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Unveiling inequity: diversity and power in collaborative care networks

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Unveiling inequity:

Diversity and power in collaborative care networks

Rieke van Dijk – Hengelaar

Unveiling inequity: Diversity and power in collaborative care networks

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Ken je mij, wie ken je dan?
- Huub Oosterhuis

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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 Ama¹ 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).

¹All 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 through 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; Adler 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).

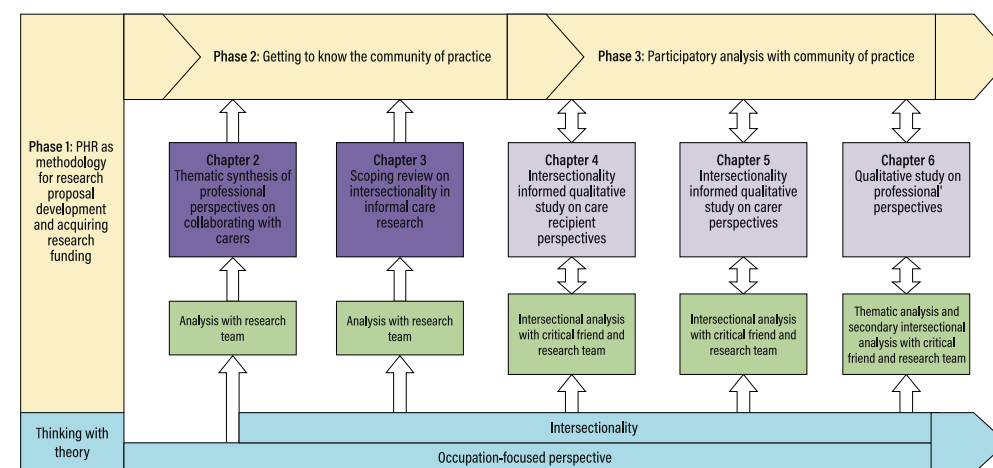


Figure 1. Visualisation research process PhD thesis

Participatory health research

PHR is a form of 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?

Chapter 2

Exploring the collaboration between formal and informal care from the professional perspective - a thematic synthesis

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Abstract

In Dutch policy and at the societal level, informal caregivers are ideally seen as essential team members when creating, together with professionals, coordinated support plans for the persons for whom they care. However, collaboration between professionals and informal caregivers¹ is not always effective. This can be explained by the observation that caregivers and professionals have diverse backgrounds and frames of reference regarding providing care. This thematic synthesis sought to examine and understand how professionals experience collaboration with informal caregivers to strengthen the care triad. PubMed, Medline, PsycINFO, Embase, Cochrane/Central and CINAHL were searched systematically until May 2015, using specific key words and inclusion criteria. Twenty-two articles were used for thematic synthesis. Seven themes revealed different reflections by professionals illustrating the complex, multifaceted and dynamic interface of professionals and informal care. Working in collaboration with informal caregivers requires professionals to adopt a different way of functioning. Specific attention should be paid to the informal caregiver, where the focus now is mainly on the client for whom they care. This is difficult to attain due to different restrictions experienced by professionals on policy and individual levels. Specific guidelines and training for the professionals are necessary in light of the current policy changes in the Netherlands, where an increased emphasis is placed on informal care structures.

¹ In chapter 2 and 3 informal carers are referenced as caregivers. In the later stages of this PhD thesis, chapter 4-6 and the general introduction and discussion, the term caregiver has been changed to carer. This choice was made in order to emphasize the reciprocal relationship between carers and care recipients.

Introduction

Care for people with chronic conditions is often provided by informal caregivers combined with support from professionals arranged in so-called 'care triads' (Kemp et al. 2013), a care network consisting of a client, informal caregiver, and healthcare (allied health and nursing) and social professional(s). Professionals together with informal caregivers create support plans for the person for whom they care (Talley & Crews 2006). However, the collaboration between informal care and professionals is not always effective (Lefebvre et al. 2007).

In the Netherlands, there is an increased emphasis on informal care structures. Based on developments from policy and social perspectives (Boer de & de Klerk 2013), the number of informal caregivers will rise in the next decade (Verbeek-Oudijk et al. 2014). Given the shift from the traditional welfare state to the participation society, where citizens are expected to be primarily responsible for their own health and welfare, de-institutionalisation of healthcare is taking place. Care will be provided in the community with support of informal caregivers and professionals, and only complex care will be given within an institution (Kalsouw & van Vliet 2015). Given this shift, it is important to find out how the collaboration between professionals and informal care is taking place.

Twigg (1989) describes three models that outline frames of reference for the relationship between professionals and informal care: informal care as resource; informal care as co-worker; and informal care as co-client. On the Dutch policy level, informal caregivers are ideally seen as essential team members (Verbeek-Oudijk et al. 2014). Consequently, when referring to informal caregivers as co-workers, we use Twigg's outline. In this frame of reference, the professional works in parallel with the informal sector, having an enabling and supportive role (Twigg, 1989). However, this might create underlying difficulties when put into practice because informal caregivers and professionals have different perspectives in providing care to the care recipient (Jacobs et al. 2014).

Research on the informal caregivers' perspective shows that most problems arise in communication and results from different expectations between professionals and informal caregivers (Jacobs *et al.* 2014). Dutch research has shown informal caregivers have mixed feelings about their collaboration with professionals. They do not feel involved or recognised as a partner in the care provided by professionals (Wittenberg et al. 2012; de Boer & de Klerk 2013). Almost half of the informal caregivers claim they rarely or never get the opportunity to participate in decisions or share their concerns (de Klerk et al. 2015).

In contrast, little research has examined professionals' perspectives regarding working and collaborating with informal caregivers (de Boer & de Klerk 2013; Jacobs et al. 2014). To improve the collaboration between informal caregivers and professionals, we must examine what we

can learn about the professional perspective on collaboration with informal caregivers. A quick scan of the Dutch literature revealed that this topic is marginally researched in the Netherlands; therefore, a broader review is performed based on international literature.

This thematic synthesis aimed to explore the collaboration between professionals and informal caregivers to gain a better understanding of experiences of professionals on the collaboration with informal caregivers and to further understand their perspective and to strengthen care triad in the future within the community setting.

2

Methodology

As we were interested in what is known in international literature about the experience of professionals regarding the collaboration with informal caregivers, we chose a review method in qualitative studies (Thomas & Harden 2008). Campbell et al. (2003) suggest that syntheses of qualitative research give a stronger voice to experiences than single studies do. Consequently, we performed a thematic synthesis pertinent to the topic at hand. The thematic synthesis was based on the methodology proposed by Thomas and Harden (2008) and followed four phases: 1) search and study selection, 2) critical appraisal of the selected studies 3) data extraction, and 4) thematic synthesis. Each phase will be explained in the following paragraphs.

Search Strategy and Study Selection

In phase 1, we searched six electronic databases: PubMed, Medline, PsycINFO, Embase, Cochrane/Central, and CINAHL. We systematically searched for papers published between 2000 and May 2015, based on a search strategy with the following key terms: formal care AND support AND informal caregiv* AND diversity AND perspective. The basic search strategy was expanded using synonyms, which were found in the thesaurus (see the final search strategy in Appendix 1).

The inclusion criteria were: 1) published between 2000 and May 2015; 2) written in English or Dutch; 3) describing the experiences of allied health, nursing, or social work; 4) focusing on the professional perspective of collaboration with the informal caregiver; and 5) published in a peer-reviewed journal. Although the logical choice in this review is to focus only on community settings, we also included other settings due to the lack of articles specifically focussing on community settings.

All studies were independently selected, based on titles and abstracts in the first round and full text reading in the second round. This was done by the first and second author (AHH and MvH). Disagreements about selected articles were subject to discussion to reach consensus.

Quality Appraisal

In phase 2, we used the Critical Appraisal Skills Programme (CASP) to appraise the methodological quality of the studies. All items on this 10-item CASP Qualitative checklist for the appraisal of qualitative studies were scored with 'yes' or 'no' depending on whether the topic, e.g. research design, recruitment, ethical considerations, were described sufficiently. An additional score of 'unclear' was added to differentiate between sufficiently and insufficiently. This resulted in three options: 1, 1/2, and 0. The higher the total score, the better the methodological quality, with a maximum score of 10. All remaining studies were independently appraised with the CASP by the first and second author (AHH and MvH) and all items that were scored differently were subject to discussion to reach consensus.

Data Extraction and Thematic Synthesis

Phase 3 consisted of data extraction and thematic syntheses, carried out by the first author (AHH). This process was peer reviewed by the second author (MvH). Furthermore, the findings were discussed with all authors. The goal of this process was the synthesis of the extracted findings regarding the experiences of professionals as described in each study. For this phase we followed the procedure, as described below, as proposed by Sandelowski and Barroso (2003) and Thomas and Harden (2008).

First, the results sections from all included articles were, verbatim, extracted and placed in AtlasTI. The data were read as a whole and meaningful segments were labelled. Second, the data were coded using a system of line-by-line coding followed by a process of axial coding. Using line-by-line coding made *translation* of concepts from one study to another possible, which is one of the key tasks when performing a synthesis. Third, descriptive themes were developed by looking at the differences and similarities between the codes and grouping them together. Fourth, overarching thematic themes were developed. Developing thematic themes meant that the authors went beyond the themes of the primary studies (Thomas & Harden 2008). This was done by using a cyclical process of further interpretation and discussion between the authors about the final themes to describe and explain all initial descriptive themes (Thomas & Harden 2008, p7). When the final thematic elements were developed, citations from initial studies were checked to confirm and support the different themes.

Results

Searches in all six databases resulted in 1151 possible articles. These were screened based on title and abstract. Subsequently, the full text of 68 articles was examined. Twenty-eight articles were selected for methodological appraisal, and, finally, 22 articles were used for thematic synthesis (see flow chart in Figure 1).

2

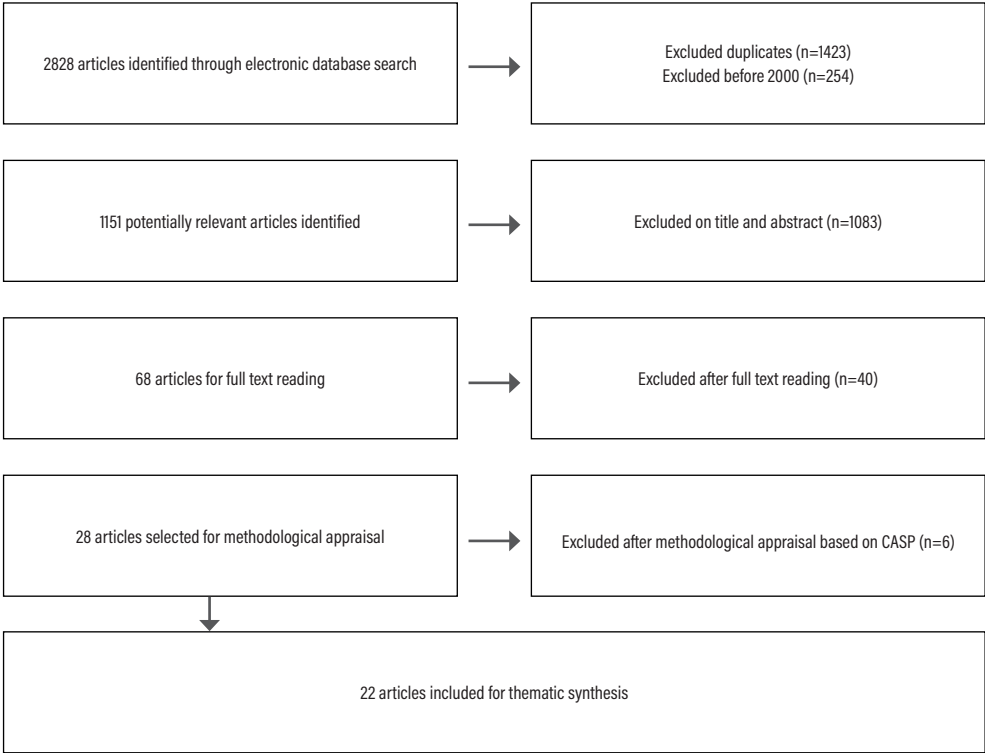


Figure 1. Flowchart of included and excluded studies

Characteristics of Included Studies

Most studies were conducted in Canada (10/22), followed by Europe (5/22). In Europe, studies were conducted in France, Belgium, Germany, Norway, and the United Kingdom. The other studies were conducted in the United States (2/22), Australia (2/22), New Zealand (1/22), Israel (1/22), and South Africa (1/22).

Table 1 provides an overview of the characteristics by study. Nurses (n=206) were most represented in the studies, followed by case managers (n=16); occupational therapists (n=6); physiotherapists (n=4); managers (n=4); social workers (n=3); and support staff (n=3). However, this overview does not give a complete picture because not all articles were completely clear on the number participants per profession. Most informal caregivers cared for a frail elder (12/22), with four studies on dementia care. There were two studies on HIV care, and two on mental health. Four studies had a diverse population in their sample.

Methods and Quality of Included Studies

Table 1 shows the study characteristics of all included studies. All studies aimed at exploring the collaboration between professionals and informal care. Most studies used interviews

(19/22) varying from semi-structured to in-depth interviews. Nine studies used a combination of interviews with either a focus group, observation, survey, or logbook. Only two studies used focus groups, and one study used thematic analyses of meetings and referral letters as well as a survey. The CASP score varied from 5-8 with a mean of 5.9. Studies with a lower score mostly lacked explanations of ethical procedures and a description of the relationship between researcher and participant.

Table 1. Study characteristics

Study	Country	Aim	Design	Data collection	Participants	Chronic condition	CASP score
Agee & Blanton (2000)	United States	To explore the professional context within which families make decisions about elder caregiving. To increase the understanding of the interface between informal structures of families/friends and formal structures of the service provider network.	Exploratory qualitative	Interviews	Health providers from adult day care, aging service, assisted living, chaplain/hospice, geriatric assessment, home health service, large- and small-scale nursing home administration, geriatric medicine (n=9)	Frail elderly	6
Aujoulat et al. (2002)	France and Belgium	To describe the communication process between healthcare professionals and family caregivers in the field of AIDS, to analyse the difficulties they face, and to get a better understanding of the experience and expectations on both sides.	Mixed methods, emphasis on qualitative methods	Survey and interviews	Healthcare professionals n=70 (nurses n=25, doctors n=19), others n=26 (pharmacists, psychologists, social workers)	AIDS	5
Boros (2010)	South Africa	Addressing identified gaps by providing information about interaction between formal and informal care.	Qualitative	Semi-structured interviews	Home based caregivers n=22, nurses n=6, other n=4	Diverse	6.5
Buscher et al. (2011)	Germany	To investigate the relationship between nurses and family caregivers and its impact of the actual care provided.	Grounded theory	Interviews	Family caregivers n=57, nurses n=31	Diverse	8
Carpentier et al. (2008)	Canada	To explore the interface between healthcare practitioners and caregivers of people with Alzheimer's disease living in the community	Exploratory interpretative	Semi structured interviews	n= 20 (nurses n=4, coordinators n=4, animator n=1, support staff n=9, substitute caregivers n=2, medical staff n=2)	Dementia	8
Cohen-Mansfield et al. (2013)	Israel	To compare formal and informal caregivers' perceptions of delusions and hallucinations in community residing older PWD's	Mixed methods	Assessments and interviews	n=151 PWD's, n=90 formal caregivers, n=151 informal caregivers	Dementia	6.5

Table 1. continued

Study	Country	Aim	Design	Data collection	Participants	Chronic condition	CASP score
Dal Bello-Haas et al. (2014)	Canada	To describe formal and informal caregivers' perceptions of the challenges and needs associated with providing services, care and support for individuals with dementia living in rural and remote regions in Saskatchewan, Canada.	Mixed methods Exploratory	Thematic analysis of consultation meetings, telephone and email questionnaire, referral letters	communities n=13, physicians n=55, referral letters n=250, caregivers n=151	Dementia	6.5
Fjelltn et al. (2008)	Norway	To describe carers' and nurses' appraisal of workload in care of frail elderly awaiting nursing home placement	Comparative cross sectional	Workload scale Interviews	Carers n=11, nurses n=11	Frail elderly	7
Goodwin & Happell (2006)	Australia	To examine the issue of consumer, carer participation in mental health care from the perspectives of consumers, carers and psychiatric/mental health nurses.	Qualitative	Focus groups	Carers n=19, nurses n=30	Mental Health	7
Guberman et al. (2006)	Canada	To identify home care practitioners' understanding of caregiver responsibilities, difficulties and need for support.	Multiple case study	Logbook and interviews	n=55 (nurses, social workers, physical therapist, occupational therapist, home care worker, managers)	Diverse	6.5
Jansen et al. (2009)	Canada	To explore formal care providers' perceptions of their experiences with Canadian home- and community-based dementia care.	Descriptive interpretative	Focus groups	Nurses, social workers, therapists	Dementia	6.5
Levesque et al. (2010)	Canada	To explore the experience of caregivers and practitioners who took part in a field test of the Family Caregivers Support Agreement (FCSA) tool.	Qualitative	Focus groups and interviews	Social workers n=4, nurses n=2, caregivers n=17	Elderly	7.5
McPherson et al. (2014)	New Zealand	Exploring carers and professional perspectives on how informal caregivers and formal services interface with one another and identifying how formal services could better interface with informal carers.	Qualitative descriptive	Focus groups and interviews	Informal carers n=39, formal care n=31	Diverse	8
McWilliam, et al. (2001)	Canada	To illuminate the components and activities of shared experience of in-home care prior to a planned shift to an approach of flexible, client-driven in-home service delivery.	Hermeneutic phenomenology	Interviews	Clients n=6, informal caregivers n=6, service providers n=9	Elderly	7
Mitchell (2009)	Australia	To bridge the gap between action focussed and structure focussed accounts of roles in mental health care	Discourse analysis	Group interview	n=41 (primary health and social care agencies, stake holders from communities)	Mental health	7

