empirical findings show that paid care workers who were not financially dependent upon their care work, often because they were older and/or in a heterosexual marriage, could more easily fit into this ideal image and narrated extensively about the solidarity within care teams. Paid care workers that had to set their

boundaries due to health issues, unpaid caring responsibilities or financial stress, were more likely to be excluded from care teams, just as care workers who experienced racism or were culturally othered at the workplace. Financial stress was more often mentioned by younger care workers, who often dealt with higher costs of living due to the current housing crisis.

Care ethics often focus on care ethical responses to close others, failing to address the political dimensions of care practices, for example when caring practices become mechanisms of exclusion to distant others. This finding emphasizes the importance of bridging the gap between care ethics and intersectionality (cf. Hankivsky, 2014)

Men negotiating caring and hegemonic masculinities at the expense of health

Men on the other hand responded to the lack of societal appreciation with more individualistic strategies, that were distinctly shaped by normative ideals around masculinity (Chapter 4). For them, the lack of societal appreciation was made personal, challenging their identity and status *as men*. They distanced themselves from LTC organizations and care teams and harnessed hegemonic masculinities, for example by emphasizing physical strength and leadership. This often materialized in financial and sexual rewards, especially for white heterosexual men.

Yet, this strategy backlashed in terms of health. For example, normative expectations around masculinity required men to do the

'heavy chores', often without assistive tools. Work-related complaints, both physically and mentally, were often the main reason to leave paid care work, but were frequently silenced to colleagues and managers. These insights could benefit managers, HRM professionals and occupational health physicians in LTC, to tailor workplace interventions to men and to avoid men to exit LTC.

Gendered strategies at the nexus of life-phase

Our study among women also showed how life-phase related issues such as menopausal transition shaped their health (Chapter 2,5,8). For example, several women opted for self-employment to negotiate menopausal complaints. Self-employment allowed them to employ health strategies, such as lowering their working hours or organizing enough rest between shifts, to continue their paid care work. From a societal perspective, the importance of menopausal complaints for women in LTC can be explained by the ageing workforce in LTC, higher workloads and increased retirement age (Verburgh, 2022). Men on the other hand often described themselves as stop-gappers, residing temporarily in LTC in times when work in more masculine-typed sectors was scarce (Chapter 4). Many men in LTC (aspired to) opt out or move up, making age-related health complaints less pressing for men.

Paid care work is becoming increasingly precarious for all

The second research question of this thesis focused on negotiations of health particularly in the context of precarious work. To answer

this question, we initiated several studies among self-employed care workers together with the co-researchers of Negotiating Health (Chapter 5 and 6). While self-employment is sometimes considered precarious work (cf. Vanroelen et al., 2021) we quickly realized that this is not necessarily so. Self-employed care workers often said that working as a hired employee felt just as much – or even more – precarious in terms of health, finances, unpaid caregiving or psychosocial working conditions than being self-employed. This resonated with our studies among hired employees: all stressed the precariousness of working in LTC. (Chapter 3-5,8).

This resonates with theoretical perspectives on *precarization*, such as from Marguerite van den Berg (2021), Isabell Lorey (2015) or Donatella Della Porta (2015). Van den Berg argues that work has become increasingly precarious for all workers, not only for those in temporary work or self-employment. Lorey states that '*precarization in neoliberalism is currently in a process of normalization, which enables governing through insecurity. In neoliberalism, precarization becomes democratizes*' (p., 11), now also reaching the white-middle class (cf. Van der Berg, 2021) A main conclusion from this thesis is that all care workers in LTC, including hired employees, suffer from *precarization*.

Lorey describes precarization as the result of policies and politics that create inequities among groups (Lorey, 2015). She conceptualizes this as 'governmental precarization'. The lack of political

appreciation and financial reward for LTC is such a policy that contributes to the *precarization* of paid care workers. The 2015 reforms have put more pressure on paid care workers in LTC. A board member of an LTC organization described the impact on LTC organizations as follows: '*We have allowed ourselves to become bad employers*' (Duijs et al., 2021x). Self-employment is a response to the precarization that hired employees face, consequently becoming a means of precarization in itself (Ch 3-7,8).

Health Inequities among self-employed care workers

While all care workers experience *precariousness* and are subject to *precarization*, studies in this thesis illustrate that some paid care workers experience more health risks than others. This is what Lorey describes as precarity: '*the distribution of precariousness in relations of inequality*' (2015, p.12). We observed inequities among self-employed care workers and these inequities were distinctly shaped by gender, class, race, and (dis)ability (Chapter 3-6).

We observed differences in the way men and women negotiated self-employment. Women often struggled with negotiating a feminine-typed caring identity versus a masculine-typed entrepreneurial identity. For some, this negotiating act materialized in making financial sacrifices as self-employed care workers to foreground a caring identity. This contributed to their precarization, particularly as self-employed *women*. Others could not afford to do so, but experienced scrutiny for 'doing it for the money' (Chapter

3,5, cf. 8). Men on the other hand benefited from self-employment, as their entrepreneurial identity could compensate the status loss of being a LTC worker. Yet, for them, self-employment allowed for risky health behavior, as several men worked ongoing shifts to higher their income (Chapter 4).

We also observed inequities among self-employed women (Chapter 5). For some, self-employment enabled health strategies without much financial risks. This was often true for older women in a heterosexual marriage who could fall back on their pensions, (partly) mortgage-free houses or their male partner's income. Yet, for the latter, their financial independency was under threat. On the other hand, we saw younger women who opted for self-employment to avoid poverty or debts, or to distance themselves from racism and discrimination in LTC organizations. For them, self-employment was not a health strategy, but rather a health risk (Chapter 5).

These health inequities were exacerbated during the COVID-19 pandemic (Chapter 6). While the first group had access to health strategies during the pandemic, self-employed care workers with financial stress had to make harsh choices. These choices often came at the expense of their own health and the health of their intimate others, for example because they felt forced to work risky shifts, particularly in the first-wave in 2020 (Chapter 6).

Institutional racism and precarization

In line with Lorey (2015), I want to address a second political practice that contributed

to (governmental) precarization. Throughout the studies in this thesis, I have observed the impact of the childcare benefit scandal. Therefore, I argue that the institutional racism in Dutch tax authorities have contributed to precarization of paid care workers of color. The impact became particularly visible in studies among self-employed care workers (Chapter 5 and 6). First, fear of tax authorities was mentioned as a reason to opt for self-employment by care workers of color (Chapter 5). Unpredictable working hours as a hired employee placed care workers with children at risk for retrospective payments of their childcare benefit. This was experienced as too precarious in the light of the childcare benefit scandal, particularly for care workers of color, so they opted for self-employment to keep their working hours stable (Chapter 5).

During the pandemic, I observed how the fear of tax authorities evolved in a more general distrust of governmental agencies. Many care workers, again, particularly those of color, did not dare to apply for the TOZO. This was a governmental policy response measures to support self-employed care workers (Chapter 6). Again, distrust of governmental agencies and fear of retrospective payments restricted their access to social security (Chapter 6) in the first wave of the pandemic, but also in the long term (Daia, Duijs & Verdonk, 2022). This resulted in precarious financial situations, with impact on health (Chapter 5 and 6, see also: Daia, Duijs & Verdonk, 2022).

Precarization and health

Della Porta states that *precarization* often starts in labor markets, but permeates all domains of one's life, including health (2015, p.2). This thesis illustrates the health impact of care workers' *precarization*. Precarious work, and precarization, have several health impacts and is increasingly put on the agenda as a social determinant of health (Van Roelen et al., 2021; Syed, 2020). This thesis underscores the following health effects.

First, poverty and job insecurity are in itself sickening, illustrated by the care workers that felt exhausted by their financial stress (Chapter 3,5,6,8). Second, financial stress leads to more exposure to unhealthy working conditions, such as working ongoing shifts to make end meets (Chapter 3-6,8). Third, self-employed care workers with financial stress felt pressured to work risky shifts in terms of infection, particularly during the pandemic, with heightened health risks for themselves and their families (Chapter 6).

The caring class

In the title of this thesis, I speak of the caring class. I use this term to illuminate the classed dynamics at play in the lives and health of paid care workers and the overall precarization of paid care workers that I describe in this thesis. This classed dynamic is shaped by normative ideals around 'caring', such as the lack of societal appreciation for paid care work. Hence, the 'caring class'. I also use this term to refer to the political dimension of the 'caring class', inspired by Standing's (2011) concept of the 'the precariat' as a new class.

Standing, as a political theorist, coined the term 'the precariat'. Standing argues that the precariat class '*is not a class in itself, because it is at war with oneself*' (p.3). In his political theory on the precariat class, he refers to the political and societal tension between groups who experience societal marginalization and the tendency to blame each other for their marginalisation, instead of forming alliances that challenge the shared structural mechanism that contribute to their marginalization (Standing, 2011). This divisive force stands in the way of a politics that unites those in precarious positions to fight the root causes of their precarization.

