Unveiling inequity: diversity and power in collaborative care networks

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Chapter 1

General introduction

Kofi sits in his chair by the window. He stares outside and his thoughts go over the conversation they had with the doctor today. Did he completely understand? He hears that Ama is busy in the kitchen, and soon she brings him a cup of tea and readjusts the pillows in his chair to keep him from slumping. He asks Ama if he has recently checked his blood sugar and if she wrote down the levels. I feel old, Kofi sighs. He is confronted every day with a body that no longer feels like his own. Every breath is a reminder of his COPD and his movements are restricted by his stroke. He spends his days at home in his new favourite place, this armchair.

The routine of hospital visits is exhausting for Kofi and Ama: neurologist appointments, physiotherapy and occupational therapy sessions, and visits from the home care nurse, it's all too much. Kofi struggles to keep up with the professionals' pace; their words come fast, as if they're from another world. Ama looks at their faces and sees their concern but feels a distance. Was it the medicine he needed? A new treatment plan? Did it matter that they didn't fully understand the doctor's advice? Ama seeks answers from the Ghanaian doctor in their neighbourhood, the man who still understands her, who speaks her language, who reassures her when the medical world leaves her more confused. The medical world also enters their home. Home care professionals are part of their daily rhythm; some faces are familiar, while others come and go. The other day, the doorbell rang, and a new home care worker stood in the doorway. Ama offered a polite smile, but she felt unease. Who was this person? Why were they changing things?

The phone rings: it is their son. Since Kofi suffered his stroke, he calls every week to check in, just to see if they are still managing. Their children, both successful professionals, have moved away from home and are absorbed by their own lives. They send money every month to help with the bills, but the hands-on care that Kofi needs is beyond their reach. That falls on Ama's shoulders, despite the pain she feels in her chest from heart failure. At the end of the day, as Ama gently helps Kofi to bed, she knows that no matter how hard it gets, she will continue to care for him. It is her duty, yes, but it is also an act of love.

Kofi and Ama[1] were the first people I spoke to when exploring the possibilities of participatory research on informal care and diversity, and for me, it is only fitting to begin my PhD thesis with their story.

People like Kofi, who have suffered some form of acquired brain injury (ABI), must reconcile immense changes to their daily lives and often have to accept that they have become recipients of care provided by others (Arntzen et al., 2015). ABI refers to the umbrella term of traumatic and non-traumatic brain injury and includes, for example, stroke, brain tumours, infections, as well as car accidents and falls that lead to brain damage (Goldman et al., 2022). Dutch government policy emphasises the provision of informal care for people with health and welfare needs in their own living environment (Klerk et al., 2015; Ministerie van Volksgezondheid, Welzijn en Sport, 2023). Such policies promote networks of care in which informal carers (referred to henceforth as carers) share care duties with professionals (Boer & Plaisier, 2020). Care networks surrounding people with an ABI consist of a broad range of professionals (Achilike et al., 2020), making them complex and making the coordination and alignment with different professionals difficult for carers like Ama (Braaf et al., 2019). Adequate collaboration between professionals and carers in care networks not only enhances quality of care, it also positively impacts perceived well-being of both carers and care recipients, and helps to reduce overall care burden (Broese van Groenou & De Boer, 2016; Jacobs et al., 2014), and contributes to increased job satisfaction amongst professionals (Bosch & Mansell, 2015). However, in practice, collaboration in care networks is not always experienced as adequate by carers and professionals (Tonkens, 2018).

Carers providing informal care for someone with an ABI experience a higher care burden compared to those providing care to care recipients with other diseases, due to the long-term nature and high level of complex care required (Kavga et al., 2021). Additionally, amongst carers with a migration background, like Ama, there is an urgent need for support from professionals, as they are more at risk of carer burden than informal carers without a migration background (Kroese et al., 2011; van Wieringen & van Grondelle, 2014). However, carers with a migration background face significant barriers in accessing adequate care, due to insufficient communication and distrust in professionals (Boateng et al., 2012). Moreover, professionals often do not feel sufficiently competent in supporting carers and care recipients with a migration background, and there is limited specific policy and few targeted interventions to support them (Peñuela-O'Brien et al., 2023).

The experiences of care recipients and their carers are multi-layered, shaped by the caring relationship, collaboration with professionals, and the broader Dutch healthcare system. Within these different layers, intersecting aspects of diversity shape their everyday experiences (Crenshaw, 1991; Hankivsky, 2014).

[1] All names used in this PhD thesis are pseudonyms

This PhD thesis aims to strengthen the empirical knowledge base on how intersecting aspects of diversity shape the collaboration between professionals and carers in care networks centred around care recipients with an ABI and a migration background, with a focus on unveiling inequities and uncovering underlying power dynamics within these networks.

Becoming part of a caring relationship

Following an ABI, a caring relationship develops between the individual and those within their social network. Becoming part of a caring relationship impacts the daily lives of both care recipients and carers. Although the severity of disability following an ABI varies (Häggström & Lund, 2008), care recipients usually experience immense changes in daily lives as engagement in meaningful activities becomes restricted (Nyman et al., 2021). Meaningful activities refer to the ordinary and familiar things that people do in everyday life, which are often taken for granted (Christiansen et al., 2024). ABI is the leading cause of disability worldwide (Sharma & Lawrence, 2014). After an ABI, people have to come to terms with the fact that their life story, ambitions and social roles have abruptly changed (Whiffin et al., 2019), and their future has become unpredictable (Satink et al., 2013). This disruption may decrease their experienced quality of life (Markle-Reid et al., 2011). Engagement in activities outside the home, such as social and leisure activities, often becomes challenging, and as a result, people with ABI visit fewer places and perform more of their activities at home and alone (Malinowsky et al., 2020). Additionally, having an ABI may result in having to deal with stigma from negative beliefs regarding their disability based on visible and invisible consequences of an ABI (Bracho & Salas, 2024).