Table 1. continued

Study	Country	Aim	Design	Data collection	Participants	Chronic condition	CASP score
Mosack & Wendorf (2011)	United States of America	To describe HIV health care providers' perspectives on the involvement of informal supporters in their HIV health care and health care decision-making.	Qualitative	Semi-structured interviews	Physicians n=7, nurse practitioners n=3, registered nurse n=1	HIV	7
Peckman et al. (2014)	Canada	To examine how professional case managers from across the care continuum perceive and attempt to balance informal and formal care in their day-to-day work.	Mixed methods	BoC model and follow up interviews	36 homogeneous BoC groups and case managers n=10	Older persons	5
Pickard & Glendinning (2002)	United Kingdom	To explore the factors which distinguish family caregiving from professional caregiving, comparing and contrasting carer's roles and approaches with that of nurses. To establish how lay and professional carers can work together effectively, ensuring that family carers will be supported in the most appropriate way.	Qualitative Ethnographic approach	In-depth interviews and observation	Carers n=24, district nurses n=12, community psychiatric nurses n=12	Frail elderly	5
Toscan et al. (2012)	Canada	To investigate care coordination for older hip fracture patients from multiple perspectives, including patients, informal caregivers, and health care providers to determine the core factors related to poorly integrated care.	Focussed ethnography	Semi-structured interviews and observations	Informal caregivers n=6, general practitioner n=1, physiotherapists n=4, occupational therapists n=4, nurses n=3, case managers n=6	Hip fractures	6.5
Walker & Dewar (2001)	United Kingdom	To produce a set of indicators for good practice that would facilitate the involvement of carers in decision-making.	Case study design	Interviews, focus groups, field notes and documentation	Carers n=20, nurses n=17, occupational therapists n=2, doctors n=5, social workers n=2, community nurses n=3	Dementia	6.5
Ward-Griffin (2001)	Canada	To describe and explore the relationship between nurses and female family members caring for elderly in the home.	Critical ethnography	In-depth interviews	Nurses n=23, family caregivers n=23	Frail elderly	6
Ward-Griffin & McKeever (2000)	Canada	To examine the relationship between community nurses and family members providing home care to older persons in urban Canada.	Critical ethnography	In-depth interviews	Nurses n=23, family caregivers n=23	Frail elderly	5.5

Synthesis of Results

Thematic synthesis of 22 articles resulted in 150 segments or codes meaningful to the aim of this research. These 150 segments were grouped into descriptive themes, and in the final phase interpreted into seven thematic themes: 1) the struggle experienced by professionals between being an expert versus partner towards the informal caregiver, 2) communication within the

care triad, 3) the experienced hierarchy in the care triad, 4) professionals regarded informal caregivers as essential, 5) professionals reported a mismatch between the provided services and the needs of informal caregivers, 6) professionals felt restricted by the collaboration, and 7) some professionals reflected on diversity in collaboration with informal caregivers. Table 2 gives an overview of the primary studies from which meaningful segments were used for thematic themes.

Table 2. Overview thematic themes

	Agee & Blanton (2000)	Aujoulat et al. (2002)	Boros (2010)	Buscher et al. (2011)	Carpentier et al. (2008)	Cohen-Mansfield, Golanderr & Heinik (2013)	Dal Bello-Haas et al. (2014)	Fjelltun et al. (2008)	Guberman et al. (2006)	Goodwin & Happell (2006)	Jansen et al. (2009)	Levesque et al. (2010)	McPherson et al. (2014)	McWilliam et al. (2001)	Mitchell (2009)	Mosack & Wendorf (2011)	Peckman et al. (2014)	Pickard & Glendinning (2002)	Toscan et al. (2012)	Walker & Dewar (2001)	Ward-Griffin (2001)	Ward-Griffin & McKeever (2000)
Professionals are expert versus partner		x			x			x	x	x	x	x	x	x		x	x			x	x	x
Communication in the care triad	x	x	x	x	x					x		x	x	x	x		x	x	x			
Hierarchy in care triad		x	x		x			x		x	x	x		x		x	x	x		x	x	x
Caregivers are essential			x	x				x		x	x	x	x			x	x	x		x	x	
Mismatch between services and needs						x	x				x		x	x				x			x	x
Professionals feel restricted in collaboration with the caregiver		x	x	x	x	x	x			x	x	x								x	x	x
Diversity in the care triad					x						x						x				x	

Professionals are experts versus partners

The professionals' perspective regarding their role in the collaboration comprised a continuum between the feeling of being the expert and trying to work in partnership with the caregiver. Dal Bello- Haas et al. (2014) found professionals saw a partnership approach as desirable for the informal caregiver. Other research shows professionals understood the importance of a partnership approach to empower caregivers 'and give them a greater sense of self-worth' (Levesque et al. 2010: 882). However, it seems that often professionals did not use a partnership approach in their practice but mostly acted as an expert. They 'use their own knowledge, status and authority to accomplish the tasks and goals of the system and their prescribed professional mandates, with little attention to the knowledge, status and authority of clients as potential partners in care' (McWilliam et al. 2001: 60).

Pickard and Glendinning (2002) and Levesque et al. (2010) showed that when professionals claimed to work in partnership this was not always a true partnership. 'Professionals and family carers work in such a way that each are able to do their allotted tasks in a process that may be described as complementarity' (Pickard & Glendinning 2002: 147). Several strategies were identified by professionals to form a partnership approach, namely sensitive listening, asking enabling questions, and not imposing own views (Walker & Dewar 2001, Levesque et al. 2010). McPherson et al. (2014) and Carpentier et al. (2008) added that taking time to build trust was essential.

These strategies sometimes contradicted the roles and approaches professionals assume in a collaboration. Agee and Blanton (2000) emphasised the professionals' role of educator, 'where teaching and sharing information are used more often than listening' (p. 322). The professionals in the research of Carpentier et al. (2008) used both roles as listener and educator. The approach which focuses on empowerment of the informal caregiver was only used sometimes (p. 725). Ward-Griffin and McKeever (2000) and Ward-Griffin (2001) described four roles for professionals of which the manager-worker and co-worker were most often adopted. Within the role of co-worker, the nurse is a teacher and there was only a notion of teamwork with a controlling role for the nurse. The manager-worker is more or less a coach, whereby the nurses gradually transfer their actual caregiving time and monitor the coping and competence of the informal caregiver. However, the nurses were not always working in partnership given the sparse meetings with the informal caregiver.

Communication in the care triad

The communication between professionals and informal caregivers was only described in terms of difficulties and no best-practices were mentioned in the included articles. Upon first contact, the collaboration was often described as difficult; professionals reported uncertainties about responsibility in collaborating and communicating with the informal caregiver. Toscan et al. (2012), Boros (2010), Buscher et al. (2011) and Goodwin & Happell (2006) described a lack of communication in general between professionals and informal caregivers, which was insufficient and irregular (Boros 2010). Buscher et al. (2011) described the communication as unstructured and informal. In Goodwin and Happell (2006), a professional described being caught between the sandwich of the client and the caregiver. Aujoulat et al. (2002) added that it was sometimes unclear what could be shared with the caregiver and what was 'creating a huge barrier for effective communication' (Goodwin & Happell 2006: 138).

Hierarchy in care triad

In the care triad, there were different forms of hierarchy between the professional, informal caregiver, and the client. Agee and Blanton (2000: 331) argue professionals will be more or less

inclined to collaborate with the informal caregiver given their perspective. Some professionals described themselves as being secondary in home care and the informal caregiver as primary (Ward-Griffin 2001). Others placed the informal caregiver at the bottom of the hierarchy, then the nurse, then the therapist, and the case manager at the top (McWilliam et al. 2001).

Sometimes there was a conflict in the professionals' reflection on the position of the caregiver with respect to the client, as mentioned by, for example, Goodwin and Happell (2006). On the one hand, the opinion of professionals was that informal caregivers have as much right to be included in the care process as the client. On the other hand, they argued that the involvement and collaboration with the informal caregiver was 'not always feasible and in the best interest' of the client (Goodwin & Happell 2006: 139).

The focus was often more on the client than on the informal caregiver (Carpentier et al. 2008). Although listening to both client and informal caregiver is often seen as essential, this was not always done in practice (Aujoulat et al. 2002, Pickard & Glendinning 2002). Carpentier et al. (2008) reported that the worries and concerns about the informal caregiver were not always reported by professionals because they did not immediately affect the relationship with the client (p. 725).

Caregivers are essential

The professional perspective on the informal caregiver was also dichotomous. Boros (2010) mentioned informal caregivers made the job easier for the professional. Jansen et al. (2009) went further by arguing that professional care is impossible to maintain without informal caregivers. In this light, professionals sometimes identified specific tasks for the informal caregiver. They were mostly seen as being able to do 'dirty hands-on work that is easily learned' (Ward-Griffin 2001: 70), keeping clients socially connected, helping with activities of daily living (ADLs'), and providing peace of mind for the client (Peckham et al. 2014). Additionally, some professionals' mention that informal caregivers were said to play a vital role in keeping older persons in the community (Peckham et al. 2014). Walker & Dewar (2001) argued that the quality of care given to the client increased when the informal caregiver was involved.

There were also concerns expressed. Mosack and Wendorf (2011) described that informal caregivers can be helpful and unhelpful in the care provided by professionals to clients. For example, the emotions expressed by the informal caregiver can influence the freedom of choice for the client (Buscher et al. 2011). Informal caregivers may also have unrealistic expectations of the service system, which leads to unhelpful behaviour (Goodwin & Happell 2006).

That caregivers were seen as essential can also create difficulties: professionals took caregivers for granted (Walker & Dewar 2001), or they confirmed that informal caregivers took on too

much responsibility (Fjellttjun et al. 2008). Although most professionals understood the informal caregiver as playing a large role, they realised this can be difficult for the informal caregivers. Professionals noted that informal caregivers need extra support services (Dal Bello-Haas et al. 2014), with a special emphasis on respite services. Jansen et al. (2009) suggested professionals should provide information about terminology unknown to the informal caregiver. When services are provided, a caregiver should be able to choose the professional for the service, although this is not always available (Ward-Griffin 2001).

Mismatch between services and needs

Professionals reported a mismatch often exists between services for informal caregivers and their needs (Jansen et al. 2009, McPherson et al. 2014). Several studies show that a mismatch might be the result of competency. For example, providing emotional or psychological support for the caregiver was seen as essential, but for professionals this was more difficult to do (Ward-Griffin 2001, Aujoulat et al. 2002, Carpentier et al. 2008). It was sometimes easier to instrumentalise the caregiver's needs, rather than providing emotional support (Levesque et al. 2010). By doing so, the caregiver turned into a quasi-professional, 'whose main role is to compensate for their frail relative's losses and to provide nursing care, obliterating the difference between intimate and professional relationships' (Guberman et al. 2006: 47). At times this created a feeling of insecurity among professionals. Fjellttjun et al. (2008) gave an example: 'regional nurses often feel helpless when they do not have the resources to relieve the situation' (p. 62).

Moreover, there were difficulties in coordinating support services (Dal Bello-Haas et al. 2014) or in unclear expectations within the collaboration. Professionals were not always proactive in offering informal caregivers rest or respite care (Ward-Griffin & McKeever 2000, Pickard & Glendinning 2002) while informal caregivers may be used to having services suggested instead of asking for them (Levesque et al. 2010). A mismatch may also be found in the difference of opinion about the provided care between professionals and informal care (Aujoulat et al. 2002, Boros 2010). Informal caregivers are often negative, while professionals are often positive about the interactions (Boros 2010). Both parties could have a different opinion and perspective on what a relationship should entail (Carpentier et al. 2008, Buscher et al. 2011).

Professionals feel restricted in collaborating with the caregiver

From the macro level, professionals described that collaborating with informal caregivers was done within a system of parameters and criteria. This often limited the possibilities for collaboration (Jansen et al. 2009). A major restriction was the societal and legislative system in which professionals work. Organisational structures and stakeholders influence the collaboration (Walker & Dewar 2001, Carpentier et al. 2008, Buscher et al. 2011). The professional has a legal obligation towards the client but not to the caregiver (Goodwin & Happell 2006).

The partnership approach is often mentioned as a way to support informal caregivers but, as already mentioned, this is a difficult thing to do. Reasons for this are found in the partnership approach because it often takes more time than is available (Leveque et al. 2010). This is based on the situation in which cost cutting solutions are implemented by the government, making the interface between professionals and informal care a constant topic of negotiation (Ward-Griffin 2001). This has a direct influence on the roles professionals want and can take.

Restriction was often further worsened by lack of agreement between professionals (Dal Bello-Haas et al. 2014) regarding how to collaborate with informal caregivers. A professional might be 'fearful of being reprimanded (by colleagues) and therefore restrict themselves to only give basic advice (Carpentier et al. 2008: 729). This may be linked to feelings of not being competent in providing support to an informal caregiver. Dal Bello-Haas et al. (2014) described that one-fourth of their sample was uncomfortable or not confident in providing support. Jansen et al. (2009) reported that more than half of their sample did not feel completely confident (p. 9). Buscher *et al.* (2011) brings to light that trust building is often seen as important when supporting caregivers, but trust building is not included in the educational preparation of nurses. Respondents in the study by Dal Bello-Haas et al. (2014) expressed a desire for more information and training on family support strategies.

Diversity in the care triad

Some professionals saw diversity as an aspect that influences collaboration and which has to be taken into account. Carpentier et al. (2008) argued that diversity can be stimulating or stressful. When the diversity in a relationship is experienced as stressful, it complicates the collaboration with the informal caregiver and becomes problematic. Pickard and Glendinning (2002) observed that cultural differences have an impact on the balance of roles within the collaboration.

Other dimensions of diversity mentioned included urban versus rural areas, gender, economic stages, and age. In an urban community, one can sometimes only rely on kin-caregivers and not on neighbours (Jansen et al. 2009). Gender matters because professionals expressed that male caregivers required more support from a professional (Pickard & Glendinning 2002). Pickard and Glendinning (2002) described the impact of economic status on the support caregivers may receive. Professionals expressed that families who have a higher economic status could not get the same support as a lower income family. Ward-Griffin (2001) argued that younger women should be encouraged to lead their lives while older women should be encouraged to be an informal caregiver.

Discussion

Based on a thematic synthesis of 22 studies, seven themes emerge in which different experiences and reflections of professionals reveal the complex, multifaceted, and dynamic interface of professional and informal care. The 22 studies were originally conducted in the United States, Canada, South Africa, Israel, Australia, New Zealand, and different countries in Europe. Table 2 shows the seven themes organised per country, with countries in Europe grouped together. It is likely that policy environments influence the professional perspective on the collaboration with informal caregivers. However, it is not possible to make the link between policy environments of the different countries and the identified themes based on the rather small number of included studies and that, as shown in Table 2, the themes are rather evenly divided among the countries.

Twigg (1989) describes three frames of reference regarding the relationship with informal caregivers. The policy structures in the Netherlands, as described in the introduction, ideally see informal caregivers as co-workers. In this frame of reference there is an aim at cooperation and an enabling role for professionals. As comes forward in the first theme, professionals themselves argued for a partnership approach or family-centred approach when working with a care triad. This partnership goes even further and includes shared decision-making about the care provided for the care recipient. However, such a thorough partnership has not yet been achieved in practice due to the complex context in which supporting informal caregivers takes place. Although the main legal obligation of the professional is towards the care recipient, the professionals acknowledged that the informal caregivers should be supported and involved in the care triad. This was, in some countries difficult due to many restrictions on the individual and policy levels.

Professionals expressed that they were not confident or qualified to support informal caregivers and work in a satisfactory partnership with them. The level of including the informal caregiver was restricted mostly to informing and involving the informal caregiver in what the professional was doing from their professional viewpoint. The final stage at the other end of the continuum of complete participation and working in a partnership with shared decision-making had not yet been reached.