In the long-term care sector, we have seen that hired employees and self-employed care workers often feel like they stand against each other. For example, hired employees point out that self-employed care workers burden them with inconvenient shifts and an extra administrative burden. In turn, self-employed care workers often expressed that they are being treated negatively by hired employees, and feel explicitly or implicitly 'punished' in the workplace. In all studies, we sense that tensions in the workplace arise between workers. This societal dynamic even trickled down into our own research process. Tensions arose when participants or community researchers started to hold each other accountable for their experiences of marginalization (Chapter 3,8). When we were able to understand the shared roots of our experiences of marginalization, this became a uniting force, leading to collective action (Chapter 8).

In this thesis I emphasize that all workers, regardless of gender or employment-relationship, experience the same precariousness. All feel that their health, unpaid caring responsibilities and financial situation is under pressure. The insight that their struggles are connected, and characteristic of 'the caring class', can, according to Standing, be a uniting force.

Concluding remarks: unveiling the hidden determinants of health of paid care workers in long-term care

Looking back upon the multiple studies in this thesis on the health of paid care workers, I conclude that we were able to unveil several issues impacting the health of paid care workers, that often remain hidden in studies into the health of paid care workers. These themes were explicitly put on the agenda by the co-researchers of Negotiating Health, and were included in the booklet 'What you can't see'. I believe that these issues require more attention in the field of (occupational) health. Therefore, I want to conclude this section by spotlighting some of these issues, including poverty, racism and menopausal transition.

Poverty

First, the lack of political appreciation for long-term care materializes in low-payment, particularly for nurse assistants or nursing aides. Several governmental advisory boards raised concerns that the 'financial independency' of paid care workers is under threat (RVS). We know that 'working poor' are overrepresented in 'vital sectors' of our society including long-term care. In this thesis,

we observe how financial stress and poverty is a constant undercurrent in all our participatory interview studies (Chapter 3–6). Studies in this thesis describe how poverty can squeeze paid care workers out of hired employment into self-employment, as a short-term survival strategy. In turn, societal organization and professional associations for self-employed care workers worry about poverty and debts among their members. Therefore, poverty and debts among paid care workers was prioritized as an urgent theme by the co-researchers of Negotiating Health (Chapter 8).

In a study we conducted among employers, HRM professionals and occupational health physicians (Duijs et al., 2021, not included in this thesis) we understood that the number of paid LTC workers with debts is high and rising. Exact numbers are currently unknown, but LTC organizations in larger cities indicate that in some instances more than half of their employees in low-salary scales has to deal with debts. These shockingly high numbers require more attention from LTC organization and particularly from politicians, who have the political power to increase salaries for care workers. For occupational health scholars and employers, poverty is an urgent theme particularly in relation to sick-absence leave and turn-over rates. Dealing with poverty and debts has a huge impact on one's health and labor market participation. The numbers of paid care workers dealing with poverty are likely to increase, with the current housing crisis and energy crisis in the Netherlands increasing the costs of living.

Racism

Second, experiences with racism also pervaded all our participatory interview studies (Chapter 3–8) and was also prioritized as an urgent occupational health issue by the co-researchers of Negotiating Health (Chapter 8). Studies in this thesis show how racism shapes mechanisms of in and exclusion within care teams, who has access to care and support from colleagues and who does not (Chapter 3). It shapes the daily realities of paid care workers in LTC organizations, with major implications for career opportunities (Chapter 3 and 4) and health (Chapter 3–6,8). We observed that care workers of color opt for self-employment to distance themselves from racism within care organizations, but that this strategy can backfire in terms of *precarization* in the labor market (Chapter 5 and 6).

In the last year, many studies have been published about racism within long-term care. Many studies focus in experiences of racism from clients to professionals, or of clients by professionals in long-term care (Nhass and Poerwoatmodjo, 2021; Van der Tuin and Fiere, 2022; Van Loenen, Hosper and Venderbos, 2022). Insights from this thesis complements these studies, focusing on the health and labor market impacts of racism. Particularly in relation to self-employment, racism remains understudied and silenced in mainstream reports and studies. If we want to understand why paid care workers opt for self-employment, we need to be willing to address racism as a possible reason.

Menopause

Third, in our studies we observe that menopausal transition has major implications for women working in long-term care, in relation to health and labor market participation (Chapter 3,5,8). Menopause is not always recognized by women themselves or their employers or silenced as the workplace as a result of taboos (Bendien et al., 2021; Verburgh et al., 2022; Verdonk et al., 2022). In this thesis, we observe that the menopause, and the lack of support from employers in this phase, is a reason for women to opt for self-employment (Chapter 5). Other studies also show that women negotiate menopausal complaints by lowering their working hours of opt for less demanding jobs, often with major financial consequences (Verburgh et al., 2022; Verdonk et al., 2022).

Informal caregiving

Fourth, the increasing responsibilities for unpaid caregiving shape the health of paid care workers, as they are relatively often carried a double responsibility of care. This thesis confirms the importance of caring organizations to enable their paid workers to combine their caring responsibilities (cf. Plaisier et al., 2015) Two new observations stood out in this thesis. First, unpaid caregiving was an important factor to opt for self-employment (Chapter 5). And second, these experiences were different for care workers with transnational caring responsibilities (Chapter 3,5,6,8). With growing shortages of staff, and increasing LTC organizations that recruit migrant care workers, supporting care

workers who care for children, friends or family members abroad becomes increasingly important.

Methodological reflection: the added value of intersectionality

Introduction

This thesis started with a participatory research project on citizen participation, which was commissioned by a LTC organization in the context of the Social Support Act (Chapter 7). Care responsibilities were shifted from professional caregivers to informal caregivers and citizens and our 'assignment' was to support citizen participation in two neighborhoods. While this was successful in one neighborhood, where we were able to set up a meaningful citizen initiative. Our project in another neighborhood had a rough and painful edge to this.

In the seventh chapter of this thesis, I describe how the aims and wishes of citizens clashed with existing policies and political ambitions of the municipality. In this, citizens drew the shortest stick, making our participatory health research a disempowering endeavor for them. Personally, as a facilitator I struggled with my role and responsibility. Did I reproduce existing societal inequalities through our participatory research project? According to Fine and colleagues, participatory research scholars should always

'contest how science is recruited to legitimate dominant policies and practices' (Torre et al., 2012, p.171, cf. Nettleton, 2013). For example, in our project social services invited citizens with an unemployment benefit to participate in our project. These turned out to be mainly women who had just lost their jobs in the health and social care sector. They were now invited to do more or less the same work, but now unpaid. Was I complicit in re-producing gender inequality with our project?

I realized that participatory health research bears the risk of becoming an instrument for top-down policy aims. Reflecting upon the societal and political context of our project helped me to express compassion about the participants' undeserved misfortune. We argued for compassion as a care-ethical practice within PHR, particularly when change appears to be difficult or out of reach (Chapter 7). Michelle Fine & Maria Elena Torre argue that PHR scholars should remain mindful *'that we are researching in landscapes that are deeply uneven and unjust'* (Fine & Torre, 2019; p.434). They advocate for a critical participatory research praxis, that embraces a critical perspective upon these unjust landscapes. This is in line with the roots of participatory research, which is historically grounded in feminist, critical race, postcolonial and queer scholarship (Wallerstein and Duran, 2017; Abma et al., 2019).

The added value of intersectionality to PHR

A main question in this thesis was how intersectionality can strengthen participatory health research practices (research question

#3). Intersectionality is increasingly embraced as a normative, theoretical and empirical framework to understand health inequities and the multiple and interlocking societal systems of inequality that shape these inequities (Crenshaw, 1991; Hankivsky, 2012; Verdonk, 2019). Therefore, the participatory health studies in this thesis (Chapter 3–6,8) have been done from an intersectional perspective. Based on this experience, I conclude that intersectionality can benefit PHR in the following ways.

First, intersectionality theory can make inequities visible that otherwise remain hidden. In our research projects, intersectionality helped to unveil issues that often remain brushed under the carpet, such as gender inequality, racism and poverty, and how they intersect (Chapter 3–8). Opening up a conversation about these issues is the first step to critical consciousness among participants in a PHR research project (Chapter 8). The co-researchers from the study *Negotiating Health* described these moments as 'eye-opening' and empowering. That was just as much true for me personally.

Secondly, intersectionality enables the academic researchers who facilitate PAR processes, like myself, to critically reflect upon their own structural social position as researchers (Chapter 7 and 8) (cf. Muhammad et al., 2015). For example, in our project *Negotiating Health*, my whiteness contributed to the silencing of racism. Critically reflecting upon my own position, helped to open up the conversation. Reflection upon my own social

location is a central part to the studies in this thesis (Chapter 3–8). I will elaborate upon my positionality more below.

Third, intersectionality can support collective action in PAR. In this thesis, I conclude that single-axis analysis often did not resonate with participants. PHR project that only focus on people's experiences as clients, as women, as people of color, does not do justice to their complex realities. In our project negotiating health, we observed that collective action sprung from anger and frustration about inequities *at the intersection* of gender, class and racialized inequities (Chapter 8) (cf. Hankivsky, 2014).