When someone with an ABI requires care by others, they must come to terms with this newfound dependence (Arntzen et al., 2015). The majority of care is provided by carers from existing social networks, such as family members, friends or neighbours (Kokorelias et al., 2020). Informal care arises from a preexisting social relationship where carers provide unpaid care without training (Bussemaker et al., 2022). In the Netherlands, approximately 650,000 people have survived some form of ABI (van Esch et al., 2019). Although there are no specific figures available for informal carers providing care to people with ABI, it can be reasonably estimated that the number of carers is roughly equal to the number of care recipients. While the contributions of carers is seen as invaluable in government policy (Boer & Plaisier, 2020), being a carer has both positive and negative consequences for the carers themselves and for their own health and wellbeing (Atler et al., 2016). Becoming an informal carer is a major life event (McIntyre et al., 2020), requiring carers to come to terms with an altered future and dynamics of reciprocity within their pre-existing relationship with the care recipient (Pont et al., 2020). Carers have to deal with demanding role adaptations (McDougall et al., 2014), as well as changes in daily routines and activities (Seguel Albornoz et al., 2023).

Many carers find a sense of fulfilment and purpose in providing care as it can be emotionally rewarding and meaningful (Mackenzie & Greenwood, 2012). The choice to care often stems from a sense of responsibility towards the care recipients or from a loving relationship (Klerk et al., 2014). Personal growth and the strength of the relationship between carer and care recipient is seen as important for carers (Kruithof et al., 2012). Providing informal care may also take its toll and result in negative consequences. Caring can lead to decreased physical and emotional wellbeing, as well as exhaustion, stress and even depression (Achilike et al., 2020; Klerk et al., 2014). Financial strain is common amongst carers, as the provision of care often requires extra time commitment which may influence carer's ability to work (Boer et al., 2019) and caring often requires extra costs which are not covered by health insurance (Klerk, 2017). Although much is known about how carers spend their time (i.e. hours spent on caregiving versus other activities), their lived experiences are less well understood (Atler et al., 2016).

Focusing specifically on carers of people with ABI, research shows that this often results in high care burdens due to the long-term and complex nature of the care required (Kavga et al., 2021). When carers live in the same home as the care recipient, there is often a spill-over effect into the daily lives of the carers. In these cases, carers also become less active outside of the home as they often jointly accept restrictions by adapting their activities together (Rudman et al., 2006). Additionally, the cognitive, behavioural, and functional disabilities following an ABI, along with accompanying invisible consequences and reduced illness perception on the side of the care recipient, contribute to the experienced care burden (Devi et al., 2020; Kjeldgaard et al., 2023). Lack of understanding by others outside the caring relationship of the cognitive and often invisible consequences of an ABI influences the relationships between carers and their larger social network. Carers often feel burdened by the continuous effort necessary to explain the situation after an ABI to enable support from others (Jurrius, 2014).

The lived experiences of carers and care recipients are shaped by aspects of diversity (Jacobs et al., 2016). Diversity encompasses a wide range of categories such as gender, age, religion, culture, ethnicity, education, occupation, (dis)ability, marital status as well as structural group memberships such as social class or belonging to historically marginalized or privileged groups, which in interaction with each other shape lived experiences (Giesbrecht et al., 2012). Recent informal care research shows, for example, that as the entire population ages, a problematic situation arises: either older people provide informal care with all its physical consequences, or younger people provide informal care, leading to the ‘sandwich’ generation in which informal care has to be combined with study, work, and family life (Berkers et al., 2021). It is also known that the prevalence of caring is highest among those aged 50-64, and that informal care is gendered, meaning that women are overrepresented. Care tasks differ between men and women, as does the experience of carer burden (Peña-Longobardo & Oliva-Moreno, 2021).

Focusing on carers with a migration background, like Ama, lower levels of well-being have been reported (Paine et al., 2020), along with negative associations with health status (Akbulut & Razum, 2022). A recent study in the Netherlands showed that carers with a migration background provide care more intensively and for a longer period than carers without a background of migration (Boer et al., 2021). Carers often take on the task of translation within healthcare settings and more often live in the same home, intensifying caring experiences (Wieringen en Grondelle, 2014). Kroese et al. (2011) show that carers with a migration background on average provide more hours of caring duties than carers without a migration background. Turning specifically to the intersection of migration and ABI, as in Kofi's case, little research exists. It is known that having a migration background may lead to a double burden in terms of socioeconomic conditions and health (Agyemang et al., 2014). Care recipients with a migration background experience poorer health and are more vulnerable to cardiovascular diseases, such as stroke (Degeneffe, 2001; Degrie et al., 2017; Solé-Auró & Crimmins, 2008). Johnson and Diaz (2023) show that health disparities exist amongst people with ABI, meaning that preventable health differences exist based on aspects of diversity (Hammarström et al., 2014).

In recent years, knowledge about informal care provision as well as sharing care in care networks has increased, but perspectives of carers and care recipients with migration backgrounds continue to be overlooked within public health research (Agyemang et al., 2014; De Boer et al., 2019; Hynek et al., 2023). When carers or care recipients with a migration background are included in research, cultural differences are often highlighted; however, insight into the intersection of aspects of diversity is lacking (Viruell-Fuentes et al., 2012). Although several local surveys in the Netherlands have been conducted amongst carers with a migration background, there is no overall insight into their living situations, wants, and needs (Kroese et al., 2011).

Collaboration with professionals

As evident in the story of Kofi and Ama, professionals enter the caring relationship between carers and care recipients, making care experiences multi-layered. The majority of those affected by an ABI return to their home from a hospital, rehabilitation centre, or nursing home (van Esch et al., 2019). Here, carers share care with a large number of different professionals in care networks (Achilike et al., 2020). To ensure that healthcare in the Netherlands remains sustainable and accessible to all, the Dutch council of Public Health and Society advocates for more network-centred care, in which informal and formal care collaborate in an equal relationship (Bussemaker et al., 2022). Care networks should be designed to provide comprehensive care for different care needs and ensure that people receive the right care at the right time (Zorginstituut Nederland, 2022). Professionals involved in care networks surrounding care recipients with ABI may include: neurologists, rehabilitation specialists, psychiatrists, geriatricians, general practitioners, psychologists, neuropsychologists, and allied health professionals such as physiotherapists, occupational therapists, and speech and language therapists, as well as community nurses, social workers, case managers, personal care support workers, and home care support (Federatie Medisch Specialisten, 2017). Professionals from the municipality, when support is needed from the Social Support Act (Wmo), may also be involved in the caring relationship, as well as professionals from the Care Needs Assessment Centre (CIZ), when support at home is needed based on the Long Term Care Act (Wlz), and/or professionals working for the health insurance company (Zvw) (Scheffelaar et al., 2024). This large number of professionals makes care networks complex, and the coordination and alignment with different professionals can become difficult for carers (Braaf et al., 2019).