Strengths and Limitations

All 22 studies focused on the professionals' experience regarding working with informal caregivers. Studies were gathered from six different electronic databases and represented 10 different countries and at least eight different professions. All studies were published after 2000. This increases the transferability and trustworthiness of the findings (Sandelowski & Barosso 2003). The search strategy, using six databases and a combination of MeSH and free-text terms, produced a heterogeneous set of studies. There are several potential limitations to

this review. Articles were included only if they were published in English or Dutch. Therefore, some assessments may have been excluded. The first selection was made on abstracts; thus, it is theoretically possible that studies about the professional perspective could have been missed. However, we checked the reference lists from the included articles, so this is unlikely.

A well-established method for reviewing, data extraction, summary and thematic synthesis was used in this study. All phases of this study were peer reviewed. Creating a thematic synthesis goes beyond the preliminary results and results in a higher level of evidence regarding the interface between informal caregivers and professionals (Sandelowski & Barosso 2003).

The findings might be less applicable to social work professionals and professionals at the management level as they are underrepresented in the included studies. This may also be the case for professionals working with caregivers with a different cultural background; the included studies mostly did not take this aspect into account. Because the included articles all originate from Western countries, there might be a bias towards perspectives on care, in that this will mainly be a Western perspective on care. Also, all caregivers were providing care for children; all care recipients in the included studies were adults. This might have affected the experienced outcome of working together with informal caregivers.

Caution should be taken when considering the transferability of our findings as the care system in each country will influence the triad. However, the act of synthesis could be viewed as similar to the role of a research used when reading a piece of qualitative research and deciding how useful it is to their own situation. In the case of thematic synthesis, professionals' experiences captured in themes translate from one situation to another.

Implications for practice, research, and education

Implications for practice become evident in all themes. A partnership approach should be pursued rather than simply working alongside an informal caregiver. Furthermore, there should be a dialogue in the interface between professionals and informal caregivers to eliminate the discrepancies in experiences between professionals and informal caregivers. Support for informal caregivers should be included more in the curricula of allied health, nursing, and social work education. This aligns with the emphasis policies are placing on informal care structures (Kaljouw & van Vliet 2015). While there is no correspondence between policy and practice, this can be addressed through education.

On the policy level, emphasis was placed on informal care structures, which requires the support of professionals to prevent caregiver burden and create a satisfactory working environment (Kemp et al. 2013). Currently, informal caregivers play a large role that can have both positive and negative impacts on the caregiver (Verbeek-Oudijk et al. 2014). It can

provide a sense of meaning and satisfaction (Tonkens et al. 2008) and can also lead to stress and caregiver burden. Providing informal care can influence aspects of emotional, relational and material wellbeing, showing that the caregiver role is adversely associated with health (Berglund et al. 2015). However, the influence on the wellbeing of the caregiver is associated with other factors, for example the timing and intensity of the provided care (Vlachantoni 2016). Vlachantoni (2013) also show that 'the impact of informal care provision on the health status of informal carers should be considered alongside other aspects of, and transitions between, an individual's social and economic roles, and alongside the carer's demographic and health characteristics before, during and after the caring activity' (p. 117).

This is put into perspective by the observation that there is often no time provided by organisations to support informal caregivers. Support for informal caregivers is in most cases only provided when there is time left over after caring for the care recipient. As a consequence, it is done informally and without structure.

Further research is necessary to deepen our understanding of collaboration within the care triad. Creating specific guidelines for professionals so they can navigate through the complex context of the care triad, with an emphasis on the partnership approach and family-centred care are needed. In particular, the diversity of informal caregivers and professionals should be taken into account, as little knowledge about the diversity component emerged in the current research included in this systematic review. Further research should be focussed on the entire care triad, therefore research should also include the care recipient. From the 22 studies included in the review, only one included care recipients in their sample. Due to the discrepancies in experiences between professionals and informal caregivers, participatory action research would be suitable; then the care triad can work together towards a satisfactory solution.

Conclusion

Working in collaboration with informal caregivers requires a different way of functioning for professionals. Professionals should not only be focussed on enabling participation of the client but also on supporting the informal caregiver by working in collaboration with him or her. The urgency to meet the support needs of informal caregivers is high. It is necessary to cultivate an awareness of how professionals can support these needs in collaboration with the caregivers and the care recipient.

From the professional's perspective, the collaboration was influenced by different factors on different levels. The context of collaboration was adversely affected by decisions of a political and organisational nature. The perspectives of the professional and informal caregiver on

collaboration differ and professionals who are not confident limit themselves to only giving basic advice. This makes the collaboration a complex endeavour in need of specific guidelines and training for the professionals. Therefore, supporting informal caregivers should be included in the curricula of allied health, nursing, and social work education with an emphasis on diversity. This is necessary in light of the current policy changes in the Netherlands where an increased emphasis is placed on informal care structures.

Appendix 1

((formal care*[tiab] AND informal care*[tiab]) OR (formal[tiab] AND informal care*[tiab]) OR (health service provider*[tiab] AND informal[tiab] AND care*[tiab]) OR (health provider*[tiab] AND informal[tiab] AND care*[tiab]) OR (health practitioner*[tiab] AND informal care*[tiab]) OR (health care practitioner*[tiab] AND informal care*[tiab]) OR (healthcare practitioner*[tiab] AND informal care*[tiab]) OR (home care service*[tiab] AND informal[tiab] AND care[tiab]) OR (practitioner*[ti] AND (family care*[ti] OR informal care*[ti])) OR formal care*[ti] OR formal support*[ti] OR formal service[ti] OR informal care*[ti] OR informal support*[ti] OR informal family care*[ti] OR ("Caregivers"[Majr] AND (informal[ti])) AND (formal OR professional* OR practitioner* OR nurse* OR occupational thera* OR physical thera* OR speech thera* OR dietitian* OR social work* OR allied health professio* OR physician assistant*) AND ("Social Support"[Mesh] OR "Communication"[Mesh] OR "Cooperative Behavior"[Mesh] OR "Delivery of Health Care"[Mesh:NoExp] OR cooperat*[tiab] OR assist*[tiab] OR communicat*[tiab] OR collaborat*[tiab] OR empower*[tiab] OR facilitat*[tiab] OR support*[tiab] OR provid*[tiab] OR affect*[tiab] OR perception*[tiab] OR coach*[tiab] OR enable[tiab] OR advocate[tiab] OR consult*[tiab] OR coordinat*[tiab] OR educat*[tiab] OR engage[tiab] OR relation*[tiab] OR reflect*[tiab]) AND ("Socioeconomic Factors"[MeSH Terms] OR "Sociological Factors"[Mesh] OR "Personality"[Mesh] OR "Demography"[Mesh] OR "Age Factors"[MeSH Terms] OR "Sex Factors"[MeSH Terms] OR "Social Class"[Mesh] OR "Culture"[Mesh] OR "Race Relations"[Mesh] OR "Interpersonal Relations"[Mesh] OR "Religion"[Mesh] OR demograph*[tiab] OR age[tw] OR gender[tw] OR ethnic*[tw] OR race*[tw] OR religion*[tw] OR social class*[tw] OR intersectionalit*[tw] OR identity marker*[tw] OR characteristic*[tw] OR factor*[tw] OR need*[tw] OR psychosocial[tw] OR difficult*[tiab] OR differ*[tiab]) AND ("Attitude"[Mesh:NoExp] OR "Attitude of Health Personnel"[Mesh] OR "Perception"[Mesh] OR feel*[tiab] OR experience*[tiab] OR perception*[tiab] OR perspective*[tiab] OR attitude*[tiab] OR view*[tiab] OR relation*[tiab] OR connect*[tiab] OR role*[tiab] OR focus*[tiab]))))

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Intermezzo

How am I a part of it? The struggles of participatory research

After a long day of teaching, I walked to the subway. My thoughts were already turning to my next appointment. I had planned a preparatory meeting, an informal gathering with a group of women who cared for family members with acquired brain injury. The meeting had been organized by a community social worker who had connected me to the organization to offer a potential starting point for carers' input into my PhD research.

On the way, I scrolled through my notes. I wanted to arrive prepared, focused and grounded. But as I left the station and tried to navigate towards the location, I felt uncertain. Was I going the right way? I hesitated for a moment in front of the building before pushing open the door. Inside, a room was filled with laughter and chatter. About twenty women stood or sat in small groups, some stirring pots in the kitchen, others handed out food. The air was filled with the smell of cardamom, fried onions and something sweet I couldn't place. For a moment, no one looked at me. I asked a woman nearby if I was in the right place. She smiled and replied that she didn't speak Dutch. Before I could feel entirely out of place, a vibrant woman walked up. "There you are!" she said loudly, clapping her hands to draw attention. The room fell silent. She introduced me to the group. Apparently, I was in the right place, but my carefully prepared notes now felt useless.

As the conversations began, curiosity emerged between us in unexpected ways. The women leaned forward with questions, not about acquired brain injury, but about me: Questions that felt intimate, even confrontational. "How much money do you make?" "Are you married? No? Why not?" "Do you have children?" "No?" "You have grey hair, it is time" I laughed but then hesitated. What am I sharing? Their questions were not harsh. They were woven with humour and genuine interest. There was no small talk, only the deep stuff, immediately. I felt the tension between wanting to be honest and the fear that honesty might set me apart. Would they feel alienated? Would they judge me, or worse, feel judged? The woman sitting next to me sensed my discomfort; she put her hand on my arm and smiled teasingly at me, which was comforting without words. As the evening unfolded, the directness of their questions was disarming, even refreshing. Curiosity softened the edges of discomfort. Despite the language barrier, we found ways to connect.

There was something deeply human about the way the conversations bounced back and forth, unstructured, sometimes off-topic, but honest. I left the meeting with more questions than answers. But I also left with a new sense of direction. I thought about trust not as something I could design or script, but as something that grows in warmth, in shared food, in stories exchanged.

In another conversation, weeks later, while visiting a Ghanaian church, I was speaking with a group of carers when someone said, mid-sentence: "We feel disadvantaged in Dutch healthcare because of our heritage." Suddenly, I was no longer in church. I was back in Ghana, walking through predominantly black communities as a white researcher. I remembered the sense of being different but never disadvantaged. My European privilege cushioned every encounter. I remembered the silent unease I felt when I visited Fort Elmina and tried to make sense, within its stone walls, of a history of colonial violence and the Atlantic slave trade. How do I respond to these comments now, not just as a researcher, but as a human being? Is it my place to answer or only to listen?

I began to see that the conversations that seemed off-topic, about history, identity, exclusion, were not detours at all. They were context. They shaped how carers entered care networks, how they were seen, heard or ignored within the healthcare system. Feelings of being an outsider or being treated differently, however subtle, colour the whole care experience.

Chapter 3

Intersectionality in informal care research: a scoping review

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Abstract

Informal caregivers share common experiences in providing care to someone with health and/or social needs but at the same time their experiences differ across diverse backgrounds such as gender, age, culture, as these aspects of diversity co-shape these experiences. This scoping review aims to explore how aspects of diversity, across their intersections, are currently incorporated in informal care research and discuss how an intersectional perspective can further develop our understanding of informal care. A scoping review was performed to map relevant caregiving literature from an intersectionality perspective. Key terms “informal care” and “intersectionality” were used for a search in four databases resulting in the inclusion of 28 articles. All 28 studies were analysed based on a for this scoping review created intersectionality informed coding scheme. Aspects of diversity are largely understudied in informal care research, in particular across their intersections and from a critical perspective. This intersectional informed analysis revealed that when studying diverse caregiving experiences the use of intersections of dimensions of diversity provides a nuanced understanding of these experiences. Aspects of diversity in caregiving experiences are largely understudied in particular across their intersections and from a critical perspective. Adopting an intersectional perspective ensures that not only different categories or social identities of caregivers are included in future studies, but the mutual relationships between these categories embedded in their specific context are actually studied.

Background

Informal care responsibilities have increased in the past decades (Verbeek-Oudijk, 2014) based on policy and societal developments, such as ageing societies, deinstitutionalization and changes in family and working life of citizens (Boer & Klerk, 2013; Daatland & Herlofson, 2003; Haberkern & Szydlik, 2010). Informal caregivers share common experiences in providing care to someone with health and/or social needs and simultaneously their experiences are unique. The experiences of caregivers are lived and therefore subject to diversity. Diversity generally refers to a plurality of categories and focuses on structural group memberships that people belong to (Kinébanian & Stomph, Marjan, 2014). Within the field of informal care research, studies show that multiple dimensions of diversity such as age, gender, religion, marital or household status, education level, socio-economic status and ethnicity influence caregiving (Giesbrecht et al., 2012; Hengelaar et al., 2018; Lindhardt et al., 2008; Skarupski et al., 2009; Wittenberg et al., 2018). Diversity aspects play a role in underlying expectations, values and norms, assumptions and behaviors regarding the provided care within collaborative care networks, (Hengelaar et al., 2018; Wittenberg et al., 2018). For example, adequately understanding differences in caregivers' experiences and assumptions may prevent possible negative consequences of contradicting expectations between informal and formal care providers, improving good collaboration between them (Wittenberg et al., 2018). This stresses the importance of paying attention to differences in roles, expectations and needs of all actors in care networks. As good collaboration in care networks increases the chance of good-quality care, the perceived well-being of care recipients and caregivers and reduces caregiver burden (Williams et al., 2016).

Categories of diversity such as culture and gender are socially constructed and power laden (Zanoni & Janssens, 2015). The role of for example gender is widely described in caregiving research. Gender hierarchies exist which entails that more status and power is assigned to what is considered masculine or male. Hence, gender must be understood not as a characteristic of the individual, but rather as a relation between groups. Furthermore, gender takes place at multiple levels, such as at the intra-psychological level conceived of for instance internalized norms and behaviors. Gender can also take place at the institutional level, where it structures how caregiving is organized and who takes care of whom, how, when, and whether caregiving is paid for or not (Connell, 2012). This example of gender shows that the provision of informal care takes place in a broader context, and can be understood as a type of relationship between individuals which is embedded within socially and politically defined sets of expectations and practices regarding rights and responsibilities (Dolan & Thien, 2008; Giesbrecht et al., 2012). Other studies show for example the role of culture, or age, or geography in relation to informal caregiving (Giesbrecht et al., 2012; Hengelaar et al., 2018). This shows that a wide range of diverse experiences can be found among caregivers, associated with group memberships. However, people do not live single-issue lives. Caregivers are a heterogeneous group which

consists of individuals who are members of multiple social groups. They are women or men of certain ages and with particular cultural backgrounds and education levels, creating unique social positions that inform caregiving experiences (Giesbrecht et al., 2012).

Intersectionality, originally coined by Crenshaw in 1989, refers to the interactions between dimensions of diversity in individual lives, social practices, institutional arrangements, and cultural ideologies and the outcomes of these interactions in terms of power and social inequities (Davis, 2008). Intersectionality is a major theoretical and research paradigm across a multitude of disciplines including health and healthcare research (Rouhani, 2014). Although the additional value of intersectionality seems evident in both qualitative and quantitative research to better understand caregiving (Chappell et al., 2015; Giesbrecht et al., 2012; Holmgren et al., 2014; Lin et al., 2012; Williams et al., 2016), it is understudied in caregiving research (Giesbrecht et al., 2012; Holmgren et al., 2014). This scoping review aims to look beyond single categories of diversity and analyze how dimensions of diversity interact with each other to shape caregivers' experiences. Such an approach provides more opportunity to analyze the complexity of caregiving and contributes to the provision of more tailor-made support for informal caregivers rather than generalized solutions (Hankivsky, 2012; Verdonk et al., 2015). By looking at how caregiving issues are shaped by the interaction of different dimension of diversity as well as by situational and contextual dimensions (Giesbrecht et al., 2012; Hunting, 2014; Williams et al., 2016), "practices that privilege any specific axis of inequality" (Hankivsky, 2012, p.1712) within informal care can be challenged.

This scoping review explores how dimensions of diversity across their intersections are currently represented in informal care research.

Methods

A scoping review was conducted based on the framework developed by Arksey and O'Malley (Arksey & O'Malley, 2005) to map relevant caregiving literature using intersectionality (Arksey & O'Malley, 2005). The framework's stages were followed: 1) identifying the research question, 2) identifying relevant studies, 3) study selection, 4) charting the data, 5) collating, summarising and reporting the results and 6) consultation of stakeholders, such as key informants, care recipients, caregivers and practitioners (Arksey & O'Malley, 2005). The sixth stage is additional and not within the scope of this review. Stakeholder consultations will be performed in a later stage as this review is part of a larger research project of the first two authors.

In Arksey and O'Malley's stage 2, key concepts of the search strategy were identified. First, "informal care" and "intersectionality" were identified as key concepts, synonyms were used for informal care, such as informal support, family care and caregiving. As it turned out, no studies

within our scope explicitly mentioned the key concept intersectionality. Therefore, search terms were expanded by formulating a broad range of concepts that are often used as synonyms for this concept, including "diversity" and "socioeconomic factors", and by incorporating single dimensions of diversity (such as age, gender, and ethnicity). The final search strategy was used in four databases: PubMed, PsycINFO, Cochrane Library and CINAHL.