Fourth, intersectionality's focus on structural inequities can shift responsibility for change away from marginalized communities to those 'in power'. PHR scholars are increasingly emphasizing the importance of doing PHR project with policy makers and politicians, and not only with people in marginalized positions (cf. Dedding et al., 2021). The co-researchers in *Negotiating Health* did not want to be made personally responsible for change (Chapter 8), but wanted to address the structural and intersecting inequalities shaped their lives and work in relation to policy makers. So, we did, in our participatory interview studies (Chapter 3–6) and with the portraits and book *'What you don't see'* (Duijs et al., 2022). This does not mean that co-researchers did not take responsibility for change. But instead of solving the problem themselves, they took the responsibility to engage LTC organizations and policy makers with their personal portraits

and narratives, to address these structural inequities.

Last, but definitely not least, intersectionality can contribute to a care-ethical research practice in PHR. PHR scholars often refer to Miranda Fricker's (2007) concept of epistemic injustice as a core element of ethical PHR practices (cf. Groot, 2021). Epistemic injustice occurs when people are not seen as reliable knowers, for example when their experiential knowledge is not taken seriously (Carel and Kidd, 2014). From Fricker's perspective, this is only one element of epistemic justice, namely witnessing justice. In this thesis, I argue that intersectionality can strengthen hermeneutic justice, which is the second element of epistemic justice. Hermeneutic justice occurs when people gain access to interpretative tropes that enable them to understand their experiences. It's about finding words and gaining access to concepts that allows participants in PHR processes to interpret and voice their lived experience as shaped by structural inequalities. A main finding of this thesis is that intersectionality provides such interpretative tropes, and is thus essential for hermeneutic justice. In doing so, intersectionality can strengthen care ethical PHR practices, by fostering epistemic justice in and through PHR (Chapter 7 and 8).

Positionality of the researcher

Intersectionality and PHR both emphasize that the social location of the researcher plays a major role in knowledge production. Therefore, in this section I reflect upon my own social

location and how this shaped the knowledge in this thesis. But while this thesis might be mine, the studies included in this thesis have been done together with several other academic researchers and co-researchers who were experts by experience as paid and unpaid care workers in long-term care. I cannot untie my own perspective from the many insights that have been granted to me by Olivia Plak, Casper Mazurel, Yvonne Jaspers, Usha Jhingoeri, Zohra Bourik, Martine van Wees, Naziha Senoussi, Janine Schrijver, Tineke Abma, Vivianne Baur and Petra Verdonk. They all have been co-authors on the studies that are included in this thesis, and the findings in this thesis reflect a choir of voices and perspectives.

That said, the studies in this thesis definitely reflect my own structural social position *and* personality. Using intersectionality theory, my identity can be mapped as a 36 year-old white woman, raised by a single-mother. My family was rich in cultural diversity, art, literature and creativity. So, I was confident making it through university intellectually, but financially it was not always easy. Nowadays, I am a mother myself, with two children, and with a modal income. Still white.

This shaped this thesis in the following ways. When I started out my work as a PHR facilitator, I was relatively unaware and uneducated about my own structural position. My first PHR project therefore often narrated about ‘clients’ or ‘citizens’, without taking into account the diversity among them. My plunge into motherhood in 2015 more or less coincided with my feminist awakening as an

academic. Pretty late, I must admit. So, the work I conducted in this time frame, mainly incorporated a gender first perspective. In the early phases of ‘Negotiating Health’, I struggled with my own position towards caregiving. At first, I could easily identify with a discourse of gender oppression in relation to caregiving (Chapter 8). It took me some work to shift my perspective, and also embrace caregiving as essential and devalued aspect in our society, also in my personal live. This perspective-shift developed from extensive conversations within the research team of Negotiating Health.

While writing this thesis I often thought back on the time that my mother worked in residential long-term care for older people. How she used to bring me to work, particularly on Wednesday afternoons, before losing her job and becoming unable to work again due to health issues. So, my interest in paid care work in relation to precarization does not come from a place of nowhere.

The studies done in ‘Negotiating Health’ incorporated an intersectional perspective, which initiated a new reflective process. In this phase, my whiteness as a researcher, and particularly my ‘white innocence’ surfaced. As a researcher, this un-reflected whiteness unintentionally brushed others’ experiences with racism under the table. It took me some time to realize that when interviewees spoke about ‘fuzz within teams’ they actually spoke about racism. These were silenced to me as a white researcher, and only surfaced when I started reflecting upon my own whiteness and was able to follow up on such remarks (Chapter 3–8).

Also, I am convinced that the important role of menopausal transition would have remained invisible for me. As a 36-year-old woman, I largely depended upon my colleagues and co-researchers to direct my attention to this issue. And it was co-researchers Casper Mazurel, together with our excellent intern Martine van Wees and with Petra Verdonk, who shifted my attention to the experiences of men in long-term care. Without them, chapter 4 would not have been part of this thesis.

With this reflection I actually want to pay attention to the important role of diversity within research teams and the importance of participatory research practices. So, while my own social location played a role, no doubt, the participatory research process has enriched the knowledge making process that forms the foundation of this thesis.

Theoretical reflection on main findings: paid care workers at the nexus of capitalist boundary struggles

Introduction

When the COVID-19 pandemic hit the Netherlands, it became crystal clear that care work was vital and essential to our society. Many realized that we are utterly dependent upon the work of healthcare professionals, teachers or workers in the food-supply chain. Without them, our society would not function. This insight yielded many heartwarming initiatives. Care organizations were flooded by

presents, flowers or even concerts in support to clients and care workers.

Yet, this societal appreciation did not materialize in higher financial rewards (RVS, 2021). Policy advisory boards pointed out that care workers earn 6–9% less than workers in other public sectors (SER, 2021a) and that the economic independency of paid care workers is under pressure (RVS, 2021). Care workers are – together with many vital and essential workers – overrepresented in what policy makers call ‘the working poor’ (SCP, 2018; SER, 2021b). Yet, finding political support for higher salaries is notoriously challenging (Westerlaken, 2019, WRR, 2021). An absolute low-point for many paid care workers was when, in the midst of the pandemic, several MPs walked out of the house of representatives to obstruct legislation to enforce higher salaries in the health and care sector (Volkskrant, 2020). The literal act of walking away from responsibility was as painful as it was symbolic.

The lack of societal, political and financial appreciation for care work is not a novel issue. It is a persistent societal issue. And it is distinctly characteristic for female-typed work. Care work is often seen as work that needs no expertise or skills, and in contrast with masculine-typed jobs, can thus be easily delegated to unpaid and unskilled caregivers. I have often imagined how what it would be like when our government would officially declared that – since we live in a participation society – all men should volunteer to build houses in response to our current housing crisis?

In search for a theoretical framework

After conducting the studies in this thesis (Chapter 3–8), I found myself struggling with several – theoretical – concerns. First, I wanted to understand how and why the lack appreciation for care work is such as persistent societal issue. I was in need for a theoretical perspective that could help me to understand the systemic nature and driving force of this inequity. Secondly, concerns about the labor market precarization and health of paid care workers are often characterized as a ‘wicked problem’ (Head, 2022). Societal, political and economic factors are entangled in complex and almost inextricable ways. I searched for a theory that helped me to unravel this ‘wickedness’, at least for a little bit. Third, throughout this thesis I described how the health and work of paid care workers in LTC is shaped at the intersection of gender, class, race, sexuality and (dis)ability. From an intersectional perspective, precarization and its impact on the health of paid care workers cannot solely be studied on a personal level. An intersectional analysis of health experiences and health inequities should also scrutinize the larger societal, political and economic context, hence, capitalism.

Capitalism?

I have to admit, the link to capitalism is of course not so self-evident as I propose it to be in this last sentence. Yet, scholars in health and in intersectionality are increasingly taking capitalism into account as a driver for precarization and as a determinant of health. After a decade of lifestyle medicine, scholars

increasingly turn their eye to structural and complex inequalities, focusing on social determinants of health (Grootegeod et al., 2022; Goijarts, Vonk and ‘S Jongers, 2022). These are the conditions in which people are born, grow, live, work and age, which shape their health and health opportunities. They include ‘proximate’ factors like socio-economic status, education, neighborhood and physical environment, employment, racism, discrimination, social support network and access to health care. Yet, these social determinants of health cannot be untied from their larger socio-economic context. Therefore, Flynn (2021) argues that health scholars need to distinguish ‘*between the deeper societal factors that shape the more proximate determinants of health. One of these deeper socio-structural factors is capitalism*’ (2021).

In the field of intersectionality, the theoretical work of Nancy Fraser and Rahel Jaeggi on capitalism is groundbreaking. Fraser and Jaeggi (2018) understand capitalism not ‘just’ as an economic practice, but rather as an *institutionalized social order*. Their work offers a unique intersectional analysis of this institutional social order, illustrating how capitalism is deeply rooted in class inequality, patriarchy, institutionalized racism and environmental injustice. The social order of capitalism is both global and local and pervades all domains of society. In this theoretical reflection, I will apply their theoretical lens to the residential long-term care sector.