Care networks are dynamic and may adapt over time in accordance with changing care needs or care contexts (Broese Van Groenou et al., 2016). Care networks emerge from the interaction of different stakeholders, professionals, carers, and care recipients, as well as the context in which they are embedded (Kemper-Koebrugge et al., 2023). Care networks may also differ in accordance with varying sizes of social networks, care needs, living situations, active social networks where informal care is possible, and the division of care between professionals and informal carers. In some cases, care networks may take the form of an actual interconnected network; in others, they may consist of multiple bilateral collaborations between professionals and carers. For example, a physiotherapist and an occupational therapist might work with a carer within the home context, while this collaboration is separate from the one between the general practitioner, the community nurse, and the carer.

Each form of collaboration requires a different way of working on the part of both professionals and carers. However a care network is constructed, there is always a need for adequate collaboration between professionals and carers with the aim of providing quality care for the care recipient. Adequate collaboration contributes to the wellbeing of both the carer and the care recipient, and may also decrease carer burden (Bauer, 2012; Hoek et al., 2021; Rønn-Smidt et al., 2020). Collaboration will reduce struggles within the care network and may have a positive effect on the job satisfaction of professionals (Bosch & Mansell, 2015). Successful collaboration between professionals and carers requires a genuine partnership (Scheffelaar et al., 2024). This requires that stakeholders within care networks know one another and understand each other's roles in care provision, share information, coordinate effectively, and engage in shared decision-making and responsibility within an equal relationship (Jang, 2020). Within the collaboration, each stakeholder's care attitude and decisions about sharing care are rooted in personal and professional frames of references (Wittenberg et al., 2018, 2023). These frames shape underlying motivations for care (Zarzycki et al., 2023), as well as expectations, assumptions, values, norms (Hankivsky, 2014b), and illness beliefs (Wikman, Marklund & Alexanderson, 2005), all of which influence the nature of the collaboration.

Professionals rely on evidence-based guidelines to guide rehabilitation and treatment (e.g. Anwert et al., 2021; Boelen et al., 2007; Ergotherapie Nederland, 2025; Federatie Medisch Specialisten, 2017; Hafsteinsdottir & Schuurmans, 2016; Hersenletsel Alliantie, n.d.; Kennisnetwerk CVA Nederland, 2012; Nederlandse Vereniging van Revalidatieartsen, 2021, 2024; Nederlandse Vereniging voor Neurologie, 2011; Verbeek et al., 2014). These guidelines are based on the most up-to date evidence intended to provide care up-to-date, transparent, effective, and of high quality. The physiotherapy and occupational therapy guidelines (Ergotherapie Nederland, 2025; Verbeek & et al., 2014) explicitly discuss involving carers in shared care and the occupational therapy guidelines state that this involvement of carers has a positive effect on rehabilitation outcomes (Graff et al., 2007). Two specific guidelines for supporting carers are available: Caring for someone after stroke (Visser-Meily & van Heugten, 2004) and an Informal care guideline focusing on nurses and prevention of carer burden (Verpleegkundigen & Verzorgende Nederland, 2021).

Carers feel supported by professionals within the phase of acute care in the hospital or rehabilitation setting; however, after discharge, this support is often experienced as inadequate (Lobo et al., 2021). In the home context, it can be difficult to find and organise appropriate professional care and carers often struggle to maintain an overview of all the professionals involved (Schoenfelder et al., 2022). Community services often fragmented, lacking adequate coordination across multiple disciplines, and carers are not well informed about available community services (Lobo et al., 2021). Furthermore, carers commonly report feeling excluded from the care within home-based networks (Bussemaker et al., 2022). In a study on developments in the field of informal care in the Netherlands, it became evident that only half of carers were involved in shared decision-making regarding the care provided and the division of care responsibilities (Boer et al., 2020, p.11). Care recipients and carers also recognise that they often receive conflicting advice or messaging from different professionals, and it is not always clear who is in charge even where there is a case manager involved (McPherson et al., 2014).

Professional support is often not sought by carers with a migration background, increasing their risk of carer burden (Kroese et al., 2011). Carers with a migration background often do not know where to go with questions, experience difficulties finding their way within the Dutch healthcare system mainly due to language barriers, or lack knowledge of where to access adequate support (Boer & Plaisier, 2020). This may also originate from the fact that they do not see themselves as informal carers [mantelzorger] and therefore are less able seek support (Kroese et al., 2011). Carers with a migration background are often met with an essentialised view of their cultural and religious backgrounds. However, care needs or attitudes may stem from certain traditions, socioeconomic positions, or levels of education, and the image someone has of a professional can influence how carers respond to them (Achahchah et al., 2015). Recent research from Ahmad et al. (2020) demonstrates that prior negative experiences with healthcare professionals and filial responsibility may prevent carers and care recipients from sharing care with professionals. Additionally, care recipients with a migration background experience disadvantages within the Dutch care system, and experience discrimination based on, for example, their ethnic background (Badou et al., 2023). When people have experienced discrimination in a healthcare setting in the past, they might avoid seeking healthcare in the future (van Loenen et al., 2022). This may suggest that access to healthcare and opportunities to receive adequate healthcare is unevenly distributed in the Netherlands, and care recipients with migration backgrounds who belong to minority populations may experience diminished health outcomes (van Loenen et al., 2022).