In stage 3, the databases were searched using the concepts and keywords identified in stage 2 and applying two inclusion criteria: 1) articles published in peer reviewed journals between January 2008 and March 2018 and 2) articles published in English or Dutch. Because of the small number of articles found and doubts about the relevance of some articles, it was decided post-hoc to use a third inclusion criterium namely, 3) studies using a minimum of four dimensions of diversity. There was no pre-set demarcation of which dimension of diversity should be studied in the included studies. Table 2 shows the dimensions of diversity which were included in the studies. Studies in which informal care was provided in all kinds of contexts (community, residential, etcetera) and to all types of care recipients were included. Empirical studies were not excluded based on research methodology.

All articles were selected based on title and abstract and subsequently based on their full text. This selections were performed independently by the first two authors and a junior researcher. This resulted in a collection of 53 articles. After applying the additional third inclusion criterium, 28 articles were selected to include in this scoping review. The Prisma Flow Chart is presented in Figure 1.

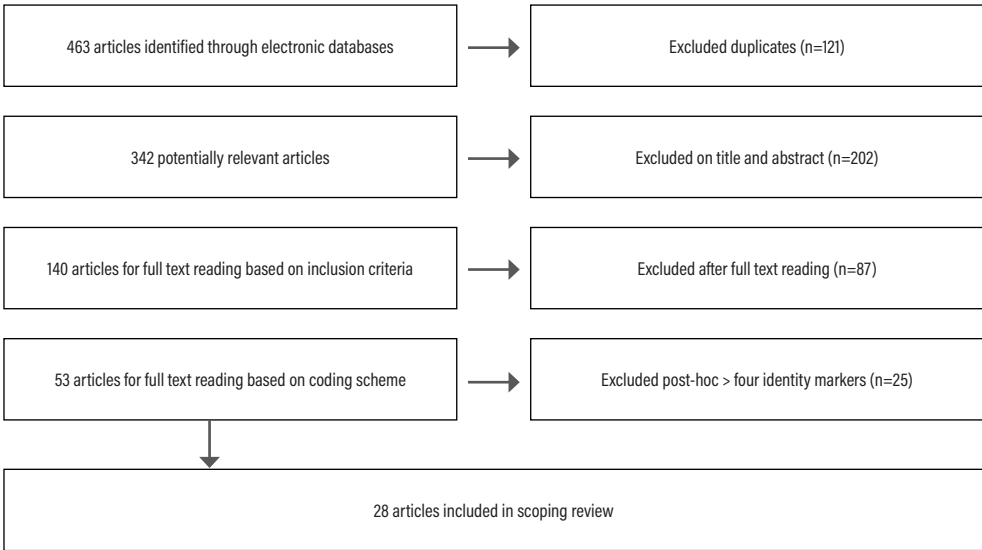


Figure 1. Prisma flow chart

For the next stage, charting the data, a coding scheme was created by the first two authors. The coding scheme is based on two primers on intersectionality informed research (Hunting, 2014; Rouhani, 2014) and “*The complexity of intersectionality*” in which McCall (2005) describes three empirical analytic approaches to intersectional research (McCall, 2005). Combining the key principles of conducting research from an intersectional perspective and the aim of our scoping review, the following was included in the coding scheme: 1) the consideration of intersectionality in the context in introductions, aims, samples and in the methods of data collection (including analytical approach); 2) used dimensions of diversity; and 3) the intersection of dimensions of diversity, thus investigating the intersectional identity matrix and the relatedness of diversity to the main conclusions of the included studies. The topics we inserted in our coding scheme are clarified in Table 1.

Table 1. Intersectionality informed coding scheme

#	Code	Description
1.	Context in introduction	Does the introduction consider the historical, cultural and societal/political context in line with the aim of the research? Does it consider the different power relations within and between axis of diversity?
2.	Aim	Does the research question/aim consider an intersectional perspective? If not; what is the direction of the research question/aim?
3.	Sample	Sample size? Does the sample represent caregivers, care recipients, other actors in the social network and/or (healthcare) professionals? Does the sampling method reflect the complexity of social life? Have different dimensions of diversity been considered prior to the data-collection?
4.	Method of data collection	How were the respondents approached? Is there mentioning of reflexivity of the researcher during the data collection? Method of data collection? Was an intersectional perspective considered while formulating the method of data- collection?
5.	Identity markers	Which identity markers of caregivers are measured/considered? Is there also mention of contextual dimensions, care characteristics and identity markers of the care recipients? Are there arguments for the chosen intersections investigated?
6.	Analytical approach	<u>Quantitative</u> : Additive approach, multiplicative approach and interaction terms. <u>Qualitative</u> : Thematic synthesis, narrative, grounded theory, IPA, etc. Which analytical approach was used? e.g. based on McCall (2005) anticategorical, intercategorical, intracategorical?
7.	Intersectional identity matrix	Do the identity axes intersect with each other in the analyses? How do these axes influence each other and the topic of research? Is attention given to the influence of power-relations?
8.	Main conclusions	How is diversity related to the main conclusion of this study?

Based on (Hunting, 2014; McCall, 2005; Rouhani, 2014).

Following the Arksey and O'Malley framework, charted data were synthesized in order to present a narrative account of existing literature (Arksey & O'Malley, 2005; Braun & Clarke, 2006). Axial coding was applied based on the created coding scheme. Subsequently descriptive and overarching themes were developed, by using thematic synthesis, based on Thomas and Harden (Thomas & Harden, 2008). Performing a thematic synthesis while applying an intersectionality lens meant that the authors went beyond the themes of the primary studies (Thomas & Harden, 2008). Analysis was performed by the first and second author and a junior researcher (researcher triangulation). Disagreements about analysis were subject to discussion in the team of authors to reach consensus.

Results

None of the 28 included articles mentioned intersectionality explicitly as a theoretical or analytical perspective. All studies included four or more dimensions of diversity when researching informal care, and 13 of the included studies researched intersections of dimensions of diversity. All study characteristics of the included studies are summarized in Table 2.

Table 2. Study characteristics of included studies

Study	Country	Aim	Sample	Analytical approach	Method of data collection	Dimensions of diversity caregiver
Vroman & Morency (2011)	Belize	To develop a profile of the informal care of elders living with families. To identify and describe the characteristics of the informal caregivers, to achieve an understanding of their perceptions of caregiving and to recognize the socio-cultural factors that shaped their caregiving.	N=29 informal caregivers of older adults in Belize	Thematic analysis	Semi-structured interviews	Age, gender, employment status, ethnicity, relationship, marital status, household situation, financial status
Ratcliffe, Lester, Couzner, & Crotty (2012)	Australia	Aims to utilize the ICECAP-O instrument to access the quality of life of a representative sample of the older South Australian population differentiated according to carer status, also determine the influence of several socio-demographic characteristics on the quality of life.	N=786, caregivers n=115, non-caregivers n=671	Kruskal-Wallis test, Multivariate linear regression	Health Omnibus Survey, face-to-face survey	Age, gender, ethnicity, educational level, marital status, financial status, employment status, place of residence
Gupta, Isherwood, Jones, & van Impe (2015)	France, Germany, Spain, Italy, UK	This study examined health-related quality of life and comorbidities experienced by informal schizophrenia caregivers compared with non-caregivers and caregivers of adults with other conditions.	Total n=159.387, non-caregivers n=158.989, schizophrenia caregivers n=398	Chi-square, ANOVA, single logistic regression	National Health and Wellness Survey, annual, cross-sectional, self-administered questionnaire (2010, 2011 and 2013)	Age, gender, self-rated health, educational level, marital status, financial status, employment status, place of residence
Tokunaga & Hashimoto (2017)	Japan	The aim of this study was to examine the association between women's SES and the likelihood of being a primary caregiver in Japan.	N=2399, female caregiver	Chi-square and t-test, multivariate logistic regression + interaction terms	Comprehensive Survey of Living Conditions of the People on Health and Welfare (2010 and 2013)	Age, gender, marital status, self-rated health, employment status, educational level, financial status, household situation
Vaingankar et al. (2016)	Singapore	This study aimed to describe the care participation, care needs, and care burden among informal caregivers and examine factors related to the care burden experienced by their informal caregivers.	Total n=2421, n=693 informal caregivers	Mann-Whitney U test, X2-test, Multivariate logistic regression	Well-being of the Singapore Elderly survey (2013)	Age, gender, ethnicity, marital status, educational level, employment status, care arrangement, support of others, relationship, place of residence

Table 2. continued

Study	Country	Aim	Sample	Analytical approach	Method of data collection	Dimensions of diversity caregiver
Toribio-Diaz, Medrano-Martinez, Molto-Jorda & Beltran-Blasco (2012)	Spain	This article aims to describe the caregiver network providing service to dementia patients in the province of Alicante, Spain. It analyses characteristics of the patients receiving care in the network, as well as the profiles and roles corresponding to the different types of caregivers involved in patient care and management.	Total n=303, n=129 primary caregivers, n=114 secondary caregivers, n=15 formal caregivers, n=45 absent caregivers	Chi-square test, t-test	Multi-centre prospective study in 4 general neurology departments	Age, gender, educational level, marital status, relationship, household situation, employment status, care motives, self-rated health
Eby et al. (2017)	United States of America	The goal of this research is to gain a better understanding of the characteristics of informal caregivers who provide transportation assistance and to explore the types and frequency of this assistance.	Informal caregivers n=268	T-test, Rao Scott modified chi square test	Telephone survey	Age, gender, marital status, household situation, ethnicity, financial status, educational level, employment status, self-rated health
Wang et al. (2016)	China	The aim of this exploratory study was to examine the prevalence and the related factors of depression among the female informal caregivers of disabled elders; to analyze the correlation of the depressive emotion between the informal caregivers' care burden and disabled elders' quality of life; and to investigate the influence of informal caregivers' depressive emotion on informal caregivers' care burden and the quality of life among disabled elders.	Female Uyghur and Kazakh informal caregivers n=444	Multivariate logistic regression, Spearman's RHO	Cross-sectional study: Self-Rating Depression Scale questionnaire, Social Support Rating Scale, Zarit burden interview, Katz ADL, SF-36 questionnaire, demographic characteristics self-report	Age, gender, ethnicity, marital status, educational level, relationship, employment status, financial status, household situation, place of residence, self-rated health
Sequeira (2013)	Portugal	The aim of this study is to determine the impact associated with caring for a dependent older person in terms of difficulties, coping strategies, sources of satisfaction and levels of burden and to compare the impact associated with caring for an older person with dementia versus a dependent older person without cognitive impairment.	Informal caregivers n=184 (n=83 mental dependence, n=101 physical dependence)	Comparative analysis, linear regression, t-test	Questionnaire, Barthel Index, Lawton Index, Mini Mental State Examination, Clinical Dementia Rating, Caregiver Assessment of Difficulties Index, Caregiver Assessment of Managing Index, Caregiver Assessment of Satisfaction Index, Scale of Caregiver Burden	Age, gender, marital status, educational level, employment level, household situation

Table 2. continued

Study	Country	Aim	Sample	Analytical approach	Method of data collection	Dimensions of diversity caregiver
Hastrup, van den Berg & Gyrd-Hansen (2011)	The Netherlands	The aim of this study was to compare the subjective burden in a broad group of caregivers to care recipients with mental illnesses or a combination of mental and somatic illnesses, with caregivers to care recipients with somatic illnesses in order to test for a possible extra subjective caregiver burden in mental illnesses. The second aim was to test for an association between the subjective caregiver burden and caregivers' characteristics and objective burden.	Informal caregivers n=865	Chi-square test, t-test, interaction variables, multi-collinearity	Postal questionnaire: Caregiver Strain Index, EQ-5D Index	Age, gender, educational level, employment status, financial status, relationship
Williams et al. (2008)	United States of America	The objectives of this study were to examine the relationship between caregiver characteristics, facility-related perceptions, and emotional and physical health of 434 informal of recently deceased residents of residential care/assisted living facilities and nursing homes. The potential mediating effects of social support (informal, staff, and spiritual) were also examined.	Informal caregivers n=434	Linear mixed models	Telephone interviews	Age, gender, ethnicity, marital status, educational level, employment status, relationship
Tuijthof, ten Have, van Dorsselaar, & de Graaf (2015)	The Netherlands	The aim of this study was to examine whether informal caregiving is associated with presence of any emotional disorder in the past year; and which characteristics (i.e. sociodemographic, caregiving-related and other characteristics) are risk indicators for any emotional disorder among informal caregivers.	General n=5.303, non-caregiver n=3.544, caregiver n=1.759	Logistic regression models, bivariate logistic regression	Netherlands Mental Health Survey and Incidence Study-2, face-to-face interviews	Age, gender, educational level, employment status, relationship, household situation
Schmidt et al. (2016)	Austria, Germany, Sweden, the Netherlands, Spain, Italy, France, Denmark, Switzerland, and Belgium	Focusing on care provision to grandchildren and (older) relatives ('informal care') as forms of engagement, this paper aims to identify which individual characteristics may compensate for health deficits and enable individuals with multimorbidity to provide informal care.	Extra-residential care n=13.020, Grandparent n=18.946	Multivariate logistic regression models	Survey of Health, Ageing and Retirement in Europe (2004-2005, 2006-2007, 2011-2012)	Age, gender, ethnicity, culture, educational level, employment status, household situation
Joyce, Berman, & Lau (2014)	United States of America.	The aim of this study was to explore factors related to caregivers' support with managing medications for end-of-life home hospice patients.	Informal caregivers n=120	Univariate analysis, bivariate generalized logistic regression	Computer-assisted telephone interviews	Age, gender, ethnicity, relationship, educational level, employment status, financial status, household situation

Table 2. continued

Study	Country	Aim	Sample	Analytical approach	Method of data collection	Dimensions of diversity caregiver
Rio-Lozano et al. (2013)	Spain	The aim of this study was to identify how gender roles and identity influence the assumption of the caregiving role in men and women and to analyze gender differences in dealing with caregiving and in health outcomes.	Informal caregivers n=32	Sociological discourse analysis, comparative analysis	Semi-structured interviews, selected people with different individual characteristics	Age, gender, educational level, employment status, place of residence, relationship
Kenny, Hall, & Davis (2011)	Australia	This article aims to advance the understanding of the health impacts of caregiving in the palliative care context. It reports a study that investigated associations between health and a range of caregiving context variables, which represent potential stressors or resources, among current informal carers of patients receiving palliative care at home.	Informal caregiver n=178	Ordinary least-squares regressions	A cross-sectional observational study of the HRQOL of the carers of patients receiving palliative care (2005-2006)	Age, gender, relationship, employment status, ethnicity
Verbakel et al. (2017)	Finland, Denmark, Norway, Sweden, France, Switzerland, Belgium, Netherlands, Germany, Czech Republic, Poland, Slovenia, Portugal, Estonia, UK, Spain, Ireland, Lithuania, Austria, Hungary.	The aim of this study is to offer a more complete picture of informal care, covering more types of relationships between care receiver and caregiver than the parent-child relationship and, consequently, also a more diverse set of reasons for providing informal care.	Total n=28.406, Informal caregivers n=9.422	Logistic multilevel analysis, linear multilevel analysis	European Social Survey-7 collected through face-to-face interviews	Age, gender, marital status, employment status, educational level, household situation, religiosity, time spent caregiving
Doebler, Ryan, Shortall & Maguire (2017)	United Kingdom	The aim of this study is to address several gaps in the literature regarding the impact of caregiver burden, employment, gender, age and proximity to services on the relationship between informal caregiving and mental ill-health.	Non-caregiver n= 321.972, caregiver n=56.393	Binary logistic multilevel models	Northern Ireland Longitudinal Study, Northern Ireland Enhanced Prescribing Database, Northern Ireland Statistics and Research Agency	Age, gender, marital status, educational level, employment status, place of residence, self-rated health