Outline

In this theoretical reflection, I reflect upon the main findings of this PhD-project using Fraser and Jaeggi’s work on capitalism (2018). First, I will provide a definition of capitalism and particularly of our current neoliberal and financialized version of it. Second, I will introduce the concept of boundary struggles which is central to Fraser and Jaeggi’s work. And last, and this is my core argument, I will illustrate how care workers find themselves at the nexus of these boundary struggles. I will argue that these boundary struggles play out politically, but also in care workers individual lives, impacting their health, health strategies and the health inequities. In the end, I will conclude that these boundary struggles are driving forces behind the *precarization* of care workers, which I have described in this thesis.

Defining capitalism

Defining capitalism is a tricky endeavor. There are many definitions of capitalism and capitalism has different characteristics in different time frames or places. Historically, Fraser and Jaeggi distinguish between early mercantile capitalism, followed by ‘liberal’ capitalism, then state-managed or social-democratic capitalism (beginning of the welfare state), and finally, now, financialized capitalism (p.9). Financialized capitalism has moved away from state-managed capitalism and is characterized by the rise of neoliberalism (p.77) (cf. Stanford, 2017).

Fraser & Jaeggi define capitalism according to four foreground/background divisions: production/reproduction, polity/

economy, exploitation/expropriation and human/non-human nature. Profit making in capitalism is enabled by four ‘*background conditions of possibility*’. Capitalism cannot function without (women’s unpaid) care work (reproduction), without public institutions (polity), without expropriation of racialized groups worldwide (expropriation) or without natural resources (non-human nature). These background conditions make profit-making possible, while at the same time their value is structurally disavowed in capitalism. Fraser and Jaeggi use the 3D’s to refer to the process of rendering background possibilities invisible: division, dependance, disavowal. These divisions are gendered (e.g. production/reproduction), classed and racialized (e.g. exploitation/expropriation). As such, societal inequities, such as gender, class and race, are fundamentally ingrained in capitalisms DNA, according to Fraser and Jaeggi.

Fraser & Jaeggi’s concept of boundary struggles

These background conditions are neither infinitely elastic, yet treated as such in capitalism, nor replenished, and hence, exhausted. Where societies draw the line between these foreground/background conditions is contingent and is different in each version of capitalism. Therefore, societal and political struggle about these foreground/background divisions are inherent to capitalism. Fraser and Jaeggi conceptualize this as boundary struggles, which ‘*erupt at the site of capitalism’s constitutive institutional division: where economy meets polity, where society meets nature, and where production*

meets reproduction. At those boundaries, social actors periodically mobilize to contest or defend the institutional map of capitalist society – and sometimes they succeed in redrawing it’ (p.69).

At the societal level, boundary struggles can take the shape of emancipatory movements, political debates, policy measures. Boundary struggles erupt for instance when a background condition is stretched too far, or becomes morally contested in a given society. Fraser and Jaeggi mainly conceptualize boundary struggles in the political and societal realm, but they can also manifest in individual lives and health, through feelings of anger, frustration, individual choice or experiences of inequity and exhaustion. In this thesis, I will refer to this as ‘embodied boundary struggles’ that occur in the daily lives of paid care workers in long-term care.

Care workers at the nexus of capitalist boundary struggles

In this thesis I want to unravel how the health of long-term care workers is shaped by capitalism (cf. Flynn, 2021). I will do so by contextualizing the main findings of this thesis in relation to Fraser and Jaeggi’s concept of boundary struggles. In this part, I will argue that the health of paid care workers in LTC is distinctly shaped at the nexus of capitalist boundary struggles. We will focus on the first three boundaries. We will shortly touch upon struggles at the human-non human boundary. Not because they are irrelevant, but because they move beyond the scope of this thesis (cf. Chapter 6).

Production/reproduction boundary struggles

The production/reproduction division is theorized as a gendered division between ‘work’ and ‘care’ (cf. Bhattacharya, 2017; Bergeron, 2016; Vogel, 1983). It divides what societies consider productive work – worthy of wage – and which work is made invisible and left unpaid. Marxist feminists argued that Marx’ focus on men’s productive and waged-labor largely overlooked women’s reproductive labor (Vogel, 1983). Therefore, reproduction theorists put forward the question: ‘*Who produces the worker?*’ (Bhattacharya, 2016, p.1). Where to draw the line between paid and unpaid work has been historically contingent and has been the focus of feminist emancipatory movements in the last decades (cf. Bergeron, 2016). A historical example was the Wages for Housework Movement in the 1970’s. They campaigned to make domestic labor into paid labor, as a way to counter gender inequality (cf. Bergeron, 2016, van den Berg, 2021). In financialized capitalism, we see that domestic work is increasingly allocated to lower-paid (and often racialized) women (Hochschild, 2012).

The work of Fraser and Jaeggi, in line with reproduction theorists, helps to articulate the economic logic behind the lack of appreciation for care work. The 2015 policy measures, enacted in the Social Support Act and the Long-Term Care act, were legitimized by a discourse that framed ‘reproductive work’ as financially burdensome to society instead of as a precondition for productive work (Maarse and Jeurissen, 2016). These policy measures can be understood as a political production/

reproduction boundary struggle; an attempt to move the boundary between paid and unpaid care work. Or, in other words, by allocating paid care work to unpaid care workers. In the Netherlands, feminist and women’s organizations voiced concerns in response to policies that relegated caring responsibilities from public to the private sphere, because they contribute to growing gender inequality in the Netherlands (Schenk, 2013). Their protest against these policy measures can also be seen as political boundary struggles. Yet, these concerns did not spark a major societal debate or policy changes. The policies were enacted without measures to avoid growing gender inequality.

As the shifted boundary could not be countered politically, it had to be negotiated at the personal level. The main findings of this thesis can therefore be understood as embodied boundary struggles. Such an embodied boundary struggle becomes visible in the co-researchers experience of ‘*being invisible, doing hidden work*’ (Chapter 8). It was felt in paid care workers’ frustration about the lack of societal and financial appreciation for work in LTC (Chapter 3–6), which was consequently negotiated differently by men and women in LTC (Chapter 3,4), pressing their health and squeezing them into self-employment (Chapter 5). Opting for self-employment can also be seen as a boundary struggle: a protest against the gendered devaluation of reproductive work and an attempt to revalue their care work. Or in the words of a self-employed care worker: ‘*In long-term care, you don’t earn much while*

your health is ruined. As a self-employed, at least I am the one making some money out of it’ (Chapter 5).

Fraser and Jaeggi state that women’s reproductive work is not infinitely elastic. In this thesis, I have observed that in the past years, women’s reproductive work was particularly exhausted during the first wave of the COVID-19 pandemic (Chapter 6). This exhaustion should also be understood as an embodied boundary struggle, where the devaluation of long-term care led to harsh dilemmas for paid care workers in LTC, as they could no longer attend to all their caring responsibilities, both paid and unpaid, as well as self-care (Chapter 6).

In this thesis, we focus mainly on paid care work in residential LTC for older people. Reproduction theorists, including Fraser and Jaeggi, employ a broader conceptualization of reproductive work, including childcare, healthcare and education. The production/reproduction boundary struggle does not limit itself to long-term care, but has to be understood in a broader societal perspective. Societal advisory boards have indicated that when politicians continue to stir on limiting expenditures in public settings, harsh choices have to be made between public services such as care, education and poverty reduction (WRR, 2021). Fraser, in line with others (cf. Way and Gilligan, 2018), thus position the experiences within LTC as part of a broader ‘*crisis of care*’, referring to

'the pressures from several directions that are currently squeezing a key set of social capacities: those available for birthing and raising children, caring for friends and family members, maintaining households and broader communities, and sustaining connections more generally' (Fraser, 2016).

Economy/Polity boundary struggle

Economy/polity refers to the division between the market and the public realm. At the societal level, the economy/polity boundary is characterized by ongoing debates about how much the 'economy' can retract from political power and public institutions. Or, vice versa, how much the state intervenes in the economy. In this thesis, we describe how paid care workers resort to self-employment (Chapter 5 and 6). This was enabled by neoliberal policies that shifted away from state-regulated work and fostered precarious work and employment, framed as 'a flexible labor market' (Stanford, 2017). In other words, neoliberalism diminished regulations that supported the standard employment relationship and pushed tax regulations that made access to self-employment more attractive.

The increase of self-employed care workers can thus be understood as both a reproduction/production boundary struggle, as well as a polity/economy boundary struggle. On the one hand, the lack of appreciation for reproductive work squeezed their health and financial situation while working in LTC. On the other hand, neoliberal policies enabled a way out into self-employment.

In previous decades, these neoliberal policies mainly served the interest of employers by enabling LTC organizations to organize care work around clients' and organizational needs, through flexible and temporary employment (Conen and Schipper, 2019). By opting for self-employment, care workers employ these neoliberal policies to benefit themselves. As such, paid care workers effectively used the system (neoliberalism) against itself, in terms of finances, but also because of valid concerns about the quality of care. LTC organizations now suffer under increasing numbers of self-employed care workers.