There has been increased attention to family or informal care within professional guidelines, highlighting the impact of an ABI on families and carers. Guidelines focus on establishing a contact person within the family, ensuring families and carers are equipped to cope with and accept the new situation, and analyse carer burden. However, the available guidelines do not provide specific insights on collaborating with carers in a partnership. Additionally, the available guidelines do not provide tools for supporting carers and care recipients with a migration background, which might suggest a guideline bias. This may lead to a misalignment of professional practice and support needs of carers and care recipients with a migration background, which might reinforce health inequities. From a professional perspective, recent research has shown that professionals do not always feel competent to provide care to care recipients with a migration background, or to collaborate with carers with a migration background (Peñuela-O'Brien et al., 2023). Adopting a health inequity perspective, as this PhD thesis does, highlights that unequal access to healthcare and disparities in health outcomes among diverse populations stem from systemic injustices. The emphasis is on addressing health needs, whether similar or different (Buchbinder et al., 2016; Hammarström et al., 2014). Achahchah et al. (2015) provide an advice report on how to support isolated carers with a non-western migration background, but in general there is limited specific policy for carers with a migration background and no specific interventions are available (Peñuela-O'Brien et al., 2023).

Influences on the Dutch healthcare system

Collaboration in care networks is also influenced by the larger healthcare system in the Netherlands, adding an additional layer of complexity to the daily reality of collaborative care networks. The Dutch welfare state, grounded in neoliberal ideological principles, was transformed into a participation society in 2015. Government policy has shifted its focus to self-reliance as underlying principle, and reforms are needed to create a sustainable healthcare system in an aging society with an increasing demand for healthcare (de Visser et al., 2022). This need is accompanied by an emphasis on informal care as a mechanism to meet increasing

care demands within the Dutch society (Verbakel, 2018). Demographic changes create a situation where more people need care and fewer people can provide this care, causing workforce shortages within the healthcare system. These challenges emphasise the necessity for professionals to collaborate with informal care to keep our health system sustainable (den Broeder et al., 2023, 2024). Currently, the Netherlands has around five million carers, and with the aging of the population it is expected that everyone will become a carer at some point in their lives (Dekker et al., 2024; Ministerie van Volksgezondheid, Welzijn en Sport, 2023).

Healthcare policy is organised in a decentralised way at national and regional levels. From a policy perspective, there are several fundamental aspects established in rules and regulations to ensure quality care for all. These include providing care recipients with understandable information about care possibilities and supports to make their care needs known. Care needs are known to professionals and recorded in a care plan. Care recipients are in control as much as possible though self-determination. Additionally, care recipients can count on professionals to share important information with each other and coordinate care with one primary carer (Inspectie Gezondheidszorg en Jeugd, 2023). On a policy level, collaboration between carers and professionals is guided by the Long-Term Care Act (WLZ), which regulates complex, intensive care for frail elderly people, people with disabilities, and people with mental illnesses. This is supplemented by the Health Insurance Act (ZVW), which is responsible for covering medical care costs to ensure that everyone is entitled to the same and affordable care. Further, the Social Support Act (Wmo) is carried out in a decentralised manner by 323 municipalities. The Social Support Act is mandated amongst other foci with the support of carers (Zorginstituut Nederland, 2022).

Carers meet the enormous demand and pressure that the Dutch government places on them in their care policy (Kromhout, 2018). In times of increasing healthcare costs, informal care is seen as a more cost-effective alternative to care provided by professionals. The provision of informal care has a societal expenditure of 22 billion (den Blanken et al., 2021, p.7). However, concerns about the accessibility of care within the complex Dutch healthcare system are increasing (Duijs, 2023). The emphasis on informal care in the Netherlands is not without scrutiny and there are debates which focus on the overall sustainability of informal care. These debates highlight ethical as well as moral dilemmas in relation to what can reasonably be expected of people caring for each other (Zorginstituut Nederland, 2022). Verdonk et al. (2024) argue that we are only beginning to understand the influences of these reforms and specifically in terms of health and participation in paid and unpaid care work.

There is a focus on the aging population generally in the Netherlands, but the topic of diversity amongst the aging population receives less attention (Bussemaker et al., 2022; van Wieringen & van Grondelle, 2014). This raises the question of whether the Dutch healthcare system

adequately provides care, regardless of background (van Loenen et al., 2022). It is expected that by 2050 in the Netherlands, around 12% of all people over 65 will have a background of migration (CBS, 2024) and an educated guess can be made that numbers of care recipients and carers will increase as a result. It is necessary to recognise that there is a growing plurality within the group of people with a migration background in the Netherlands. These within-group differences include, for example, differences in nationality, religion, motives for migration, legal status, and the way people with a migration background stay connected to their country of origin (Kremer, 2023).

Historically, migration to the Netherlands has been shaped by colonial influences, economic factors, and political choices (Manning, 2022). During the colonial era, migration from colonies including present-day Indonesia, Suriname and the Dutch Antilles, began in the late 19th and early 20th century. After World War Two, the Netherlands experienced shortages in labour, leading to agreements with countries such as Turkey and Morocco for guest workers. While their migration was initially temporary, they eventually settled in the Netherlands. Migration from Suriname followed in a second wave and more recently migration has been triggered by various humanitarian crises, the expansion of the European Union, and ever-increasing globalisation influences (Manning, 2022). Included within the group of people with a migration background are people who themselves are born outside the Netherlands (first generation), and people born within the Netherlands with one or two parents born outside the Netherlands (second generation). People born in the Netherlands to parents also born in the Netherlands but having one or more grandparents born outside the Netherlands (third generation), do not fall within the group of people with a migration background (CBS, 2024). However, people belonging to the latter group often have to deal with the same prejudice as the first and second generation (Ghorashi, 2023).

In the Dutch public space, generations of people with a migration background encounter racialisation (Ghorashi, 2023) and discrimination (Thijssen, 2023). This is also present within the Dutch healthcare system, where these issues occur in a variety of ways including unequal access to care, a lack of cultural sensitivity, and prejudice held by professionals towards certain groups of care recipients. Cultural incompatibility is most commonly linked to discrimination (Kunst et al., 2025). Discrimination can occur directly between people or indirectly through research, policy or interventions which are not tailored in a person-centred way (Badou et al., 2023). It is known that “white (middle-aged, male) patients are overrepresented in clinical studies and most of what we consider evidence is not, or is insufficiently, studied in other groups” (Bakkum et al., 2023, p.603). These disparities are based on the social position of care recipients and their carers, and contribute to systemic inequality while also significantly affecting the quality of care, and impacting the health and wellbeing of care recipients (Adelson, 2005; McCartney et al., 2019). Moreover, the experience of discrimination can lead to negative

health outcomes and exacerbate existing health disparities (Ikram, 2016; Van Loenen et al., 2022).