Table 2. continued

Study	Country	Aim	Sample	Analytical approach	Method of data collection	Dimensions of diversity caregiver
Robards, Vlachantoni, Evandrou & Falkingham (2015)	United Kingdom	The key aim of the study is to understand 'what became of carers in 2001, 10 years later'.	Non-caregiver n=240.979, caregiver n=76.953	Cross-sectional analysis	Office for National Statistics Longitudinal Study, (2001 & 2011)	Age, gender, ethnicity, marital status, employment status, educational level, financial status
Rogero-Garcia & Rosenberg (2011)	Spain	The goals of this article are: to estimate the proportion of co-resident informal caregivers with paid (by the family) and unpaid (informal) support furnished by persons from outside the home; to identify the factors associated with both types of support and to quantify such support in terms of hours of help received over the preceding 4 weeks.	Informal caregivers n=404	Cross-tabulations, Chi-square, binomial logistic regression models	Spanish Time Use Survey, conducted by the National Institute of Statistics (2002-2003)	Age, gender, educational level, employment status, marital status, relationship, place of residence, support of others, household situation
Schulz et al. (2011)	United States of America	The purpose of this article is to address three important questions about choice among informal caregivers: to what extent do caregivers report having choice in taking on this role; what factors are associated with the perceived lack of choice; and how does this perception affect caregiver outcomes?	Informal caregivers n=1397	Bivariate x-square test, multivariate logistic regression, regression analysis, ordinary least square regression, binary logistic regression	National Alliance of Caregiving and the American Association of Retired Persons. Telephone survey	Age, gender, ethnicity, educational level, employment status, relationship, burden
Chang et al. (2016)	Singapore	This study aims to examine socio-demographic correlates of caregiving reactions and the associations of these experiences with caregiver psychological distress.	Informal caregivers n=344	Linear regression, multivariable linear regression, Spearman's rank correlation	Questionnaire through convenience sampling	Age, gender, ethnicity, employment status, relationship, financial status, self-rated health, educational level
Vincent-Onabajo, Ali & Hamzat (2013)	Nigeria	The aim of this study was to explore the quality of life of caregivers of community-dwelling stroke survivors in north-eastern Nigeria.	Informal caregivers n=59	Kruskal-Wallis test	Cross-sectional questionnaire: World Health Organization Quality of Life brief version questionnaire (WHOQoLBREF)	Age, gender, educational level, relationship, employment status, self-rated health
Koker de (2009)	Belgium	The aim of this study is to add to the literature on the 'supply side' of informal care, by extending knowledge on the sociodemographic determinants of caregiving for a person living in the same household and caregiving for a person living in another household.	Informal caregivers n=2559	Cross-tabulations, chi-square, multinomial logistic regression	Survey Care in Flanders, 2003	Age, gender, marital status, educational level, employment level, self-rated health, household situation

Table 2. continued

Study	Country	Aim	Sample	Analytical approach	Method of data collection	Dimensions of diversity caregiver
Weinland (2009)	United States of America	The aim of this study is to describe the lived experience of informal African American men providing care for a relative within the home and explores their definition of caregiver distress.	African American male caregivers n=10	Thematic coding/analysis	In-depth personal interview	Age, gender, ethnicity, marital status, educational level, employment status, financial status, religiosity, relationship, self-rated health
Kenny, King, & Hall (2014)	Australia	The purpose was to investigate changes in health status after the commencement of care-giving relative to the change for similar non-carers over the same period, examining the effects of quantity, duration and other aspects of the care-giving context, which may exacerbate or moderate care-giving impacts.	Informal caregivers n=424	Logistic Regression model	Household Income and Labour Dynamics in Australia	Age, gender, ethnicity, marital status, financial status, educational level, employment status, household situation, self-rated health.
Vecchio (2008)	Australia	The aim of this study is to examine the use of respite services among carers of non-institutionalised individuals aged 15 and over with either profound or severe disabilities.	Informal caregivers n=243.690	Binary logistic regression	Australian Survey of Disability, Ageing and Carers (2003)	Age, gender, ethnicity, culture, employment status, relationship, financial status, household situation, support of others, place of residence
Stacey et al. (2016)	Australia	The aim of this study was to demonstrate the prevalence and demographics of adult carers aged 15 and over in the state of South Australia over 20 years between 1994 and 2014.	Informal caregivers n=1.504	Age-Period Cohort (APC) analysis	Health Omnibus Survey	Age, gender, ethnicity, marital status, employment status, financial status, educational level

Contextual dimensions

Many of the included studies described contextual dimensions in introducing their studies, embedding their study in a specific context. Distinctions were made, in the included articles, between dimensions in the historical, cultural and societal/political context.

Three articles (Doebler et al., 2017; Stacey et al., 2016; Vroman & Morency, 2011) take account of the historical context influence: for example, it is argued that informal care is 'as old as time', but that it was often taken for granted by traditional attitudes towards family responsibilities until the later twentieth century (Stacey et al., 2016). Historical context is also taken into account when explaining specific cultural situations that influence caregiving situations, for example how the post-colonial culture, which came forward in the role of Christian beliefs and values, influences care attitudes in Belize. *"These beliefs were represented in the caregivers volition to assume a caregiver role"* (Vroman et al., 2011, p.17). Or for example, Doebler (2017) studied the influence of the "Northern Ireland conflict", which resulted in increased mental health issues, on caregiver-burden.

Eight articles discussed the influence of cultural context on caregiving situations (Chang et al., 2016; del Río-Lozano et al., 2013; Robards et al., 2015; Stacey et al., 2016; Tokunaga & Hashimoto, 2017; Vincent-Onabajo et al., 2013; Wang et al., 2016; Weinland, 2009). It is often acknowledged that women are more likely to provide informal care than men (e.g. 28–31), which can be explained by the locally prevailing cultural context. For example, Rio-Lozano et al. (2013) described that in Spain, *"care attitudes can be sexist with women being pressured to provide care to others"* (p.1507). Other studies underlined strong filial obligation norms influencing caregiving situations (Chang et al., 2016; Stacey et al., 2016; Vincent-Onabajo et al., 2013). For example, *"the cultural structure in many African countries encourages community and family care rather than institutional and nursing home care"* (Vincent-Onabaja et al, p.978). Wang et al. (2016) described that the unique endowment culture of the Uyghur and Kazakh, encompassing *"honoring and respecting elders, helping and loving mutually and being filial towards parents"* (Wang et al., 2016, p.19), results in family members taking care of disabled elderly in their own homes.

Stacey's (2016) description of the importance of family members caring for ill or aged relatives is an example of the societal/political contexts' influence on caregiver experiences. She described that nowadays, the importance of caring family members is being recognized in social policies in Western countries, which leads to acknowledgement of informal care's significant economic contribution (Stacey et al., 2016). With this political shift, Stacey (2016) concludes that, caregivers in current societies are *"recognized as a separate group in their own right"* (Stacey, 2016, p.15). The influence of the societal/political context on informal care situations is mentioned in 21 articles. In general this is limited to ageing; an ageing population leads to increasing age-related health issues, which consequently leads to higher and policy changes related to deinstitutionalization (Chang et al., 2016; De Koker, 2009; Eby et al., 2017; Hastrup et al., 2011; Ratcliffe et al., 2013; Robards et al., 2015; Toribio-Díaz et al., 2013; Tuithof et al., 2015; Vaingankar et al., 2016; Vecchio, 2008; Verbakel et al., 2017; Vincent-Onabajo et al., 2013; Vroman & Morency, 2011; Weinland, 2009). Some articles described the change in family structures caused by ageing, women's growing labor force participation, and changing gender roles (De Koker, 2009; del Río-Lozano et al., 2013; Tokunaga & Hashimoto, 2017; Toribio-Díaz et al., 2013; Vaingankar et al., 2016; Vroman & Morency, 2011; Weinland, 2009). Also other contextual dimensions that influence caregiving situations were described, such as the influence of rurality (del Río-Lozano et al., 2013; Doebler et al., 2017), welfare state regimes (Ratcliffe et al., 2013; Rogero-García & Rosenberg, 2011; Wang et al., 2016), and migration (Vroman & Morency, 2011).

Within these different context descriptions some attention is given to power relations and social inequality regarding caregiver experiences (del Río-Lozano et al., 2013; Verbakel et al., 2017; Wang et al., 2016). For example Verbakel et al. (Verbakel et al., 2017) describe that in

policies, an increased reliance on informal care is assumed but simultaneously informal care remains hidden. This is *“unfortunate because informal care responsibilities disproportionately fall on certain social groups, such as middle-aged women”* (Verbakel et al., 2017, p. 90). Another example comes from a cultural context where, *“filial piety is the most distinct characteristic in the traditional old pension culture. Parents have the supreme power in the family”* (Wang et al., 2016, p.18). A lack of choice whether or not to become a caregiver, was then associated with an increased risk of depression (Wang et al., 2016).

Types of research questions

Three types of research questions could be distinguished in the included articles. The first type focused on the profile of caregivers. In eleven studies, diversity was used to get a better understanding of the caregivers' backgrounds (De Koker, 2009; del Río-Lozano et al., 2013; Eby et al., 2017; Rogero-García & Rosenberg, 2011; Schmidt et al., 2016; Schulz et al., 2012; Stacey et al., 2016; Tokunaga & Hashimoto, 2017; Toribio-Díaz et al., 2013; Verbakel et al., 2017; Vroman & Morency, 2011), for example, to get a better profile of the group of caregivers providing co-resident care (De Koker, 2009; Vroman & Morency, 2011) or of caregivers providing care to someone suffering from dementia (Toribio-Díaz et al., 2013).

The second type of research questions focuses on the consequences of providing informal care (Chang et al., 2016; del Río-Lozano et al., 2013; Doeblér et al., 2017; Gupta et al., 2015; Hastrup et al., 2011; Kenny et al., 2014; P. M. Kenny et al., 2010; Ratcliffe et al., 2013; Robards et al., 2015; Sequeira, 2013; Tuithof et al., 2015; Vaingankar et al., 2016; Vincent-Onabajo et al., 2013; Wang et al., 2016; Weinland, 2009; Williams et al., 2008). Sixteen articles used diversity to better understand caregiving burden, caregiving health impact and/or quality of life of caregivers. Sometimes, a study focused on a specific group of caregivers and their burdens, for example caregivers of persons suffering from schizophrenia (Gupta et al., 2015) or caregivers in the palliative care context (Kenny et al., 2010). The last type of research questions, studied in five articles, focused on caregiver-coping (del Río-Lozano et al., 2013; Joyce et al., 2014; Sequeira, 2013; Vaingankar et al., 2016; Vecchio, 2008). Examples are differences in support needs, coping strategies, sources of satisfaction (Sequeira, 2013) and use of respite care (Vecchio, 2008).

Power structures and social inequity within informal care were not mentioned explicitly in the research questions. The research questions were mainly focused on the outcome and not framed from a contextualized and intersectional perspective. To formulate an intersectional informed research question it is important to consider which categories are relevant to include (Rouhani, 2014), and to address that intersections between these categories are open empirical questions (Hankivsky, 2012).

Used methodologies

The intersectional lens was used to analyze the used methodologies by looking at the sample of the studies, the method of data collection and the analytical approach, step 3,4 and 6 from the coding scheme shown in table 1. In 25 studies, quantitative methods were used. Most of these studies used existing datasets in order to answer their research question. Sample sizes varied a lot, five studies were based on large datasets containing up to 378.365 respondents, for example by linking several national datasets (Doeblér et al., 2017; Robards et al., 2015) or using European data (Gupta et al., 2015; Verbakel et al., 2017). In these large datasets, often a subset was used containing information about caregivers. Besides the information about this group, information about other members of care networks or about non-caregivers was used as well. This shows the challenge described by Rouhani (2014) that the datasets were not designed a priori with intersectionality in mind and an analysis of intersections was only possible post data collection (Rouhani, 2014, p.8).

Regarding the analysis an additive approach was adopted in 15 of the quantitative studies. This type of analytical strategy enables researchers to quantify differences in social positioning within an identity group (Rouhani, 2014). Using bivariate (Eby et al., 2017; Gupta et al., 2015; Joyce et al., 2014; Robards et al., 2015; Rogero-García & Rosenberg, 2011; Stacey et al., 2016; Toribio-Díaz et al., 2013; Vecchio, 2008; Vincent-Onabajo et al., 2013) or multivariate regression models (Hastrup et al., 2011; Kenny et al., 2010; Ratcliffe et al., 2013; Schulz et al., 2012; Vaingankar et al., 2016; Verbakel et al., 2017), the association between several independent variables and the outcome variable was investigated. A multiplicative approach was adopted in 11 studies (Chang et al., 2016; De Koker, 2009; Doeblér et al., 2017; P. M. Kenny et al., 2014; Schmidt et al., 2016; Schulz et al., 2012; Sequeira, 2013; Tokunaga & Hashimoto, 2017; Tuithof et al., 2015; Verbakel et al., 2017; Wang et al., 2016). In most of these studies, interaction terms were added to the multivariate linear or logistic regression analyses. Using this multiplicative approach allowed the researchers to analyze social and health inequities based on intersections of axis of diversity (Rouhani, 2014).

Although qualitative research is more compatible with intersectionality (Hunting, 2014), as it allows for a greater understanding of people's live experiences of complex inequities (2, p.8), only three studies used qualitative methods. When qualitative methods were applied thematic analysis (Vroman & Morency, 2011; Weinland, 2009) or sociological discourse analysis (del Río-Lozano et al., 2013) were used. This way researchers aimed to preserve the uniqueness of caregivers' experiences (Weinland, 2009). The studies mainly focused on describing the lived experiences of caregivers and explore and interpret the influence of the axis of different dimensions of diversity on for example caregiver distress (Weinland, 2009), coping strategies, the choice to become a caregiver (del Río-Lozano et al., 2013) or the perceived caregiver role (Vroman & Morency, 2011).

Dimensions of diversity

When diversity was taken into account in informal care research, different dimensions of diversity were included as well as care characteristics. The dimensions of diversity of both the caregiver and the care recipient, care characteristics and the earlier mentioned contextual dimensions are visualized in figure 2. Although intersectionality assumes contextualized interconnectedness of axes of diversity and does not view dimensions of diversity as single issues (Hunting, 2014; Nash, 2008; Rouhani, 2014), this section first provides a description of the different dimensions of diversity which emerged from the included studies. As intersectionality demands in-depth reasoning about the study sample to enable researchers to think beyond existing categories (Hunting, 2014), a description of categories studied may create space for the complexity of informal care (Hankivsky, 2014b).

As seen in figure 2, a distinction was made between the caregivers’ and care recipients’ dimensions of diversity, which influence each other. In the description below N is used to indicate the number of included articles using the described dimensions of diversity. For caregivers, dimensions of diversity that were most often used were: age (N=28), gender (N=26), household situation, which means living with or without the care recipient (N=26), employment status (N=25), education level (N=24) financial and marital status (both N=18) and ethnicity, that is the use of race or country of birth as determinant (N=15). Finally, a few studies also included religion, culture and care motives in their analysis.

For example, Wang and colleagues (Wang et al., 2016) investigated the prevalence and related factors of depression among low-income female Uyghur and Kazakh caregivers of disabled elders residing in China’s far west. Their study showed that demographic characteristics of caregivers, caregiver burden, and the care recipient’s impairment significantly correlated with depressive emotion among women caregivers. Chang and colleagues (Chang et al., 2016) used these characteristics to investigate the impact on caregiving reactions and the associations of these experiences with caregiver psychological distress, their study results showed differences between groups (Chang et al., 2016).

Regarding care recipients, the following dimensions of diversity can be distinguished: the impairment the care recipient has, the age or gender of the care recipient and other characteristics such as education level, marital status, ethnicity and household situation. Type of impairment of the care recipients was included the most (N=16). For example, authors used the type of disability (physical, psychological or both) (del Río-Lozano et al., 2013), investigated whether care recipients’ impairment was experienced as mild or severe (Vecchio, 2008), the degree of cognitive decline and the type of dementia care recipients suffered from (Toribio-Díaz et al., 2013), and the influence on the caregiving situation. For example, Hastrup et al. investigated the correlation between the care recipients’ impairment and burden among

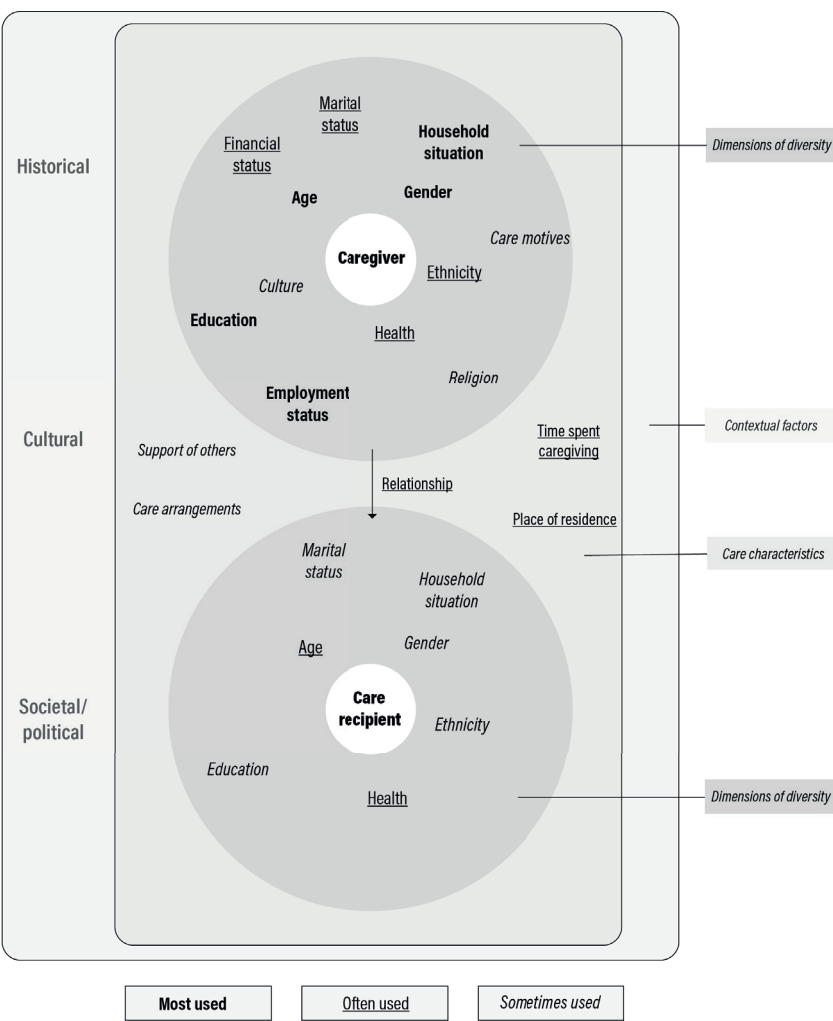


Figure 2. Visualisation of used dimensions of diversity in context

caregivers, showing that caregivers who provide care to someone with a mental illness feel more burdened than others (Hastrup et al., 2011). In addition, studies also included the care recipients’ age (N=10) and gender (N=7) while only a few studies also included the other dimensions.