In response, many societal organizations lobby for regulating labor markets and diminishing the flexibilization of labor market (cf. Commissie Regulering van Werk, 2020). This can be understood as a political boundary struggle. They aim to 'push the boundary back', as neoliberal policies have allowed 'too much' or have gone 'too far'. Also, political debates around social security for self-employed care workers can be seen as a boundary struggle, as it resolves around the question how much the state has to intervene in the economy or 'free' market. In this thesis, we particularly describe how boundary struggles had to be negotiated at the personal level, at the expense of health and financial security. This became visible in the way care workers navigated the different moral landscapes of polity and economy. Men could use self-employment to mitigate the gendered devaluation of paid care work by foregrounding their identities as entrepreneurs (Chapter 4). Women often described how they struggled to unite a feminine-typed caring

identity with a masculine-typed entrepreneurial identity (Chapter 5). Having shifted from the organizations of the welfare state (polity) into the market (economy) they felt as if they had to prove they were not 'doing it for the money'. These moral tensions materialized into financial sacrifices to foreground their caring identities, exposing how these 'gendered ideologies of care' contribute to the *precarization* of self-employed women. Here, we recognize a polity/economy boundary struggle, that intersects with the production/reproduction boundary struggle.

Findings in this thesis illustrate that self-employment was precarious and a health risk for some, but a health strategy for others (Chapter 5 and 6). So, access to self-employment needs to be tackled to stop the precarization of paid care workers, particularly those who resort to self-employment to navigate racism and poverty. For them, self-employment will backfire. Financial risks are disproportionately faced by younger workers, who are simply not able to save for their pensions based on the low tariffs as a nursing aide or advanced nursing aide. They will probably face severe financial adversity at retirement age. Yet, limiting access to self-employment, while not simultaneously addressing the lack of societal appreciation for LTC (Chapter 3-8) would leave many paid care workers stuck between a rock and a hard place. The work of Fraser and Jaeggi helped me to understand that paid care workers find themselves (at least) at the nexus of two boundary struggles (production/reproduction, polity/economy). Therefore, solutions need

to address changes at both boundaries, to counter the precarization of paid care workers, as we will argue in more detail below.

Exploitation/Expropriation boundary struggle

Fraser and Jaeggi understand the exploitation/expropriation boundary as a primary source of classed and racialized oppression within capitalism. Capitalism thrives upon a racialized divide between expropriation of racialized others at 'the periphery', versus exploitation of white workers at the 'core'. They understand this divide between periphery and core both geographically, in terms of global north versus the global south as well as in terms of a divide within countries as vertical segregation. Expropriation is not conceptualized in terms of land or natural resources. Fraser and Jaeggi speak of expropriation when care workers no longer have access to means necessary to sustain themselves, for example when their health is endangered, or when they face financial indebtedment.

In this thesis, we describe that many paid care workers experience that their health or financial situation is at risk while working in LTC (Chapter 3-6,8) (cf. RVS, 2020). We also raise concerns about the increasing number of paid care workers dealing with poverty or debts, particularly for care workers in lower salary scales such as nursing aides (main findings). So, throughout the empirical findings in this thesis, there is a strong, but often implicit, gender/class/race intersection at play. In the long-term care sector globally, and in the Netherlands as well, lower educated care work is often done by racialized women (Syed, 2020).

Based on these findings, we can conclude that particularly racialized care workers are at risk for expropriation while working in LTC. In this thesis, we present evidence that support this claim. In all studies, care workers of color, women and men, describe experiences of racism and which squeezed people into self-employment (Chapter 3–8).

On a political level, racism is not at the top of the labor market agenda, nor at the top of any policy issue, for that matter. Racialized dynamics tend to stay hidden for (mostly white) researchers and policy makers. They are hardly mentioned in political debates and policy papers on the health of healthcare workers or on labor-market challenges in the long-term care sector (RVS, 2021; VWS, 2019). None of these analyses mention racism as an important issue. Yet, this ‘white innocence’ and ‘white ignorance’ is increasingly challenged (Wekker, 2016; Mills, 1997), which can be read as a sign of a political boundary struggle. In the summer of 2020, The Black Lives Matter movement in the Netherlands succeeded in getting racism, also in healthcare, on the public and political agenda. In 2021 and 2020 several scientific studies on racism in the Dutch long-term care sector were published to raise attention (Nhass and Poerwoatmodjo, 2021; Van der Tuin and Fiere, 2022; Van Loenen, Hosper and Venderbos, 2022). This growing awareness has yet to trickle down into debates and policies on labor-market dynamics and self-employment. Again, as a consequence, this thesis illustrates how these boundary struggles are negotiated in peoples’ daily lives. Opting for self-employment to negotiate

experiences of expropriation, shaped at the nexus of poverty and racism, can be seen as an embodied boundary struggle. This became particularly visible in chapter 5 and 6, where we described how younger, single and *racialized* care workers are more likely to experience precariousness as a self-employed care worker, and that this inequity was exacerbated during the pandemic.

Human/non-human boundary struggle

Discussing struggles at the human/non-human boundary moves beyond the scope of this thesis. Yet, the COVID-19 pandemic has made clear that there is no such thing as a boundary between human and non-human nature. The current pandemic, but also climate change, has showed that ‘planetary health’ and ‘human health’ are intertwined and mutually dependent. While I finish this thesis, we find ourselves in the midst of an energy crisis, which has led to inflation and increasing costs of living, further contributing to the precarization of paid care workers, leaving over 70% percent of care workers deeply concerned about their financial situation, and debts among paid care workers are growing (PGGM, 2022). So, without stepping outside of the scope of this thesis, maintaining, restoring and protecting the health of paid care workers, cannot be understood without taking the multiple crisis in capitalism into account (Fraser and Jaeggi, 2018).

Concluding remarks

Reflecting upon my main findings through the lens of Fraser and Jaeggi’s conceptualization of capitalism, enabled me to understand why

the lack of appreciation for long-term care work in general, and the concerns around the health of healthcare workers, are such a persistent societal issue. Paid care workers do not simply suffer from bad workplaces, or bad employers (of course whilst not denying that these exist). Care workers and care organizations collectively suffer from societal, political and economic systems that squeeze their ability to take good care of their clients and each other. They have to work and care in the midst of a ‘crisis of care’.

Second, the work of Fraser and Jaeggi helped me to understand that the ‘wicked problem’ of precarization of paid care workers in long-term care cannot be fixed by simple solutions. Limiting access to self-employment, without addressing the lack of financial appreciation for paid care work, will continue to press care workers’ health while robbing them of an ‘emergency exit’. Polls already show that many self-employed care workers rather leave the care sector, than going back into hired employment. So, simply limiting access to self-employment can become a new problem for the LTC sector, rather than a solution. On the other hand, addressing the lack of financial appreciation in combination with limiting access to self-employment, will continue to press the health of care workers of color when racism within long-term care organizations is remains unaddressed. Again, this illustrates the need for holistic solutions ‘at all boundaries’, as Fraser and Jaeggi might say.

In our main findings we describe openings for practice improvements for employers, HRM

professionals in LTC. In this section, I claim that the health of long-term care workers is a societal, political and economic issue, shaped by political choices. Protecting, maintain and restoring the health of care workers in long-term care thus requires a political answer, which we will formulate in the concluding remarks of this general discussion.

Recommendations for research, practice and policy

Implications for Research

This thesis couldn’t have existed without the expertise and effort from the (un)paid care workers. They participated in the photovoice project to set the agenda for our study and participated as community researchers in the empirical studies that form the heart of this thesis. Our participatory approach helped to unveil new and hidden themes and make sense of our findings in a collective and embodied way. This underscores the importance of participatory research approaches on health and health inequities (Abma et al., 2019). The professional photographer played a pivotal role in our PHR process, illuminating the added value of arts-based approaches and collaborations with scholarly artists in PHR. These insights could benefit participatory health research, and related practices such as citizen science.

An intersectional approach enables more diversity-sensitive research on the health of healthcare workers. In a society that is characterized by growing health inequities,

we need more knowledge on growing health inequities among paid and unpaid care workers. With growing care needs and political policies aimed at limiting health care expenditures, the health of care workers will be increasingly under pressure. Yet, as I have argued, not for all care workers alike. For the long-term care sector specifically, more research is needed on poverty and debts among paid care workers in long-term care, as this issue appears to be largely under the radar, and diversity-sensitive studies are lacking. Yet, the urgency has increased in the last years, and will continue to increase, due to increased costs of housing and energy, particularly in the big cities.

This thesis also illustrates the importance of incorporating intersectionality in health research in general, and particularly in participatory health research projects. Intersectionality can strengthen diversity-sensitive research, develop critical consciousness on the 'deeply unjust landscapes' in which we conduct our PHR projects. Intersectionality can strengthen collective action in PHR and foster more care-ethical research PHR practices (Verdonk et al., 2019; Hankivsky, 2014).

Implications for Practice

This thesis provides openings to make occupational health care for paid care workers in residential long-term care more gender and diversity sensitive. First, knowledge on gendered health strategies from chapter 4 and 5 can be used by occupational health physicians and managers in LTC to support

(gendered) relational health strategies, rather than focusing solely on individualistic approaches to strengthen care workers autonomy and ability for boundary setting. Yet, this cannot be done without addressing mechanisms of in- and exclusion within care teams. This requires interventions and sensitivity from managers to make care teams more inclusive. This thesis also described how normative expectations around masculinity can contribute to the silencing of health issues by men working in long-term care. Insights from this study suggest that early recognition of these health issues may help to avoid men leaving paid care work prematurely.