By focusing on health inequities, underlying causes of health disparities become evident. This perspective is necessary to facilitate a needs-based approach to healthcare and to overcome health inequities (Hammarström & Annandale, 2012; Hammarström et al., 2014). There is an ongoing debate about the sustainability of informal care in the Netherlands. In these debates, there is a growing attention to diversity. Verdonk et al. (2024) argue that public policy reforms inadvertently affect the lives of differently situated individuals, such as Kofi and Ama. There are persistent health inequities in the Netherlands, and the development of inclusive care is necessary for care to be person-centred, value-driven and contribute to quality of life. Recent research shows that carers and care recipients with a migration background are not receiving the same treatment as carers and care recipients without a migration background (van Loenen et al., 2022). To contribute to a more inclusive healthcare system, it is essential to recognise that country of origin is only one factor; gender, income, and generational differences must also be taken into consideration, without relying on stereotypes (Kremer, 2019) and recognise that health disparities between populations are predominantly based on socioeconomic differences (Badou et al., 2019). Health inequities are not only based on individual lifestyle choices but also from existing societal inequalities, which is insufficiently addressed in current policy (Bussemaker et al., 2022).

Research question

While the importance of adequate collaboration between professionals and carers is evident, current research insufficiently addresses the diverse realities of carers with a migration background. There is currently limited insight into the lived experiences of carers and care recipients with a migration background. On the policy level, while there is increasing attention to carers generally, little attention is given to carers and care recipients with a migration background. Collaborative care networks are multi-layered, and at every level it is crucial to acknowledge health inequities and understand how intersecting aspects of diversity can influence care.

Accordingly, the central focus of this PhD thesis is to critically understand how intersecting aspects of diversity shape collaboration between professionals and carers in care networks surrounding care recipients with ABI and a migration background, with a focus on uncovering underlying power dynamics in order to address existing inequities. This PhD thesis aims to provide insight into the lived experiences of stakeholders in diverse care networks, in order to contribute to a more inclusive way of care provision in collaborative care networks. The following research question is central in this PhD thesis:

How do aspects of diversity shape the collaboration in a care network of carers with a migration background and professionals for the purpose of caring for someone with acquired brain injury?

Methodology

Participatory Health Research (PHR) is the research design used in this PhD thesis, based on the International Collaboration for Participatory Health Research (ICPHR 2013, 2021) and Participatory Research for Health and Social Wellbeing (Abma, 2018). Participation was achieved through the involvement of the community of practice (CoP) (Bindels et al., 2014; Li et al., 2009), critical friends (Blake & Gibson, 2021), and students from the bachelor's and master's programmes. In addition, care recipients, carers, and professionals contributed through informal conversations, interviews, and dialogue sessions, in the empirical studies of this PhD thesis (see Figure 1). Additionally, this section explores the theoretical concepts and underpinnings of the research, specifically the occupation-focused perspective (e.g., Abigail Reid et al., 2023; Atler et al., 2016; Hasselkus & Murray, 2007) and intersectionality (e.g., Crenshaw, 1989; Hancock, 2019; Hankivsky, 2014; McCall, 2005). The empirical studies all use a form of intersectionality-informed qualitative research methodology (Stuij et al., 2020; Windsong, 2018). The author also elaborates on her epistemological standpoint and positionality (Darwin Holmes, 2020).

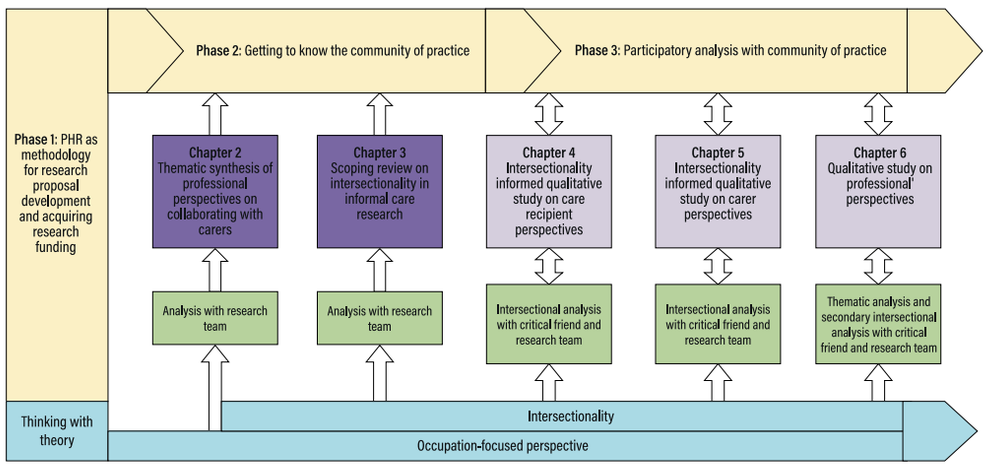

Figure 1. Visualisation research process PhD thesis

Participatory health research

PHR is a form or self-reflective enquiry undertaken by participants; importantly, it is an approach to research that is not done 'on' people providing data but 'with' people (ICPHR,

2013). Involvement of stakeholders in care networks is a primary value of PHR (Abma et al., 2018; Abma et al., 2017). This was achieved by: in Phase 1, writing the research proposal through informal conversations with carers, care recipients (amongst others, Kofi and Ama), and professionals, as well as different health and welfare organisations; in Phase 2, forming the CoP parallel to the first two sub-studies; and in Phase 3, including the CoP and critical friends within the analysis. This process stimulated mutual understanding of perspectives regarding care networks, and promoted individual and reciprocal learning on different levels (Abma et al., 2018).