Besides dimensions of diversity several care characteristics proved to be connected to the caregiving experience. The most commonly used care characteristic consists of relationship elements between the caregiver and the care recipient (N=16). Also, the time spent providing informal care (N=14), caregiver place of residence (e.g. living with or without the care recipient or rural or urban geography) (N=12), care arrangements (e.g. type of provided help, N=9) and availability of support of others (N=7) were used to investigate differences in informal care situations.

Intersections of dimensions of diversity

The intersectionality lens was used to see if intersections of diversity dimensions emerged and if so, how this was reflected. In 15 articles the included dimensions of diversity were studied as single issues. For example Vecchio (2008) found that several factors were associated with not using respite care, for example being a wife or being younger in age. Or, single issues were used to provide insight in the caregiving demographic of a particular region.

13 articles studied the intersections of diversity dimensions and their impact on caregiver health, the caregiver experience or on the time spent caregiving. Seven articles used two or three dimensions of diversity (De Koker, 2009; Ratcliffe et al., 2013; Robards et al., 2015; Schmidt et al., 2016; Schulz et al., 2012; Tokunaga & Hashimoto, 2017; Verbakel et al., 2017). In six articles, intersections between four or more dimensions of diversity were part of the analysis (del Río-Lozano et al., 2013; Doebler et al., 2017; Kenny et al., 2014; Vroman & Morency, 2011; Wang et al., 2016; Weinland, 2009). Table 3 shows per article which intersections of diversity dimensions were analyzed.

Table 3. Representation of intersections of dimensions of diversity

	Gender	Ethnicity	Caregiver	Time spent caregiving	Age	Employment status	Religion	Financial status	Education	Health care recipient	Relationship	Marital status	Place of residence	Age care recipient	Care arrangements	Geography	Support of others	Household situation
Wang et al. (2016)	X	X			X		X	X										
	X	X		X			X	X										
	X	X					X	X		X								
	X	X					X	X			X							
	X	X					X	X									X	
Vroman & Morency (2011)		X						X						X				X
		X		X						X				X				
		X					X							X				
Doebler et al. (2017)	X			X	X	X												
			X	X		X												
			X			X												
			X												X			
				X	X													
	X			X														

Table 3. continued

	Gender	Ethnicity	Caregiver	Time spent caregiving	Age	Employment status	Religion	Financial status	Education	Health care recipient	Relationship	Marital status	Place of residence	Age care recipient	Care arrangements	Geography	Support of others	Household situation
Kenny, King & Hall (2014)	X		X	X		X												
			X	X		X												
				X	X	X												
			X	X														
			X			X												
			X		X													
	X		X	X														
	X		X															
Verbakel et al. (2017)			X	X														
	X		X															
	X								X									
	X					X												
Ratcliffe et al. (2012)			X									X						
			X										X					
Robards et al. (2015)	X				X													
Tokunaga & Hashimoto (2017)	X				X													
	X											X		X				
	X					X												
Schmidt et al. (2016)						X			X		X							
Schulz et al. (2011)				X						X								
Rio-Lozano et al. (2013)	X					X									X			
	X		X															
	X				X				X							X		
	X				X				X							X		
	X				X													
	X				X													
de Koker (2009)					X									X				
											X		X					
												X	X					
Weinland (2009)	X	X					X					X						
	X	X					X				X							
	X	X					X										X	
	X	X					X	X										
	X	X					X								X			
	X	X					X											
Total:	30	14	14	14	12	11	7	7	6	5	5	4	4	3	3	3	2	1

In general, gender is the most common single dimension of diversity used in an intersection (N=30) (del Río-Lozano et al., 2013; Doebler et al., 2017; Kenny et al., 2014; Robards et al., 2015; Tokunaga & Hashimoto, 2017; Verbakel et al., 2017; Wang et al., 2016; Weinland, 2009). Regarding intersections, gender, ethnicity and religion and their relation to caregivers' experience were most studied (N=6). For example, Weinland (Weinland, 2009) studied the lived experience of informal African American male caregivers. *"Participants discussed their use of prayer, faith in God or religion as a coping mechanism...their spiritual beliefs guide African American male caregivers as they cope with the illness of their loved one"* (Weinland, 2009, p.20). Sometimes other dimensions of diversity were added to this intersection, such as marital status, relationship, support of others, or care arrangements.

Second, gender, ethnicity and class or financial status were studied (N=5) in relation to the caregivers' health. For example, Wang et al. (2016) studied depression among low-income female Muslim Uyghur and Kazakh informal caregivers of disabled elders in far western China. *"The results of this study indicated that the depressive emotion of female informal caregivers of disabled elders was primarily associated with the caregivers' demographic characteristics...caregivers' age and self-evaluation of health were each associated with an increased risk of depressive mood"* (Wang et al., 2016, p.13). Sometimes other dimensions of diversity were added to this intersection, such as age, marital status, relationship, support of others, or care arrangements. As table 3 shows, several other patterns could be discovered whilst analyzing which intersections of diversity dimensions were used in the included studies. For example, intersections of gender, age and level of education; gender and employment status; and employment status, being a caregiver and time spent caregiving were used.

Within the 13 studies that included intersections or dimensions of diversity, two articles made a reference to power and social inequality (del Río-Lozano et al., 2013; Tokunaga & Hashimoto, 2017), both in relation to caregivers' choice. Tokunaga and Hashimoto (2017) described that *"being female, low educational attainment, and being single are known to be associated with a lack of power in the household"* (Tokunaga and Hashimoto, 2017, p.50). This influences the caregiving experience as this may lead to the fact that *"informal caregiving is distributed in a biased way to women with less power in the household system"* (Tokunaga and Hashimoto, p.52). According to Río-Lozano et al. (2013): *"women of a lower educational level living in rural areas expressed that they had no choice but to take on socially imposed caregiver roles"* (del Río-Lozano, 2013, p.1511). Both quotes clearly show how inequality plays a role in caregivers' choice of becoming a caregiver based on different axis of dimensions of diversity, mostly being female and lower educated.

Discussion

This scoping review of 28 articles explored how intersectionality is currently used within informal care research, and what such a perspective might add to informal care research. Within the included studies none of the articles explicitly mentioned an intersectionality perspective. However, two approaches have been used to study diversity in relation to caregiving experiences. First, diversity studied as single issue, in which the influence of different dimensions of diversity on for example caregiver burden was examined separately and not in interaction with each other (Vaingankar et al., 2016). Second, dimensions of diversity were (partially) studied in intersections in 13 of the included studies, but not explicitly framed from an intersectionality perspective.

In the included articles several aspects emerged that could be associated with intersectionality. For instance, most included quantitative studies used existing datasets, which often do not allow for the consideration of intersecting dimensions of diversity prior to data collection or for taking into account different categories with a reflection on the complexity of social life (Hunting, 2014). As a consequence, data on particular groups are missing, and the sample size may not be sufficient enough to fill all the cells in the analyses (McCall, 2005; Rouhani, 2014). *"When developing an intersectionality-informed research question, researchers must consider which categories will be included"* (Hunting, 2015, p.5). When an intersectional perspective is used statistical analysis can investigate whether *"statistical interactions between inequity variables manifest significant effects above and beyond their main effects seen in the additive models"* (Rouhani, 2014, p. 11). As another example, qualitative studies aimed to preserve the uniqueness of caregivers' experiences (Weinland, 2009) by analyzing intersections of dimensions of diversity of caregiver experiences in relation to for example the outcome stress, burden or coping. Although this resulted in a rich description of caregiver experiences, an intersectional perspective could have brought a deeper level of analysis by paying attention to social inequities and power relations (Hunting, 2014; McCall, 2005).

Consequently, two aspects come forward which can be associated with intersectionality namely, the description of contextual factors and a relation to power and social inequality. Intersectionality is grounded in from the assumption that research is context bound (Hankivsky, 2012), and many included studies embedded their studies in their specific context (Chang et al., 2016; Doebler et al., 2017; Stacey et al., 2016; Vincent-Onabajo et al., 2013; Vroman & Morency, 2011). However, most studies use dimensions of diversity rather as descriptives without analyzing their meaning. Some account was taken of a deeper layer in which those categories harbor power relations that in and of itself shape the caregivers' experience, for instance, when articles reference power or social inequality in relation to caregiver experiences (del Río-Lozano et al., 2013; Tokunaga & Hashimoto, 2017; Verbakel et al., 2017; Wang et al., 2016).

This was mainly done to put a study in a specific societal/political or cultural context. Río-Lozano et al. (2013) suggest that *"there are significant gender inequalities in caregiving driven by stereotypes and gender norms"* (p.1515). Power relations are also mentioned in caregiver experiences in relation to different dimensions of diversity directly, providing a detailed and nuanced understanding of the lack of choice whether to become a caregiver and the influence of this lack of choice on caregiver health (del Río-Lozano et al., 2013; Tokunaga & Hashimoto, 2017).

Aspects of diversity in informal care in particular across their intersections and from a critical perspective are largely understudied. However, the analysis of the 28 included articles, from an intersectional perspective, showed several aspects that can further our understanding of caregiving experiences: caregiving experiences are unique, there are many different caregiver experiences, and that dimensions of diversity play a role (Dolan & Thien, 2008; Hengelaar et al., 2018). Gender was most often used in intersection with other dimensions of diversity. From a historical perspective informal care is gender-biased but obviously the group of caregivers is more diverse (Verbeek-Oudijk, 2014). For example, when researching partner caregivers, Stacey et al. (2016) showed that caregivers were pre-dominantly female but looking at the intersection of gender, age and life course revealed that *"from the age of 75 there were slightly more male primary caregivers"* and *"after the age of 85, carers were frequently males caring for a disabled wife"* (Stacey et al., p.9). It is evident that it becomes more and more important to pay attention to differences in the roles, expectations and needs of caregivers (7) in order to improve collaboration between caregivers and professionals and developing serviceable policies (Hengelaar et al., 2018; Wittenberg et al., 2018).

Adopting an intersectional perspective can also clarify differences in caregiving experiences within and between groups (Wittenberg et al., 2019). For example, Verbakel et al. (2017) describes the following intersection regarding informal care, *"the demand for informal care is experienced mainly by middle-aged women"* (p.94). When looking at women caregiver experiences from an intersectional perspective Giesbrecht et al. (Giesbrecht et al., 2012) explain that *"by adopting an intersectional approach, it became apparent that women are not one homogenous group, but are complex and diverse individuals who simultaneously inhabit other distinct socioeconomic, cultural, political, and historical locations, and as such, their caregiving experiences are likely to vary dramatically"* (Giesbrecht et al. 2012, p.2). Their study provides deep insight in the structural positions of caregivers within Canadian society (Giesbrecht et al., 2012).

Using an intersectional perspective provides the opportunity for intentional use of diversity dimensions from a relational and critical perspective, allowing researchers to dig deeper for whom and under which conditions the knowledge is 'true' or 'valid'. For example, who is the most burdened or about whom is the least knowledge created (McCall, 2005). By doing so, power is

made visible and diversity is translated as questioning inequality and structural disadvantages (McCall, 2005). For example, Holmgren et al. argued that caregivers have to deal with different obligations, interests and power structures which can create a feeling of being caught in between different expectations and structures (Holmgren et al., 2014). *"Becoming a caregiver relative means establishing oneself in a betweenship of a traditional gender power structure and a division of labor conditioning what male and female relatives 'naturally' should be involved in, as well as how to perform care activities"* (Holmgren et al. 2014, p.234). When focus lies on mapping how people are made vulnerable, not necessarily being vulnerable, a representation of their voice and assessment of their situation from their perspective is required.

This scoping review has several limitations; First, only articles published in English or Dutch were included, therefore some studies may have been excluded. Second, several studies (Chappell et al., 2015; Giesbrecht et al., 2012; Holmgren et al., 2014; Lin et al., 2012; Williams et al., 2017) that explicitly used intersectionality were not included in our review. Neither did they appear in the used databases with the used search strategy, nor in the reference lists of the included articles, or they did not meet our third inclusion criterium of using four or more dimensions of diversity. As these articles do provide valuable insights, they are used extensively in the introduction and the discussion. Several decisions were made in order to improve the strength of our study. First, a well-established method was used for reviewing, data extraction, summary and thematic synthesis (Thomas & Harden, 2008). Researcher triangulation was used in all phases of our study. Second, creating a thematic synthesis goes beyond the preliminary results and results in a higher level of evidence and understanding about the meaning of diversity in caregiving experiences (Sandelowski & Barroso, 2003). Third, studies were gathered from four different electronic databases and represented different countries all looking at least at four different dimensions of diversity in regard to informal care. The search strategy, using four databases and a combination of MeSH and free-text terms, produced a heterogeneous set of studies.

Based on this scoping review several recommendations can be made for the future. First, the use of intersections of dimensions of diversity to interpret caregiver experiences must be amplified by encouraging researchers to incorporate an intersectionality perspective in a structured manner and integral to all parts of design. This way research can *"develop more contextualized and reflexive understandings"* (McCall, 2005, p.17) of caregiving experiences and effectively *"capture social and health inequities"* (Hunting, 2014, p. 15) in caregivers' experiences. Second, this review focused on the caregivers' perspective. Analyzing the included studies showed that several authors also included care recipients' dimensions of diversity. Based on the concept of positionality, which describes how identity influences, and potentially biases understandings of and outlook on the world (Rudman, 2018), it can be assumed that the dimensions of diversity of formal care providers also influence their perspective on informal care and their way of

collaborating and supporting caregivers. Therefore, it would be interesting to include the perspective of formal care providers in further research. At policy level, using an intersectionality lens can provide insight in the usual assumptions stakeholders have about the provision of care and to rethink collaborative care networks (Holmgren et al., 2014). Taking diversity into account can support informal and formal care providers to better understand each other and thus improve collaboration and policy makers to create socially relevant, inclusive and effective policy solutions that contribute to social justice (Rouhani, 2014).

Conclusions

Aspects of diversity are largely understudied in informal care research, in particular across their intersections and from a critical perspective. This review shows that studying dimensions of diversity across intersections makes room for a more nuanced understanding of informal care. However, adopting an intersectional perspective can clarify differences in and between informal care groups, providing the opportunity for intentional use of diversity dimensions from a relational and critical perspective. Making sure that not only different categories or social identities of caregivers are included in future studies, but the mutual relationships between these categories embedded in their specific context are actually studied. Enabling a focus on power relations and social inequalities in informal care research. This provides insight in how caregivers are being made vulnerable, not necessarily how they are vulnerable. A representation of the voice of different caregivers within future caregiver research is required and an emphasis on health disparities in and between informal care groups and let future informal care research be responsible for embedding the role that socio-structural dynamics play in informal care.

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Intermezzo

Religion as part of my life whether I want it to or not

I was born and raised in the Netherlands, shaped by the norms and values of the Protestant church. That background forms part of my foundation, even though I no longer identify as Protestant; I call myself a non-believer. This term feels like a better reflection of where I stand: not against religion, but outside of it. That may sound neutral, but it is not. I have quite normative views on my Christian upbringing, and it is also difficult for me to put this struggle on paper, because part of my family are devout, pious Christians. There is a story behind it, and it has everything to do with why I chose how I now move through the world.

That turning point came years ago in Nepal, where I was working as an occupational therapist with children with cerebral palsy, an incurable form of brain injury. Many Christian missionaries were active in the region and offered parents healing if they would abandon their Hindu faith or Buddhist beliefs and convert to Christianity. In countless conversations with families, I saw the emotional toll of these offers: the hope, the coercion, the silent devastation when miracles failed to materialize. It planted a lasting sense of injustice in me. I could no longer reconcile these actions with the faith in which I had been raised.