Also, this thesis shows that the lack of societal and political appreciation for paid care work, poverty, menopause and racism can squeeze care workers out of the organizations into self-employment (Chapter 5). Self-employed care workers lack support from managers or occupational health physicians. Yet, this thesis shows that for younger women without financial buffers, particularly young single mothers in the lower salary scales, or men, self-employment comes with health risks. Therefore, we need to ensure that all workers have access to occupational health care, including self-employed.

Several societal organizations have been advocating to put issues of poverty, precarious work and menopause higher on the occupational health agenda. Professional association for occupational health physicians increasingly paying these issues. Yet, attention for racism remains scarce. We hope that

this thesis, and the book we developed, will inspire occupational health physicians to move forward with these issues to enhance occupational health. Acknowledging the impact of racism on individual care workers health during consult is an important (first) step and can contribute to epistemic justice in the consultation room. Also, occupational health physicians can play an important role in feeding back the impact of racism on care workers health to LTC organizations, stressing the importance of anti-racism an essential element of HRM policies in LTC.

Good employership is increasingly recognized by many LTC organizations. Most organizations direct great efforts to enhance working conditions for care workers, particularly in the face of an ageing population and increasing shortages of staff (WRR, 2021; SER, 2021). Shortages of staff currently concentrate on advanced nursing aides (level 3) and nurses (level 4–6) (AZW, 2021). It is crucial that efforts to enhance the quality of work will also benefit nursing aides (level 2) and care assistants (level 0/1). They are lower paid, most at risk in terms of finances and health, but less scarce in our current labor market (AZW, 2021). This work is relatively often done by care workers of color or with a migration background. As shortages of staff don't concentrate on the lowest-paid workers, improving their working conditions might not be equally high on the agenda of LTC organizations. Therefore, current efforts from the Social and Economic Council and the ministry of Health, Welfare and Sports to enhance working conditions in LTC need

to incorporate a critical race and class perspective to ensure better quality of work for all care workers (SER, 2022; WRR, 2022; Ministry of Health, Welfare and Sports, 2022).

Findings from this thesis also have implications for the way we educate future care workers. Educational institutions, such as ROC's and MBO's, could strengthen future care workers' health in two ways. First, insight into the gendered dynamics that shape their health strategies could strengthen self-care, for men and women. Second, critical reflection on mechanisms of in and exclusion within care teams can benefit psychosocial working conditions. Care workers of color feel largely unprepared for the racism they encounter in the workplace and white colleagues are relatively uneducated to recognize and resist racism in the workplace. Educational institutions for care workers in long-term care can thus play an important role in preparing care workers for the institutional conditions they will work in.

Implications for Policy

The lack of societal appreciation for (residential) long-term care for older people is a persistent societal concern. This is not only true for the care sector, but all public sectors that do 'reproductive work', such including poverty reduction, social care and education, are under pressure in the 'crisis of care' (Fraser, 2016; Fraser and Jaeggi, 2018; Bhattacharya, 2015). As a society, we need to revalue the care sector in order to protect to health of care workers in long-term care. This policy recommendation is a long-shot,

as a major political revolt appears to be out of reach and, in the close future, society is expected to make harsh choices between poverty reduction, care and education (WRR, 2021). Yet, several economic scholars have provided us with alternatives, arguing that healthy economies, and healthy societies, cannot exist without public investments (Chancel et al., 2021; Raworth, 2017; Pettifor, 2020).

Nonetheless, current political debates around heightening the minimum-wages or increasing salaries for paid care workers are mildly hopeful. In the Netherlands, care workers increasingly mobilize themselves and strike for higher financial rewards. Their efforts in particular give hope. Insights from this thesis stress the importance of higher salaries for paid care workers, in particular because we observe that poverty among care workers in LTC is growing. This poverty is squeezing them out of the organization into self-employment, where they experience higher health risks and – again – new financial risks. Higher salaries can counter this process of precarization.

At the same time, this thesis illuminates that some care workers are more at risk for precarization, in particular younger women and/or racialized women who are overrepresented in lower salary scales. They often resorted to self-employment, but faced precarization as a self-employed. This precarization can be countered by better working conditions and payment in LTC. But, in line with recent policy advices (cf.

Commissie Regulering van Werk), access to self-employment needs to be diminished. Yet, if we would only limit self-employment without advancing the payment and working conditions in long-term care, we leave a large group of paid care workers stuck between a rock and a hard place. Protecting the health of paid care workers can thus only be done when these two issues are addressed simultaneously.

Third, the impact of racism in long-term care is increasingly put on the political agenda by health scholars and civil society. This thesis illuminates the impact of racism on health and labor market position of paid care workers. Racism is a driver of precarization. We can only underscore existing recommendations to counter racism in labor markets.

Concluding remarks

In a society that is increasingly characterized by inequality and a growing gap between the haves and the have-nots, I am deeply worried about the increasing numbers of care workers who find themselves at the wrong end of the gap. Caregiving is an essential and crucial aspect of our society. As such, care workers should be able to sustain themselves while caring for others. Or, in other words, while their efforts might be priceless, they still need to be paid.

Yet, in the years that took me to start and finish this thesis, I have observed the precarization of paid care workers. Four years ago, the people I spoke to were frustrated

and worried. Now, in 2022, many are angry, exhausted and/or have left their profession. The pandemic has taken its toll. Some have lost confidence in our government, sometimes not even daring to rely on social security anymore, due to the childcare benefit scandal. Younger care workers lost hope of finding affordable housing and cannot buffer the increasing costs of energy and living with their current salaries in long-term care.

In this thesis I set out to explore the complexity – and even ‘wickedness’ – of this societal issue. This did not yield easy answers, but rather complex ones. But even complex answers are answers. I hope that this thesis can strengthen current efforts, undertaken by politicians, policy makers, unions, care organizations, care workers, researchers, professional associations, to enhance the quality of work and livelihood of those working in long-term care for older people.

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appendices



Summary

General introduction

In this thesis, I study the health and wellbeing of paid care workers in residential long-term care for older people from an intersectional perspective. I describe how societal inequities permeate labor markets and workplaces, leading to precarization of paid care workers and impacting their health. But not for all workers alike. Not for all *bodies* alike.

Chapter 1: General introduction

In chapter 1, I describe public concerns about growing societal inequities in the 'participation society' and about the health and wellbeing of paid care workers in particular. In 2015, major policy transitions were enforced to respond to an ageing society and to constrain health care expenditures. Societal organizations expressed concerns about growing inequities, particularly for paid care workers who had to attend to more and more complex care responsibilities, in the workplace and often at home as well. Since then, concerns about the health of paid care workers in residential long-term care (LTC) have increased. Sickness absence rates are high, the highest in the entire care sector and shortages of staff continue to grow. Many paid care workers leave the sector or opt for self-employment. The health of paid care workers is under pressure, but not for all care workers alike. Likewise, self-employment can be precarious work and thus a health risk, but this is not necessarily so for all care workers. Therefore, there is a need for intersectional approaches to understand these growing (health) inequities among paid care workers in LTC.

In this thesis, I address the following research questions. First, how is the health and wellbeing of (advanced) nursing aides and nurses in long-term care shaped by gender in intersection with class, race, sexuality and (dis)ability? Second, how is care workers' health and wellbeing shaped by gender, across its intersections, particularly in the context of self-employment? As a participatory health researcher, I want to understand how we can develop critical perspectives on health inequities in collaboration and dialogue with those whose lives are subject to the study. Therefore, this thesis also includes a methodological and epistemological research question: How can intersectionality strengthen participatory health research?

This thesis is a participatory health research project (PHR) with several sub-studies, five of which took place within the four-year research project 'Negotiating Health'. In this participatory project, (un)paid care workers in long-term care set the agenda, initiated several sub-studies, participated in data-collection and analysis and took collective actions to enhance the health of themselves and their colleagues.

Chapter 2: Theoretical key concepts

In chapter 2, I introduce the theoretical concepts which are presented in the title of this thesis; the caring class, precarization and intersectionality. Researching care practices needs to include a critical gender perspective, as caring practices are particularly shaped

by gender at the personal, organizational and societal level. I named this thesis ‘*the caring class*’ to emphasize the intersection between gender and class in caring practices. I felt inspired by Standing’s concept of the precariat class. Standing turns to a class narrative to foster collective action of those who find themselves in precarious positions. Thus, the caring class is not just a descriptive title and a theoretical concept, but it is also an activist approach, challenging the growing class inequalities in the Netherlands and the impact this has on paid care workers.