In phase 1, PHR was used as a methodology in the development of the research proposal as well as in the phase of acquiring research funding. In this phase, consultation took place by conducting informal conversations with: (1) four care recipients with ABI, two of which also had a migration background; (2) three managers at organisations who provide support for carers as well as three groups of carers with and without a migration background (N=17) and 5 individual conversations with carers with a migration background within these organisations; (3) an occupational therapist and community nurse; (4) two managers at healthcare organisations; and (5) three volunteers at organisations which provide support to people with a background of migration in the Netherlands. The consultation focused on demarcating the topic, scope and aim of the research. Stakeholders involved thus contributed to the overall direction of this PhD thesis and the social relevance of the study. The practical experience of those stakeholders involved was supplemented with knowledge from existing literature to formulate the actual research question and guide the methodology.

A CoP ran parallel to the sub-studies of this PhD thesis. The CoP consisted of care recipients with an ABI, carers, and professionals (N = 8), and established to incorporate input from representatives impacted by the study and foster mutual learning (Abma, 2018; Dedding et al., 2022). In phase 2, the CoP meetings focused on getting to know each other, building trust, and getting familiar with the way of working of the CoP. The systematic review as well as the scoping review were used as input for initial dialogue, as well as the personal experiences and positionality of the CoP members. In phase 3, the CoP was involved in the actual participatory analysis of the results of the three empirical sub-studies. By involving diverse perspective in the analysis, our finding were enriched and reinforced, respecting multiple forms of knowledge and helping to prevent reproduction of dominant narrative and perpetuate inequalities (Groot et al., 2022). The participatory analysis created a space to share CoP members' accounts of their experiences in collaborative care networks, creating a mutual understanding of the influence of diversity on care provision to care recipients with ABI, and highlighting opportunities for change (Abma et al., 2020).

During the analysis of the three empirical studies, the preliminary analysis was conducted by the research team in close collaboration with three critical friends, to ensure rigor and establish trustworthiness (e.g. Blake & Gibson, 2021; Van Wees et al., 2023). Critical friends were invited in the analysis to ensure research triangulation and reflexivity, because none of the members of the research team have a background in migration. The critical perspectives of the critical friends who could provide insights invisible to the research team were welcomed. All three critical friends identified as bicultural and came from the author's existing network, and all express a desire to engage in research. The support of critical friends, allowed for critical discussions during the analysis, intentional introspection, and action (Gani & Khan, 2024; Kapinga et al., 2022).

As a research team, we understood that our own positionality would influence the research, so a critical reflexive approach was adopted (Lazard & McAvoy, 2020; Verdonk, 2015). Accordingly, communicative spaces were central to the PHR design of this PhD thesis (Abma, 2018). The CoP members, critical friends, students, and members of the research team came together, in their respected group, to share their understandings and experiences and reflect on the results of the different sub-studies. A communicative space is an ideal place for people to come together for reciprocal perspective thinking, and to foster a shared willingness to consider reflecting on one's own perspective through the eyes of another (Abma, 2018; Habermas et al., 2007; Kemmis, 2012; Tanner, 2019).

Thinking with theory

The practice context of care networks formed the starting point for the PhD thesis, but theory helped illuminate the complexity of how diversity and power dynamics shape collaborative care networks. Thinking with theory supports rigor and transparency in the analysis to comprehend empirical sub-studies in a nuanced way. This thesis acknowledges the equal relationship between theory and practice, in which one is not seen as more important than the other (Jackson & Mazzei, 2012). It also recognises that no theory is neutral, and no single theory can possess the whole truth, but that each can contribute to understanding the complexity of care networks (Glasdam et al., 2024).

Occupation-focused perspective

Being an occupational therapist myself, my worldview is partly rooted in occupational science as part of my professional identity. This resulted in an occupation-focused perspective informing the methodological choices, as well as an empirical focus on meaningful everyday activities, however this was not an explicit theoretical frame within the sub-studies. Insight from occupational therapy practice context has shown first-hand difficulties in the collaboration with

carers and additionally a lack of diversity-responsive care. These observations highlight the practical relevance of this research by emphasizing doing research 'for' and 'with' stakeholders from the healthcare practice. This PhD thesis contributes to critical inquiry from a starting point of occupational therapy, based on scientist-practitioner principles (Stricker, 2002).

An occupation-focused perspective highlights the importance of meaningful activities in shaping who we are and how we experience the world (Fisher, 2013). In the context of this PhD thesis, this perspective acknowledges how meaningful activities shape professional, carer, or ABI survivors' experiences. An occupation-focused perspective emphasises participation in meaningful activities, the ordinary and familiar things that we do in everyday life (Christiansen et al., 2024) are an essential contributor to health and well-being (Yerxa, 1990). While they are specific to each individual (Pierce, 2024), activities are always embedded in the environment and larger context in which they are conducted (Abigail Reid et al., 2023). To be perceived as meaningful, these activities must possess value for the person (Hasselkus, 2021).

An occupation-focused perspective acknowledges that the meaningful activities we do in everyday life and identity formation are connected. Engaging in meaningful everyday activities is a transformative process that shapes who we are, contributing to our sense of self, personal values, and social roles (Maersk, 2021). Someone's occupational identity changes when surviving an ABI, but it also changes when becoming a carer for someone with ABI, as people often have to change their daily lives to accommodate the needs of the person with ABI (Larsen et al., 2024). Through this occupation-focused perspective, caring is recognised as a meaningful activity, allowing research to focus on what carers need to be able to be effective at the individual and social level. This perspective provides insight into how provision of informal care alters the environments in which carers and care recipients live, while also informing understandings of how caregiving not only occurs through relationships, but shapes people experience overtime (Abigail Reid et al., 2023).

Intersectionality

To critically understand how intersecting aspects of diversity shape collaboration between professionals and carers in care networks surrounding care recipients with ABI and a migration background, intersectionality is used as an empirical and theoretical framework (Hancock, 2019).