When I started my PhD research on carers and care recipients with acquired brain injury from diverse migration backgrounds, religion was of course omnipresent. It came up in interviews, in informal conversations and in dialogue sessions. In order to reach participants, I often had to visit churches and mosques, gateways to communities that would otherwise be inaccessible. Yet in our secularized society, religious backgrounds often remain unspoken, tucked away in the shadows of care research. Early on in my research, I was confronted with a question that I had not fully considered: how does my own religious background

shape my presence in this work? At first, I was not sure whether it mattered. But the deeper I went, the more I understood that my reason for no longer believing is, in fact, deeply relevant. I have struggled with the question of how open I should be. Some participants ask me directly about my beliefs. I wondered: Is this the moment to share? Will my honesty open or close doors? In Ghana, identifying as a non-believer meant that conversations ended abruptly. There I was not completely honest, which challenged my sense of ethics.

This inner conflict is not easy to resolve. I know I have to learn how religious beliefs shape the role of carer, how faith helps us understand life with acquired brain injury and how spirituality influences professional identities. This means dealing with discomfort, both my own and that of others. It means recognizing that faith is sometimes more than just a belief; it is belonging, trust and legitimacy. As a non-believer, I have entered sacred spaces with humility, aware of my otherness, but determined to listen. In listening, I hope to find not only understanding, but also respect for the beliefs of others and for my own journey away from belief.

Chapter 4

Experiences of disadvantage and privilege of care recipients with a migration background in acquired brain injury rehabilitation - an intersectional analysis

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Abstract

Health inequities exist between care recipients with or without a migration background, but there is insufficient knowledge about the mechanisms that lead to the reproduction of health inequities. This article aims to contribute to the understanding of how Diversity, Equity and Inclusion (DEI) shapes the experiences of care recipients with a disability and migration background in collaborative care networks, through an intersectional lens. A participatory study was conducted with professionals, carers, and care recipients with acquired brain injury (ABI) in nine community of practice (CoP) meetings. The study is part of a larger study and was guided by a hermeneutic framework focusing on reciprocal learning in the CoP through co-creative reflection and intersectional analysis of data. The experiences of nine care recipients with ABI and a migration background, collected in open interviews, were central to the analysis. Analysis was further substantiated by analyzing the stories of 21 carers with a migration background and 17 professionals, collected in semi-structured interviews. An intersectionality lens was applied to understand the power dynamics in the experiences as expressed in the interviews and stories. Using vignettes of care recipients' experiences, we present the following intersectional mechanisms that reproduce health inequities: (1) navigating diversity, (2) gender-related loneliness, (3) hidden challenges, and (4) challenging assumptions. We conclude that upon discharge home care recipients with ABI and a migration background fall into a lonely state of being, often with a lack of social support and experience financial difficulties. Care recipients disappear out of the healthcare system's sight and are unable to find their way back. Diversity responsive healthcare begins with a critical awareness of health inequities and the underlying mechanisms among professionals, healthcare institutions, and policy.

Introduction

Becoming someone with an acquired brain injury (ABI) turns your world upside down. People with a disability have to reconcile immense changes in their daily lives and often must accept that they have become dependent, and recipients of care provided by others (Arntzen et al., 2015). A disability like ABI not only affects the personal life of the individual, but also the lives of the people in their social networks, e.g. family, friends or neighbors, many of whom provide a form of informal care (Kokorelias et al., 2020). ABI is one of the leading causes of disability worldwide with a large societal impact, and societal costs will rise rapidly (King et al., 2020; Luengo-Fernandez et al., 2020). In the Netherlands, the context of this study, approximately 3.5% of the population suffers from a type of brain injury (van Esch et al., 2019). Research on the lived experiences of people with ABI shows that people may go through a process of coming to terms with their new identity (Arntzen et al., 2015; Masel & DeWitt, 2010).

There are persistent health disparities in the Netherlands. Health disparities are not only the outcome of unhealthy behaviors, but also of complex inequality in society (Bussemaker et al., 2022). Health disparities exist among people with ABI (Johnson & Diaz, 2023b), meaning that preventable health differences exist based on aspects of diversity, e.g. race, ethnicity, gender identity, sex, age, sexual orientation, religion, disability, education, and income, and their intersections (Hammarström et al., 2014). In this study we adopt a health equity perspective by focusing on meeting health needs, however similar or different (Buchbinder et al., 2016; Hammarström et al., 2014). Recognizing health inequities points to underlying causes of health disparities that are systematic and based on the social position of care recipients. Health inequities are socially produced and therefore avoidable and unjust (Adelson, 2005; McCartney et al., 2019). Acknowledgement of disadvantage and privilege among care recipients is necessary to facilitate a needs-based approach in healthcare and overcome health inequities (Hammarström & Annandale, 2012; Hammarström et al., 2014).

Johnson and Diaz (2023) reveal that health inequities exist across the continuum of care for ABI and that race and ethnicity were most impactful on care received after ABI and overall perceived health outcomes. Research from the United States shows, for instance, that with stroke treatment ethnic minorities are underserved and have less confidence in healthcare facilities than people with a majority background (Cruz-Flores et al., 2011). Williams and Ovbiagele (2020) report that post-stroke disparities are widespread and may be attributed to experiences of racism within healthcare systems, which in turn disproportionately affects the health of minorities. It is therefore necessary to recognise that disparities in brain injury care and the fundamental causes of these disparities are social and structural as well as medical and biological in nature (Reeves et al., 2015). Mikolic et al. (2021) show that gender also matters as men and women differ in ABI epidemiology. Women show worse functional, health-related

quality of life and mental health outcomes following mild ABI. However, men have a higher likelihood of sustaining a traumatic brain injury, for example. For this study we zoom in on people with ABI who also have a migration background. In the Netherlands, care recipients with a migration background belong to a minority group. However, it must be recognised that there are also differences within the group and that their experiences are based on their social position, which finds its basis in the contextualised intersections (Hankivsky, 2014).

Inequities do not exist in isolation. To mitigate health inequities in ABI rehabilitation, explicit attention should be given to the underlying structures (Bowleg, 2023), that are influenced by the socio-political, cultural, and relational context of care (De Waure et al., 2015; Morgenstern & Kissela, 2015). Darwin Holmes et al. (2021) show how professionals’ implicit moral routines determine whether care recipients and carers with a migration background are involved in collaboration. The professional identity of being an expert may lead professionals to take on their role as experts and exercise power to determine what is needed and by whom (Hengelaar et al., 2018). Looking at carers, it is known that carers with a migration background often do not feel heard in the collaboration and express a lack of trust in professionals. Carers’ lack of trust is further magnified by the fact that, when concerns are raised, these concerns are sometimes being considered irrelevant by professionals (Hengelaar et al., 2024).

We lack in-depth studies of the dynamics in ABI care networks that lead to health inequities, and until now the voice of care recipients with a disability and migration background has been underrepresented (Badou et al., 2023). Therefore, this article aims to contribute to the understanding of how Diversity, Equity, and Inclusion (DEI) shape the experiences of disadvantage and privilege of care recipients with a disability and migration background in collaborative care networks.

Methodology

Given the research question, we conducted a qualitative study amongst persons with ABI and a migration background with the focus on their perspective on the collaboration within care networks. Subsequently, the stories of nine care recipients were central in this participatory analysis, which concluded with a series of community of practice (CoP) meetings. The participatory analysis focused on reciprocal learning and was informed by intersectionality. This intersectional framework helped to unravel contextualized disadvantages and privileges within and between groups across their intersections (Bowleg, 2021).

This study is part of a larger research study from which the experiences of professionals (Hengelaar et al., 2025) and carers (Hengelaar et al., 2024) have been published. During the interviews, both professionals and carers discussed the role of care recipients in care networks.

Segments from the professional interviews and carer interviews and dialogue sessions were used to substantiate the results, shown in Figure 1.

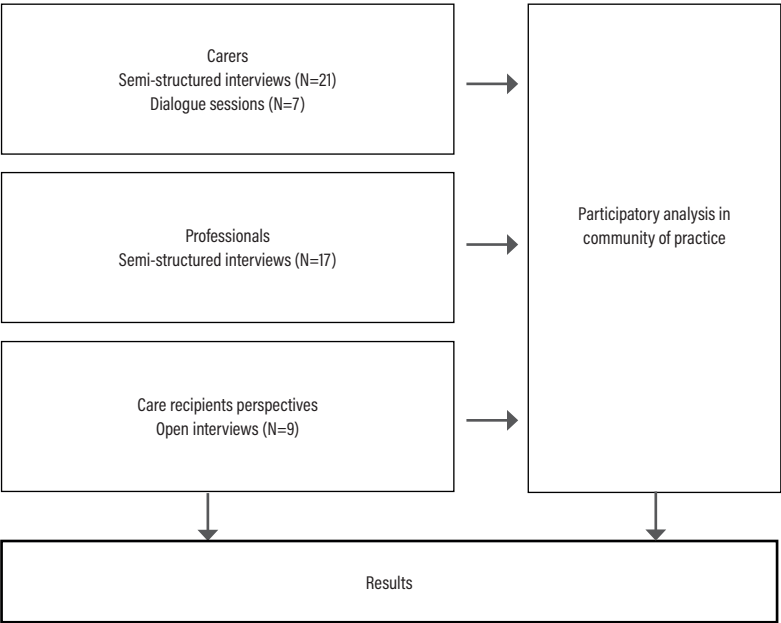


Figure 1. Visualisation data collection and analysis

Below we present methodological details of the qualitative study (Phase 1) as well as the participatory analysis by the CoP (Phase 2).

Phase 1: Qualitative study

Participants

Care recipient recruitment started purposively through informal conversations in patient organisations as well as other social organisations focusing on supporting carers and care recipients with ABI, as well as supporting people with a migration background. Nine informal group conversations took place with people with ABI and a migration background; in total 32 people participated in these informal conversations. However, only three people wanted to continue with a formal interview, who after their own interview pro-actively supported the recruitment process through snowball sampling. Others were hesitant about their language skills or the formal procedures of consent. Simultaneously, recruitment was done via telephone and email in the existing networks of the authors, with the addition of snowball sampling, leading to additional interviews with six care recipients (see Table 1 for N=9 care recipient characteristics).

Table 1. Care recipient characteristics

Name	Gender	Age	Occupation	Religion	Marital Status	Ethnicity	Place of residence	Health status
Fatima	Woman	36	Unemployed	Muslim	Divorced	Dutch- Morocco	Urban	Stroke
Zainab	Woman	43	Unemployed	Muslim	Divorced	Dutch- Moroccan	Urban	Multiple Sclerosis
Elif	Woman	33	Unemployed	Hindu	Single	Dutch- Turkish	Urban	Traumatic Brain injury
Malti	Woman	45	Unemployed	Hindu	Single	Dutch- Surinam	Urban	Traumatic brain injury
Imane	Woman	37	Unemployed	Muslim	Divorced 2x	Dutch - Moroccan	Urban	Traumatic brain injury
Zofia	Woman	40	Volunteer	Atheist	Married	Dutch - Polish	Urban	Traumatic brain injury
Tamar	Woman	29	Secretary	Muslim	Divorced	Dutch - Turkish	Urban	Meningitis
Aleks	Man	46	Volunteer	Atheist	Divorced	Dutch - Polish	Rural	Traumatic brain injury
Harry	Man	60	Unemployed	Atheist	Divorced	English	Urban	Traumatic brain injury

Data collection

Open interviews with nine care recipients were conducted, by the first author, in the care recipients’ homes, with the exception of two interviews that were conducted online due to COVID-19 restrictions. Interviews lasted between 59 and 72 minutes in length. The interview guide consisted of two open-ended questions: (1) *Can you describe your experience of becoming someone with acquired brain injury?* and (2) *Can you describe your experiences of being cared for by a care network of professionals and informal carers?* Probing questions were used when aspects of diversity, power dynamics, social (in)justices, or contextual factors emerged in the stories. For example: a participant explained she felt left out of the conversation between professionals and her carers. This comment was subsequently explored by probing questions such as: *How does this make you feel? Why do you think this happened? What is the consequence of this for the care provided?* For all participants Dutch was their second language. Seven participants chose to do the interview in Dutch, with the occasional support of a translation app on our phone, and two participants, Tim and Fatima, expressed that they felt more comfortable to tell their story in English.

Intersectional analysis

Audio recordings were transcribed verbatim and summarised. Our analysis started with summarising interview transcripts and creating a vignette for each participant. The vignettes were created based on intersectional analysis carried out by the first author and a critical friend (Van Wees et al., 2023), MAXQDA was used to manage the data. The first author is a trained occupational therapist and PhD-researcher born and raised in the Netherlands. A critical friend was invited to add to researcher triangulation and offer insights from someone with a migration background. The intersectional analysis was guided by the following steps (based on: Hunting, 2014; McCall, 2005; Stuij et al., 2020): (1) identifying aspects of diversity within the interview transcripts mentioned by the participants and portraying the social identity of the participant; (2) determining where participants social identity is influenced by aspects of power and social (in)justice; (3) identifying relevant contextual aspects relevant in the participant stories; and (4) writing the vignettes. Vignettes were sent for member checking after which five care recipients provided additional information. The vignettes represented participants’ stories of becoming care recipients with ABI and their experiences of being a part of a care network. We created these vignettes because vignettes are helpful for participatory analysis by CoP members (Cardiff & van Lieshout, 2014), in Phase 2.

Phase 2: Participatory analysis by the CoP

A CoP is a group of people who share the common interest of deepening their awareness and the desire to improve their practice and expertise (International Collaboration for Participatory Health Research [ICPHR], 2013; Li et al., 2009). In this case, the practice and expertise is ABI rehabilitation. The CoP was guided by a hermeneutic framework focusing on reciprocal learning through reflection and intersectional analysis of data. CoP members exchanged experiences and reflected upon successes and failures to improve that practice. The first author was part of the CoP meetings and shared data from the qualitative studies for participatory analysis.

CoP Participants

The CoP consisted of three care recipients with an ABI; three carers, one of whom is also a health professional; and two professionals. To ensure the anonymity of the CoP participants, no further information is provided herein. The participatory analysis in this study supported the ongoing dialogue amongst CoP members, who are all part of collaborative ABI care networks. It also created a space to share their accounts of the collaboration, to create a mutual understanding of the influence of diversity on care provision to care recipients with ABI, and to identify opportunities for change (Abma et al., 2020).

Participatory analysis using intersectionality

We used intersectionality to analyse the qualitative interview data of the care recipients from Phase 1 substantiated with the segments from the professional (Hengelaar et al., 2025) and carer (Hengelaar et al., 2024) interviews and dialogue sessions.

Intersectionality fosters responsiveness to diversity by not using a single issues approach. It allows for an analysis of care networks that recognises how interactions are relational and subject to the underlying social positions of the stakeholders involved (Crenshaw, 1991; Hankivsky, 2020; Stuij et al., 2020). This lens enabled CoP members to focus on differences, power relations, and social inequalities. During the nine CoP meetings, we looked for examples in which aspects of power and social (in)justice emerged in the vignettes of the participants. We also analysed whether and how contextual factors and stakeholders' social positioning played a role in these stories (Stuij et al., 2020; Windsong, 2018). Additionally, each member of the CoP started a reflexive journey in which critical reflection on their own positionality in care networks was central to uncover potential biases relevant to our process (Gani & Khan, 2024).

The following steps were taken in the participatory analysis (Cardiff & van Lieshout, 2014; Lieshout & Cardiff, 2011): (1) members of the CoP started with reading or listening to the vignettes from the data of Phase 1 and collected ideas, feelings, and thoughts; (2) engaged in collective reflection to start the focus on participatory analysis; (3) individual CoP members extrapolated vignettes and stakeholder perspectives (professionals, carers, and care recipients) and creatively visualised the essence by showing a photo, for example; (4) all visualisations were then shared in an open discussion and formed the basis for the dialogue in the CoP, and finally; (5) as a group, CoP members returned to the vignettes and extrapolated report from the interviews with professionals and carers and focused on structural aspects together. In this last step, different perspectives merged into a shared interpretation, forming the basis for the results section.