I emphasize the concept of *precarization* in the title of this thesis, but use this concept in tandem with *precariousness*. Precariousness refers to the lived and subjective experience of paid care workers. I focus on this lived experience in the empirical studies of this thesis. Precarization is a social dynamic in which increasing numbers of people find themselves in precarious positions as a result of governmental policies. The philosopher Isabel Lorey regards precarization as a specific mode of governing, of doing politics and economics that is built upon – or even benefits from – the precarization of groups of people. Precarization permeates all aspects of society, not just labor markets, but also the housing market or social welfare policies. I foreground the concept of precarization in the general discussion of this thesis, where I unravel the political and economic forces that drive precarization.

Obviously, not all care workers experience the same level of precariousness or suffer

equally from precarization. *Intersectionality* is a key normative, theoretical and methodological framework that enabled me to research health inequities among paid care workers across diverse backgrounds in LTC. Intersectionality also urged me to address how structural mechanisms intersect to marginalize or precarize particular groups of people.

Responding to precariousness with gendered health strategies

Paid care workers experience precariousness due to the policy transitions in LTC for older people. In this section, I unravel how their response to this precariousness is shaped by gender, in intersection with class, racism, sexuality and (dis)ability, based on two empirical qualitative studies.

Chapter 3: ‘We just take care of each other’

Chapter 3 presents an empirical study among women (N=20) working as hired employees (nursing aides and nurses) in LTC. In this study, we explored how female care workers’ health and health strategies are shaped at the intersection of gender, class, age, sexuality and race.

In our findings, we describe how many paid care workers felt uncared for by society and LTC organizations and how gendered norms limit access to self-care. This combination rendered paid care workers largely dependent upon their colleagues to protect, repair and maintain

their own health and wellbeing. However, such relational health strategies require a sense of sameness and an ethos of self-sacrifice, which limited space for diversity and for disability within care teams. Racialized care workers, or those who had to protect their boundaries due to health issues, financial struggles or informal caregiving, risked facing exclusion within care teams, and they reported that this impacted their health and wellbeing negatively.

We conclude that care workers’ relational health strategies can be understood as a care-ethical response to the lack of societal appreciation and organizational support. Therefore, occupational health interventions should not solely focus on individual autonomy of workers, but take these relational health strategies into account. Yet, these relational strategies can backfire from protective mechanisms into mechanisms of exclusion within care teams, turning into inequality regimes (Acker, 2006). We argue that the lack of societal appreciation needs to be made political by occupational health physicians and LTC organizations, to counter mechanisms of exclusion among paid care workers.

Chapter 4: Negotiating masculinity at the expense of health

Chapter 4 presents our empirical study among men (N=16) working in long-term care as hired employees and/or as a self-employed nursing aide or nurse. Men are underrepresented in paid caring roles, particularly in low-paid occupations such as in LTC, and the question arises how masculinities play a part in this underrepresentation. Our qualitative study

focuses on the negotiation of *hegemonic* and *caring masculinities* of men working in residential long-term care in the Netherlands, and its consequences for health and wellbeing. Hegemonic masculinity can be described as a gender practice that enforces the dominant position of men and the subordination of women, with dominant masculinities that tend to be white and heteronormative, display oppressive attitudes and value physical strength and leadership of men. Caring masculinities aim to incorporate caregiving into a masculine identity and has been framed as men’s investment in gender equality.

Findings describe how men move through paid work in LTC. Upon entry, men negotiate *hegemonic* and *caring masculinities* to gain access, with black men reporting that they have to work harder to get hired at the appropriate level. Once inside, men experienced working in LTC as status-loss and performed *hegemonic masculinity* to regain status, for example by reframing their work or emphasize their physical strength, which materialized in career opportunities and financial rewards such as higher wages, especially for white heterosexual men who described this privilege most explicitly. Some men turned to self-employment to emphasize their identity as an entrepreneur over being a paid care worker. Although this seemed beneficial, over time, performing hegemonic masculinity backlashed with respect to their own health and wellbeing. For instance, men described how working long hours and not getting sufficient rest led to burnouts, particularly as a self-employed. Emphasizing

physical strength and invulnerability contributed to their musculoskeletal problems. For racialized and homosexual men, experiences with racism or homophobia put extra strain on their health and wellbeing at work. All of these health issues were often silenced towards colleagues or managers, with dominant masculinities leaving little room to express vulnerability. Consequently, all men in this study aspired to move out or up from low-paid care work, and white heterosexual men seemed to be more successful in fulfilling their ambitions.

We conclude that men's investment in caring masculinities can obscure gender inequities, while simultaneously perpetuating them. Presenting a caring masculinity enabled men to gain access to paid care work, where they consequently experienced more career opportunities and material rewards in comparison with their female colleagues. However, this privilege came at the expense of their health and wellbeing. Our study illustrates the relevance of an intersectional perspective on *caring masculinities* at work, showing how *caring masculinities* perpetuate male privilege for some men more than for others, and creating health and labour market inequities among men. Our study emphasizes that gender, racism and sexual discrimination need a firm place on the occupational health agenda.

Negotiating health in the context of self-employment

Self-employment is not necessarily precarious work, but can be experienced as precarious by

specific groups. In this section, I explore the experiences of self-employed care workers with precariousness before and during the COVID-19 pandemic, based on two empirical qualitative studies.

Chapter 5: Squeezed out

Chapter 5 addresses the experiences of female self-employed care workers (N=25) in LTC. This study aimed to unravel how their experiences with precariousness and health are shaped at the intersection of gender, class, race, migration and age.

Findings indicate that feeling precarious as a hired employee – due to increasing workloads, health risks, poverty and discrimination – shapes care workers' choice for self-employment. Second, we describe inequities between self-employed care workers who could (financially) afford to turn to self-employment as a health strategy, and those who felt squeezed out of the organizations due to poverty, menopausal complaints or discrimination. The latter group more often dealt with precarious work in the context of precarious lives, negatively impacting their health and wellbeing. Third, we describe how negotiating an entrepreneurial identity as self-employed with a caring identity as care worker required material sacrifices. For instance, several women lowered their tariffs or invested their own time and expertise (i.e., working at lower level than being educated for) into their caring practices. These practices contributed to self-employed care workers' financial precariousness, particularly as women. Our findings indicate that working

in LTC is becoming increasingly precarious for all care workers, both for hired as well as self-employed, and suggest that younger, lower-paid and racialized women with unpaid caring responsibilities are most at risk for experiencing precariousness.

Chapter 6: Pushed to the Margins and Stretched to Limits

Chapter 6 describes the experiences of self-employed care workers (N=23) during the outbreak of the COVID-19 pandemic. This qualitative study aimed to explore how female care workers' health, financial situation, and paid and unpaid caring responsibilities were impacted during the first wave of the pandemic.

Findings illustrate how labor market inequalities have been (re)produced and exacerbated during the pandemic. In the first wave of the pandemic, self-employed care workers were pushed toward the margins of the labor market, working risky shifts and compromising their own interests, while being unprotected by organizations, social security, or political efforts. We observed that care workers who had opted for self-employment had more possibilities to protect the health of themselves and/or their families during the pandemic, while those who had been squeezed into self-employment were stretched to limits where they could no longer attend to their own health or to their paid and unpaid care responsibilities. Again, this mainly concerned younger, lower-paid and racialized women, often with unpaid caring responsibilities. As such, inequities that existed before the pandemic appeared to be deepened during the pandemic.

Unraveling intersectional inequities through participatory health research

Participatory health research (PHR) fosters participation of those whose lives are subject to the study, and aims to heighten the (mutual) understanding of people involved as a vehicle for collective action and social justice. But doing PHR in deeply unjust landscapes can be challenging and even disempowering for all people involved. In this section, I present two methodological papers in which I explore how PHR can address structural inequities and how PHR can be strengthened by intersectionality to foster social justice.

Chapter 7: No action without compassion – dealing with powerlessness and suffering

In chapter 7, I reflect on a participatory action research (PAR) project with unpaid caregivers and volunteers in a Dutch neighborhood. My experience in this project directly led to the research project 'Negotiating Health', as insights motivated me to explore the structural inequities that shaped caregivers' experiences in more-depth.

Participatory action research is often informed by strength-based approaches such as appreciative inquiry. However, when initiating collective action and establishing social change appear to be difficult, feelings of frustration, powerlessness and suffering can arise. In the research field, there is an ongoing debate on the place and importance of these

so-called negative emotions within strength-based approaches.

In a PAR project on citizen participation in the Netherlands we encountered a social and political context that was beyond our ability to change. We came to realize that change or action is not always possible in PAR and that 'pushing' for action can become a disempowering experience for those involved. In this article, we share the moral dilemmas that we encountered and reflect on our own learning experiences as academic researchers.

We argue that researchers need to anticipate moral challenges by reflecting upon their personal position towards powerlessness and suffering. Nussbaum's notion of compassion can help researchers to create space for these experiences, and to acknowledge that these experiences can serve as sources of generative knowledge. Researchers should carefully navigate between fostering action and expressing compassion in PAR. With this article we aim to contribute to a care ethical perspective on participatory action research that acknowledges the vulnerabilities and precariousness of those involved in PHR research practices.

Chapter 8: Navigating voice, vocabulary and silence – developing critical consciousness

In chapter 8, I present a methodological reflection upon the project 'Negotiating Health' in which we employed photovoice to foster critical consciousness. This article springs from first, second and third-person

inquiry within our research team of (un)paid care workers, academic researchers and a photographer.