The choice to use intersectionality as empirical framework arose over the course of this PhD thesis (Bauer, 2014; Crenshaw, 1991; Hankivsky, 2014b; McCall, 2005). This process unfolded as follows. Within the thematic synthesis of professionals' perspectives (Chapter 2), it became clear that professionals experienced dealing with diversity as stressful and even problematic, and that "diversity" was often used as synonym for culture. In the qualitative study focusing on the professional perspective, (Chapter 6), the preliminary thematic analysis was subjected to a secondary intersectional analysis to gain insight into the complexity of interactions in care networks – based on social positioning and focusing on power structures and social injustice. This prompted the decision to conduct a scoping review to explore what was already known about the use of intersectionality in informal care research (Chapter 3). The scoping review resulted in an intersectionality-informed coding scheme, which formed the basis for the intersectionality informed qualitative studies into care recipients' (Chapter 4) and carers' (Chapter 5) perspectives. In this PhD thesis, intersectionality helped to clarify within-group differences amongst care recipients and carers with a migration background, as well as the mutual relationship between categories of diversity when embedded in the specific context of care networks.

Theoretically, intersectionality was originally coined by Black feminist legal scholar Kimberley Crenshaw. Intersectionality was designed to analyse interlocking systems of privilege and oppression, and to develop strategies to challenge those systems with an emphasis on racism, sexism, heterosexism, and classism (Crenshaw, 1989, 1991). The concept is rooted in Black feminism, and while Crenshaw is credited with formally naming and theorising intersectionality, the concept of intersectionality existed prior to Crenshaw's work in 1989 (Aguayo-Romero, 2021). It is therefore important to acknowledge the work of The Combahee River Collective who challenged intersecting systems of oppression based on race, gender, heteronormativity, and class (Weiss, 2020). In addition, this line of thought was developed by Sojourner Truth, who as early as 1851 asked "Ain't I a woman" when challenging traditional conventions between race and gender (Buhle et al., 2013). Hancock (2016) provides an intellectual history of intersectionality and argues that, when studying power and identity, ethical consciousness is necessary in the choice of whose work is worthy of "rigorous intellectual engagement" (p.2).

Adopting intersectionality as a theoretical approach stems from the understanding that reality is embedded in, dependent on, and constituted by geographical, historical, temporal, political, social, and emotional contexts, is ever-changing and relational as it is made, (re)produced, and confirmed by people in everyday interactions, following the work of McCall (2005), Yuval-Davis (2006, 2011) and Hancock (2016 and 2019). This perspective seeks to uncover deeper, more nuanced insights into underlying layers that shape stakeholder experiences in care networks (Kapilashrami & Hankivsky, 2018). An intersectional approach provides a framework for understanding how different dimensions of diversity interact to produce patterns of (dis)advantage in people's lives, social norms, cultural beliefs, institutional structures, and understand the outcomes of these interactions in terms of power, social inequities, and health disparities (Hankivsky 2014a). This PhD thesis does not solely focus on cultural aspects or differences but goes a step further to explore the influence of the multiple intersecting aspects of diversity in the context of care networks. The intersectionality lens helps to embrace rather

than obscure the heterogeneity of peoples lived experiences (Bowleg, 2008). In doing so, intersectionality is understood to challenge health inequities and structural disadvantages within care networks (McCall, 2005; Merz et al., 2023).

To understand the different perspectives in care networks, it is important to examine how these views are constructed through the intersection of diverse identities and shaped by specific contexts and circumstances (Windsong, 2018). Public health has a longstanding tradition of investigating how both personal and systemic characteristics influence patterns of health and wellbeing (Merz et al., 2023). Individual identities and broader social structures together create the conditions that affect how people live, thereby shaping their overall health and quality of life (Sabik, 2021). When looking at processes of inclusion and exclusion, it is important to acknowledge that these dynamics result in the distribution of privilege and disadvantage. This may manifest in individuals structurally experiencing unearned benefits or advantages, or conversely, unearned detriments or disadvantages. However, experiences of privilege and disadvantage are not static, nor are they absolute. Individuals are never completely privileged or completely disadvantaged, as experiencing disadvantage in one context does not exclude experiencing privilege in another. Keeping this in mind, the focus of this research will be on the structurally unequal distribution of power, whereby certain groups are systemically favoured over others across different social contexts and interactions over time. In parallel, the focus on transformation lies in exploring how these structural inequities can be challenged. This approach allows for an emphasis not just on differences, but more critically on power dynamics and the social inequities embedded within care networks. Intersectionality enhances sensitivity to diversity by shifting away from a single-issue lens, highlighting instead how various aspects of diversity intersect and shape individuals lived experiences (Crenshaw, 1991; Hankivsky, 2020).

Epistemology and positionality

There is a need to bring epistemology into intersectionality-informed research, as researcher positionality, with its accompanying privileges, disadvantages, and ethical responsibilities, informs the way research is operationalised and shapes research methodology (Labelle, 2020). Being transparent regarding epistemology and positionality may overcome two major criticisms of intersectional-informed research. Firstly, it can counter the lack of a clearly defined intersectional research methodology by truly focusing on how intersectionality has influenced choices rather than merely describing methods. Secondly, it ensures due attention is paid to the origins of intersectionality in Black feminist scholarship (Aguayo-Romero, 2021).

Intersectionality is rooted in feminist epistemology and acknowledges that knowledge should be based on lived experiences, particularly the experiences of those who have been

traditionally excluded from knowledge production. Additionally, to disrupt and challenge reductionist views of identity and oppression (McCall, 2005), the author recognises that power is relational and shapes perceptions as well as presuppositions, which are context based and incorporate temporal contingency (Hancock, 2016; Meyer et al., 2013). This influences the knowledge created within the community of practice, as well as the perspectives of research participants. Knowledge creation is not a neutral endeavour. Using intersectionality as a way of thinking recognises the interconnectedness of numerous socially constructed identities which collectively shape the lived experiences of individuals and groups (Abrams et al., 2020). This is true for everyone: for me, for members of the community of practice, for students and critical friends involved, as well as for all research participants. Insights into how our lived experiences are shaped is put front and centre in data collection as well as analysis. Power structures do not only affect who has access to knowledge, but also who is trusted as a legitimate knower, an understanding rooted in a deeper epistemological belief about who is worthy of knowledge and whose knowledge is regarded as legitimate. These beliefs are themselves shaped by systems of social inequality, where dominant groups are positioned as more credible or authoritative knowers. Acknowledging that knowledge systems and social structures systematically deny certain groups the ability to be recognised as legitimate sources of knowledge is crucial to this thesis (Auerback, 2021; Fricker, 2007).

Since the larger research project follows a PHR approach, measures were taken to ensure the inclusion of stakeholders in every step of the research process (Abma, 2018). This requirement stems from the epistemological belief that knowledge is embedded in social relationships and is most influential when produced collaboratively (Fine, 2010); and that acknowledging a horizontal epistemology emphasising an equal exchange of knowledge and intentionally creating space where all participants, regardless of social position or background, are seen as valid knowers through the contributions that they make (ICPHR, 2013). It also requires recognising that knowledge is socially constructed and shaped by social and cultural contexts and interactions. Furthermore, it entails advocating for the use of knowledge as a tool for social change. Knowledge has transformative value, can promote justice, and dismantle oppressive systems (Abma, 2018). It is essential to not only state who you are as a researcher but also to critically reflect and self-scrutinise, explicitly describing how one's own social position may have impacted on this PhD thesis. Reflexivity involves a self-conscious awareness of the relationship between the research and the 'other' being the research participant (Bourke, 2014). This is necessary, as choices made throughout the research process are not value free (Darwin Holmes, 2020). Providing a positionality statement enhances research quality and promotes social justice. By acknowledging our own social position and the influence on the research process, a safe space may be created that prioritises participants' experiences. It opens up space for the representation of diverse perspectives within the research team, which may reduce bias (Martin et al., 2022).

Reflexive practices, including writing positionality statements and participating in dialogue about these statements, were central to my experience throughout this study. These activities took place in meetings of the community of practice, with involved critical friends, as well as with all 19 students from the bachelor's and master's occupational therapy programs who contributed to the research in some form. They were all active contributors to this research project, and therefore I felt it was necessary that everyone participated in reflexive practices. However, their statements and reflections will not be included in this PhD thesis for privacy reasons. Writing a positionality statement is also a vulnerable exercise (Martin et al., 2022) and is not intended to compel researchers to disclose personal information they are uncomfortable sharing. Therefore, before writing my positionality statements, I analysed the reflexive journal I kept during this research project and asked myself three reflexive questions to guide my analysis, based on Kapinga et al. (2022). These questions were: what role did my positionality as a white woman studying aspects of diversity in care networks play?; how did I use my positionality in different spaces?; and how did my positionality influence the interactions with professionals, carers and care recipients?

Thesis outline

The main chapters of this thesis are divided into two parts. Part I focuses on the state of the literature from an international perspective, grounding this PhD thesis in the current scientific context. Chapter 2 presents a systematic review aimed at gaining insight into professionals' perspectives on collaborating with carers. While previous research provided insights into carers' and care recipients' perspectives (amongst others; Boer & Klerk, 2013; Jacobs et al., 2014), there was a limited scope of research focussing on understanding professionals' perspectives. Chapter 3 describes a scoping review and provides insight into the theoretical and methodological foundation of intersectionality in informal care research. Part II narrows the focus to the Dutch context, with Chapters 4 to 6 presenting the perspectives of different stakeholders from an intersectional perspective: care recipients and carers with a migration background, and professionals collaborating with carers from a migration background. This provides in-depth insight into how intersecting aspects of diversity and power are shaped within collaborative care networks. The final chapter comprises the general discussion. The intermezzos between chapters consist of parts of my reflexive researcher journal, researcher positionality statements, and learning process with the CoP. In these sections, I reflect on personal experiences related to my own social position, and the possible impact of my positionality on the research conducted for this PhD thesis by quoting parts of the reflexive journal I kept from the beginning of this research.

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Intermezzo

Who am I, to study injustice in care networks?

During a short break between therapy sessions, a colleague walked into the office. He exhaled sharply, wanting to discuss a new client. I was still new in the organization. I was still finding my way and learning as an occupational therapist. He leaned against the filing cabinet and mumbled, "I don't want this new client on my caseload." I looked up from my computer, not knowing what he meant. "They're too much trouble," he said. "They're a big Moroccan family. They're never satisfied. It's never good enough. And they don't listen. I'm always the one who gets these families. I don't have the time for all their opinions. They don't help. They just complicate things."

The client in question was a young man recovering from a traumatic brain injury sustained in a car accident. His life has been turned upside down, and his family was seeking support and care as they tried to make sense of this new situation. But what I was hearing was not about the client's clinical needs, but about assumptions, fatigue and perhaps something deeper. I did not say much at the time. I nodded, perhaps too politely, and let the moment pass. That evening, on the train home, I stared out the window and reflected on the moment. Why had I so passively accepted his way of thinking? Why did I feel so insecure about confronting what felt wrong? That moment in the office was not an isolated incident. I heard variations of it over and over again as the years passed: the frustrations aired behind closed doors, the silent assumptions masquerading as practical concerns. Each time, I struggled with how to respond. Too often, I said nothing.

Later, when I found the courage to raise these questions, I was often met with defensiveness or polite dismissal. Accountability seemed elusive. I wondered what would be needed to make conversations fruitful. So when I was given the opportunity to do my own research, I knew it had to start differently. It had to begin with listening, not just to colleagues, but to the carers and care recipients with a migration background whose voices were so often spoken about but were so rarely heard. The research had to be participatory, and it had to make space for complexity, discomfort and multiple truths.

That intention is reflected on the cover of this thesis. The image is a fragment of a painting from rural South Africa, a work that now hangs in my living room. For me, it speaks of diversity, not as a concept to be managed, but as something abstract, human and deeply personal. It reminds me of how out of place I sometimes felt when I worked abroad, and yet how protected I still was by my identity and privilege. That realization changed me. It reminded me that inclusion is not passive. It is not enough to say that people are "hard to reach". We need to ask: what are we doing to reach them? This vignette marks the beginning, not of an answer, but of a question: How do we truly share care in a diverse society? What does it really take to listen?