We observed that critical consciousness on structural inequities emerged from an iterative process between silence, voice and vocabulary. We learned that photovoice scholars need to be sensitive to silence in photovoice projects, as silence can be the starting point for finding voice, but also a result of silencing acts. Social movements and critical theories, such as intersectionality, provide a vocabulary for participants to voice their critical perspectives to change agents and to support collective action.

We discuss our experiences using Fricker's concept of 'epistemic justice', arguing that critical consciousness not only requires that communities are acknowledged as reliable knowers, but that they need access to interpretative tropes to voice their personal experiences as structurally embedded within larger systems of power, such as gender relations, or institutionalized racism. Both being acknowledged as reliable knower and having access to concepts that can help situate personal experiences in societal patterns may contribute to more ethical research practices in PHR and strengthen the empowerment of those involved.

General discussion

Chapter 9

Chapter 9 '*What you don't see*' presents four portraits. These portraits are the result of our

photovoice process in Negotiating Health. Each portrait is co-created by professional photographer Janine Schrijver, a co-researcher and the academic researchers. These portraits capture and address the main findings in an arts-based way.

Chapter 10: Precarization of paid care workers from an intersectional perspective

In chapter 10, I present the main findings of this thesis and elaborate on how working in LTC has become increasingly precarious for all, with some groups experiencing more precariousness than others. Based on these empirical findings, I conclude that poverty, racism, menopausal health complaints and informal caregiving require a firm place on the occupational health agenda in LTC. Mainly focusing on for instance workload and emphasizing individual health strategies, obscures the importance of these structural 'hidden determinants' of health and wellbeing that contribute to the precariousness of paid care workers. I also answer my methodological research question and elaborate on the added value of intersectionality for participatory health research.

To unravel the structural mechanisms that drive the precarization of particular groups of paid care workers, I turn to political theories on capitalism, in particular from Fraser and Jaeggi (2018). These authors argue that capitalism cannot function without paid and unpaid care work which is done most often by women (reproduction), public institutions of the state (polity), the expropriation of racialized groups in the global south and a

worldwide (expropriation) and the use of natural resources (non-human nature). Fraser and Jaeggi argue that gender inequality, class inequality, racism and exhaustion of natural resources are not accidental side-effects of capitalism, but inherent to capitalist modes of profit making. These 'background conditions' are not infinitely elastic, yet treated as such in capitalism, and hence, exhausted. Over time, boundaries shift in regards to how reproductive work is valued, how much the market can retract from public institutions or, vice versa, how much the state can intervene in the free market. Therefore, societal and political struggles arise at each boundary, conceptualized by Fraser and Jaeggi as boundary struggles.

In the general discussion, I illustrate how these boundary struggles play out in the lives and work of paid care workers. For example, public policies such as the 2015 transitions in LTC for older persons can be understood as a political attempt to move the boundary between paid and unpaid care work (i.e., a production/reproduction boundary struggle). Such policies are legitimized by a discourse that frames reproductive care work as financially burdensome to society, instead of a precondition for production, which obscures the importance of care for societies. This boundary struggle plays out in care workers' lived experience with (un)paid care work as 'being invisible, doing hidden work', in the increased precariousness of paid care work, and the lack of political attention for LTC, particularly during the COVID-19 pandemic.

The lack of appreciation for reproductive work squeezed care workers' health and financial situation while working in LTC (i.e., a production/reproduction boundary struggle). Simultaneously, neoliberal policies fostered precarious employment, framed as a 'flexible' labor market, which enabled a way out into self-employment (i.e., an economy/polity boundary struggle). Therefore, I argue that paid care workers find themselves at the nexus of two boundary struggles. This plays out in care workers' personal lives, as self-employed care workers had to navigate the different moral landscapes of polity and economy. These moral tensions materialized into financial sacrifices, particularly for women, to foreground their caring identities, exposing how 'gendered ideologies of care' in a 'flexible labor market' contribute to the *precarization* of self-employed women. Vis-à-vis, men turned to self-employment to foreground their entrepreneurial identity, but this strategy backlashed in terms of health, as self-employment enabled them to engage in risky health behavior such as working ongoing shifts.

I also observe a third boundary struggle on the exploitation/expropriation boundary, which is a racialized inequity according to Fraser and Jaeggi. In this thesis, I observe that precarization particularly impacts care workers of color due to institutional and everyday racism in LTC organizations. In the LTC sector globally, and in the Netherlands as well, lower educated care work is often done by racialized women. Due to this institutional racism, care workers of color most often experienced

financial precariousness. In the empirical studies of this thesis, care workers of color, women and men, describe how experiences of (institutional and everyday) racism squeezed them into self-employment. As a consequence, they were in more precarious situations as a self-employed, which increased during the COVID-19 pandemic. As such, racism is a driving force of precarization.

Fraser and Jaeggi conceptualize a fourth boundary struggle on the human/non-human boundary. An important part of the research in this thesis took place during the COVID-19 pandemic. Not only has this pandemic questioned the boundary between human and non-human nature, but it can be linked to broader climate crisis. Therefore, I shortly touch upon the role of the climate crisis, the COVID-19 pandemic and the energy crisis, as they all have major impacts on the financial situation and health of paid care workers. My key argument here is that precarization does not limit itself to labor markets, but permeate all aspects of society, and takes place in a wider societal context that is characterized by multiple and intersecting crises.

The work of Fraser and Jaeggi helped me to understand that the 'wicked problem' of precarization of paid care workers in LTC cannot be fixed by simple solutions. Precarization needs to be addressed at all boundaries. Therefore, I argue that access to self-employment needs to be tackled to counter the precarization of paid care workers, particularly those who resort to self-employment to navigate racism and poverty.

Yet, limiting access to self-employment, while not simultaneously addressing the lack of societal appreciation for LTC or racism in long-term care would leave many paid care workers stuck between a rock and a hard place. Furthermore, precarization of paid workers cannot be understood in isolation, but takes place in a societal context characterized by the COVID 19 pandemic, an energy and housing-crisis. Based on these reflections, I conclude that protecting, maintaining and restoring the health and wellbeing of paid care workers in long term care is not just an issue of individual workers or employers. It is a societal and economic issue and shaped by political choices, and thus also requires a societal political answer.

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About the author

Saskia Duijs (1986) was born in Amsterdam. She holds a bachelor in Biomedical Science (Radboud University Nijmegen) and a master in Health Science (VU University Amsterdam). She worked for several NGOs/community organizations in Amsterdam before starting her career in academia as a junior teacher and researcher at the VU University/VU Medical Centre. From 2013 onwards she conducted several participatory action research (PAR) projects with clients, professionals and informal caregivers, partly within the Centre for Client Experiences (www.centrumvoorclientervaringen.nl). In 2017-2018 she worked as a researcher at the Dutch Safety Board (Onderzoeksraad voor Veiligheid) on a project on the safety of clients with severe psychiatric illness. In 2018, together with dr. Petra Verdonk and prof. dr. Tineke Abma, she acquired funding within the ZonMw program on Gender and Health for her PhD project 'Negotiating Health'. From 2018 to 2022 she worked part-time (0,6fte) on her PhD, besides teaching and coordinating (0,2fte). Duijs teaches and coordinates courses on qualitative methodology, medical sociology, sexual health and participatory research within the VU University and the Amsterdam School for Medical Sciences. She is a trainer of the (postgraduate/PhD) training on 'Intersectionality and I' and within the School for Participation (www.schoolforparticipation.nl). She continues teaching and researching as an assistant professor in the dept. of Ethics, Law and Humanities of the Amsterdam UMC.

Saskia lives with Ruben and their two children in a community in the East of Amsterdam, where they are actively involved in several citizen initiatives in their neighbourhood.

The health of paid care workers in long-term care is under pressure, but not for all care workers alike. Therefore, this thesis addresses health inequities among paid care workers.

This thesis presents several participatory studies which were conducted by the author, together with paid care workers and a professional photographer. These studies unravel the health strategies of men and women working in long-term care and the health issues of self-employed care workers before and during the COVID-19 pandemic.

All studies were done from a critical gender, diversity-sensitive and intersectional perspective and present insights for care workers, occupational health professionals, HRM professionals and policy makers in long-term care. This thesis is also relevant for Participatory Health Researchers (PHR) who aim to make their research more critical and diversity-sensitive, as it explores the relevance of intersectionality for PHR.

A series of portraits 'What You Don't See', made by photographer Janine Schrijver in co-creation with care workers and the author, is part of the research presented in this thesis. These portraits address urgent health issues that often remain invisible, including racism and poverty.

Concerns about the health of paid care workers are a persistent societal issue in the Netherlands. Concerns have become increasingly pressing as more and more paid care workers find themselves in precarious positions, no longer able to sustain their own health or support themselves financially.

Therefore, this thesis explores the economic, societal and political forces that contribute to the precarization of paid care workers in the Netherlands. Protecting, maintaining and repairing the health of paid care workers is not just an issue of care workers or employers. It is a societal issue and shaped by political choices.