Ethical considerations

Ethical approval was granted by the Medical Ethics Review Committee of VU University Medical Centre, project number 2017.395. Informed consent was provided by all participants prior to all forms of data collection. In the participatory analysis specific attention was given to fairness and authenticity of stakeholder accounts, and measures were taken to ensure the inclusion of stakeholders in every step of the research process (Abma et al., 2017). In order to do so we did the following: (1) invited carers, care-recipients and professionals to provide input in the phase of writing the research proposal guiding aim, research questions and demarcation of the larger research project; (2) organized a multi-stakeholder CoP that ran parallel to the

research process and provided input from data collection to data analysis; (3) held informal conversations to reach as many care-recipients with a migration background; (4) besides written consent the use of verbal consent was taken into account during ethical approval, allowing for the participation of care recipients who were hesitant to provide written consent. These foci and steps stem from the epistemological belief that knowledge is embedded in social relationships and is deepened when produced collaboratively (Fine, 2010). Additionally, an individual reflexive journal was kept by the first author, critical friend as well as all members of the CoP, because it is important to not only state who you are, but also to reflect critically and self-scrutinize on yourself as a researcher and to explicitly describe how your own social position may have impacted this study (Darwin Holmes, 2020; Gani & Khan, 2024). The reflexive accounts were used as input for the dialogues amongst the first author, the critical friend and the members of the CoP. This influenced the findings because these dialogues deepened the interpretation of the data by bringing in various perspectives. For instance, as someone experienced the same as a research participant or the opposite, both helped to gain a better understanding of the influence of DEI on care recipients experiences.

Results

Fatima described her life as very lonely; she explained that she left her life in Morocco a couple of years ago to live in the Netherlands with her husband, but they divorced, making it impossible for her to return to Morocco because of the taboo on divorce in her family. Her now ex-husband became violent when she arrived in the Netherlands which resulted in a traumatic brain injury. Since then, she suffers from memory loss and is unable to walk long distances. Fatima is lonely because her family is still in Morocco except for her sister, who lives in Brussels. Upon her arrival in the Netherlands, she did not do paid work as it was expected of her to stay home. Her ex-husband had a traditional view on family life and gender roles. Now, her traumatic brain injury impedes participating in the labour market, but Fatima needs to work because she lives in poverty. She receives some support from her neighbour and recently joined a peer group for women who survived partner abuse. She does not visit professionals in the Netherlands anymore because her experiences with them are not positive. In her encounters with professionals, she did not feel heard and taken seriously. Fatima blames herself that she does not speak Dutch well enough to receive adequate care. Once a year she travels to Brussels with her sister to visit a familiar neurologist who works in a clinic. Fatima says that he mainly focusses on her depression and not her brain injury. Her depression is a consequence of her brain injury, and her depression gets so bad that she does not leave the house for weeks and stays inside with the curtains closed. Since her brain injury she often is unable to deal with all the stimuli outside her house, only when she has a good day (Fatima).

The vignette about Fatima encompasses major topics that need to be addressed within care networks. It served as a starting point for participatory analysis in the CoP. The participatory analysis developed four overarching topics which are the basis of this result section: (1) navigating diversity, (2) gender-related loneliness, (3) hidden challenges, and (4) challenging assumptions.

Navigating diversity

In general, care recipients explain that their world is turned upside down when their brain injury occurs. Their main focus in the aftermath of their ABI is rehabilitation and they are not concerned with other aspects of diversity than their disability. When care recipients were given some time to think about the consequences of their ABI for their daily lives, they recognised that there were several other aspects than disability linked to diversity that were worth mentioning. When specifically asked about their experiences, care recipients with ABI separate their experiences of having to deal with ABI from having a migration background:

'I feel judged by society for my ABI but also for the fact that I am Turkish, reducing my range of motion within society, I have very little possibilities.' (Tamar)

Difficulties are experienced in care networks, and carers relate these difficulties to cultural aspects of diversity. Carers do everything they can to protect care recipients from having to deal with these difficulties. Having to deal with the consequences of the disability is difficult enough without having to deal with prejudice or a lack of diversity responsive care, as evinced by the following quote:

'I constantly had to check whether or not my daughter was fed halal food. I had many discussions with the nurses and dietitians about this, I even took my concerns to the management but was not heard. I want to do this for my daughter, she does not have the energy to deal with things like this.' (Carer)

However, care recipients cannot be fully protected. The *participatory analysis* showed how the intersection of the disability with gender, class, and education level shapes everyday life of care recipients with a migration background, which will be unpacked in the following themes.

Gender-related loneliness

The loneliness described by Fatima is shared by the other care recipients. Over time, most have seen their social networks disappear. This impacted the participants, for instance, because the person with ABI had less energy to engage with people, and their social participation decreases due to diminished possibilities. Within the CoP loneliness was a known problem for care recipients with ABI. The *participatory analysis* also showed the impact of cultural taboos on ABI as an additional layer contributing to loneliness:

'My family does not understand all the consequences of my ABI, especially the invisible consequences. When you cannot see something there is no need to be involved and care, but there is also another thing I am hesitant to explain....my invisible consequences are often confused with psychiatric issues and mental health is not something we do not talk about in my culture, I am from Morocco. It is taboo to talk about mental health because it is something that may not be in your family. This does not only count for my family but also for the larger community that I was proud to be a part of, for example I am not welcome anymore in the Mosque that I always went to, because people do not want to interact with me anymore.' (Imane)

The fact that care recipients have migrated to the Netherlands left them with an even smaller social network than they had to begin with. Finally, relational issues arose between care recipients and their spouses especially when women were not able to fulfil the required traditional gender roles within the relationships. When divorce became inevitable, it added to a diminished social network. For some people, the stigma on divorce further added to losing a social safety net. Several participants had been married before their disability and all of them divorced in the aftermath of their disability. The consequences of the disability had made staying married too difficult.

'After my ABI I was unable to fulfil my duties in the household, my husband was very traditional in his beliefs on what role belongs to the wife and which to the husband. Things I was unable to do after my ABI were unthinkable for him to do. The situation triggered such aggressive behavior that over time the only way forward for me was divorce.' (Tamar)

The participants who divorced after their ABI explained that their divorce had strained the contact they had with family in their country of origin *'as there is a taboo on getting divorced'* (Fatima). But for some participants, their disability hinders contact with family and friends *'back home'* because they have difficulty processing stimuli that arise from using FaceTime, for example. For most care recipients, their remaining social network consisted of family and for some also their children. Additionally, some participants found connection and comfort in peer support groups.

'I am 43 years, and my life is very isolated, I only have contact with my family in Morocco via telephone or internet, when I am able to. I was diagnosed a couple of years ago, I thought the first symptoms like dizziness and fatigue were a result of stress following my divorce. Unfortunately, when I was diagnosed, I was, and still am, on my own. I only find comfort in a peer support group.' (Zainab)

For the CoP members, the fact that care recipients did not speak about getting support from a carer was as much an eye opener as it was a painful observation. The assumption that care recipients with a disability and migration background have family to support them upon

discharge is an assumption overly present in professional accounts, and this assumption does not coincide with the reality told by care recipients. Additionally, when professionals lose care recipients out of sight after discharge this has a tremendous impact on their daily lives as they do not seem to find their way back to care organisations which contributes to loneliness.

Hidden challenges

Financial difficulties are omnipresent in the stories of care recipients and rooted in the unemployment status of the care recipients. The financial difficulties and unemployment status makes care recipients dependent on disability benefits or welfare. Aleks, Harry, and Zofia were employed before their disability, but were now unable to fulfil the job they had before, making it difficult to make ends meet.

'In 2004 I was employed as a professional motorcyclist, like a test driver on the circuits. When traveling home one day I got hit by a truck, the start of all this misery. Of course, I am unable to go back to work since I am in a wheelchair, and my other injuries obstruct me from working at all unfortunately.' (Harry)

Participatory analysis recognised that financial difficulties often arise following an ABI. Two aspects are particularly worth mentioning. Fatima, Zainab, Malti, Imane, and Tamar were unemployed before their disability based on their social position, highlighting fixated gender roles. The intersection and disadvantages of gender with class and disability becomes visible in how the women in particular have to deal with the consequences of low education combined with oppressive gender roles. Being forced into marriage meant a life with no or little education and resulting in no earning capacity. For them, it did not make sense to their families for them as daughters, to be educated, because *'that is not our [women's] purpose'* (Zainab).

'I was married when I was 14 years old to someone I had not seen before. I was taken out of school, and I never got the opportunity to go back. I have two daughters who I have not seen since my divorce as they were taken back to Turkey. I know they have been taken out of school since, which makes me miserable.' (Tamar)

Not having prolonged education also influences their lives in other domains. For instance, they experience difficulties accessing healthcare or finding suitable organisations to support them in everyday life, especially for their financial worries.

'I have always wanted to be a chef, study cooking, but that is something I did not get to do in my lifetime. I always stayed at home to take care of everything, as was expected of me.' (Imane)

Participatory analysis recognised in the story of Elif that family values might still be traditional but that this results in a very different struggle, which requires a different focus of professionals.

Where some care recipients might benefit most from guidance in the welfare system and where to receive support, Elif might benefit most from other strategies.

'I am searching for my own place because I want to increase my independence. I am proud that I got my secretary degree and have been employed by the same company for twelve years. They stood by me during my accident and recovery and are willing to think along to adjust my job what I am able to do now. I struggle every day with my parents, we migrated to the Netherlands as a family, but my parents' mind is still in Turkey. They do not want my independence, they want me to get married and settle down, especially since they are convinced, I am not able to take care of myself after my accident.' (Elif)

For women, this is not just about living with a disability and migrant background, but this is also about being dependent on a family that does not value your independence either and holds traditional gender beliefs.

Challenging assumptions

Support provided by professionals to the participants is different for each care recipient and based on the varied nature of ABI. Care recipients claim that professionals sometimes make assumptions that are not changed after they are challenged by care recipients. For some care recipients, this led to seeking treatment from professionals abroad, like Fatima, Harry, and Aleks. Even though they have different countries of origin, they are confronted with similar assumptions and accompanying difficulties. Harry explains that he has a strange walk, resembling a drunk, due to his ABI: *'Because I am from the UK, I am often mistaken for an alcoholic instead of a brain injury survivor. This hurts because I am unable to consume alcohol since my ABI.'* Aleks explained that this happens to him more often which, according to him, causes frequent changes of professionals caring for him.

'I do not appreciate being accused of being a drunk, which happens a lot by professionals. Maybe it is because I am from Poland, I don't know, but I have a lot of difficulties walking, speaking coherently especially when I did not sleep well, all consequences of my ABI. The fact that the professionals who provide me with personal care do not recognise this as being part of my ABI astonishes me.' (Aleks)

Elif and Tamar attribute their difficult encounters with professionals to the fact that their wishes are not taken into account, rather, choices within care are made based on the assumptions of professionals. They describe situations where they were pushed into agreeing to have homecare provided by an organisation specialised in care for care recipients with a Turkish migration background, which feels not right in terms of procedural justice and leads to disadvantages.

'I truly felt overruled by this choice, I clearly stated more than once that I am not opinionless and that I have a preference. My preference is not to be cared for by an organisation caring for and only employing professionals with a Turkish background. I am born and raised in the Netherlands and there is no need to provide specialised homecare that fits the cultural norms and values of my parents, it makes me feel unwelcome in the Netherlands. I feel more self-value when I am cared for by the organisation of my choice.' (Elif)

Lack of understandable information is difficult for care recipients, especially when there is no carer present to ask the difficult questions. This was the case with Zainab: *'I only knew my condition was serious because I couldn't move, but that was as far as my understanding went.'* This might lead to misunderstandings with the professionals about, for example, the prospects for recovery or the ability to arrange adequate care for themselves.

'I understood that I would recover within a week, it is not like I had a stroke or something, just meningitis. But now a few years later I am still not recovered fully, that is very difficult to cope with. They could have been more careful, but it felt like they were always in a hurry, too busy to take the time to explain to me what was going on. I need extra time because I have difficulties understanding.' (Tamar)

Care recipients recognise that the lack of insight into the recovery process of ABI has a major impact on their well-being, as it decreases their self-esteem, increases stress, and in some cases may even result in depression. Malti explains that arranging additional personal care with the municipality drains all her energy, which is already limited due to the disability:

'It takes too much time, and I never get the result I want. When my social worker arranges it, it is done in a heartbeat, but I want to show that I am able to do this by myself.' (Malti)

In the participatory analysis it was recognised that dialogue between carers and professionals is essential, not only for the coordination of care, but more importantly to understand underlying norms and values regarding the necessary care. Through dialogue, specific choices of carers and care recipients to match their care needs may become visible. Preferences and choices are influenced by underlying aspects of diversity and understanding this is a prerequisite for implementing needs-based approaches and for working in a true, collaborative partnership. Participants of the CoP reflected on the learning process we went through during our CoP meetings, which is necessary for every professional to go through in order to be able to provide diversity responsive care.

'Every meeting we have had I learned something new, about myself and why I think the way I do, the work that I do, or my eyes are opened by the story of one of the other CoP members or participants. It would be amazing if every professional who works in complex collaborative

networks would have the time to focus on what I call sensitive learning. In my workplace, as is common in others, we have clinical lessons where we discuss new evidence-based interventions for example, but learning about the role diversity has within our work is something we do not create space for. It is a process that you need to go through, it cannot be solved in one meeting or separate meetings, there needs to be a red thread of learning together, asking the difficult questions to realise that there is a layer underneath our work that needs exploring, and I found that the reflexive process we went through very insightful. There is no toolkit, you need to be willing to do the work.' (Occupational Therapist)

Discussion

This article shares the results of a qualitative interview study with nine care recipients with ABI about their experiences in collaborative care networks and the subsequent participatory analysis within a CoP. In our results, we unpacked the role DEI plays within collaborative networks from care recipients' perspectives, and how this leads to disadvantages and privileges. The impact of the disability stands out, other aspects of diversity are not foregrounded in care recipients' experiences. However, the reasoning that rehabilitation after ABI and coping with changes in daily life required all their attention does not mean that there is no relation to other diversity aspects. Standing out in care recipients' stories are gender-related loneliness, gender-related financial problems, and difficult encounters with professionals within the context of ethnic and cultural backgrounds that may differ from the Dutch cultural majority backgrounds.

As mentioned by members of the CoP, loneliness and social isolation are quite common among people living with ABI. Care recipients in this study quite desperately expressed the need for social support. Our participatory analysis unraveled that loneliness amongst care recipients is coloured by their social positioning and their intersections. Care recipients in this study, in particular women, described cultural stigma on being divorced following their disability. This heavily contributed to feeling lonely, as their possibility of returning to their country of origin was diminished or gone. Our results corroborate the findings of other researchers. The finding that 'the disability comes first' in the ranking of what is considered important by patients is in line with the work of Salas et al. (2022). They describe that persons with ABI are vulnerable in society based on severe cognitive and socio-emotional impairments. Lowe et al. (2021) add that ABI directly impacts a sense of belonging and being socially connected which may also lead to internalised loneliness, and 'feeling broken inside' (p. 458). When zooming in on small or non-existing social networks as described by care recipients, it is worth noting that being alone may contribute to feeling lonely and isolated which has a negative impact on care recipients' well-being. A social network is important for experienced quality of life (Jellema et al., 2022). Additionally, having a small social network means that there are limited people available who are willing to provide a form of informal care.

Care recipients in this study also referred to cultural taboos regarding invisible consequences of ABI, which were often confused for mental health issues or alcohol abuse. The consequence of existing cultural taboos and stigma on ABI contributed to loneliness as care recipients lost social contacts and possibilities to participate in social activities. Additionally, they actively retracted themselves from social contact as they doubted their abilities. Bracho and Salas (2024) show in their research that stigma about ABI exists on three levels: self-stigma, stigma by association, and public stigma. They also state that stigma and disabilities like ABI in minority groups deserve specific attention in further research. The stigma experienced by the care recipients in this study shows there is a need to further research stigma and disability in particular in minoritised groups. Ownsworth et al (2024) highlight the importance of professional care in community-based programs in the first few months upon discharge to decrease stress and enhance the connection within the community. This is especially important when care recipients are aware of pre-existing stigmatizing views regarding their disability within their community (Ownsworth et al., 2024).

The financial disadvantages mentioned by the care recipients in this study are not new. Amongst many other studies, Humphreys et al. (2013) and Libeson et al. (2020) focus on returning to work after ABI. Our study adds insight into another layer of experienced financial difficulties, as several of the interviewed care recipients were already unemployed and had nothing to return to. In our study, women were particularly at risk for poverty because of beliefs about traditional gender roles and the expectation that women should not work when married, making them dependent on their husbands. Williams et al. (2017) explain that women often adhere to stereotypical gender norms implying a duty to care. After divorcing in the aftermath of their ABI, they were left with the financial consequences. Their ABI created an inability to start work when necessary. Gary et al. (2009) show that ethnic minorities in general are less likely to be employed post-ABI.

Most care recipients disappear from the health care system 'radar' after discharge home, and the question arises about how to keep them in sight of healthcare organisations upon discharge or when it becomes necessary over time. This may signal a severe disadvantage and health inequity, as Johnson and Diaz (2023) show in their international scoping review, according to which persons belonging to the majority population, in comparison to persons with ABI and a migration background, are more often discharged to a rehabilitation center or nursing home rather than to the home context. These groups are thus somehow privileged over people with a disability and migrant background, yet this privilege might be invisible to the people involved. Additionally, being married is often a determining factor in the decision of whether or not a care recipient is able to be discharged home (Nguyen & Connelly, 2017). For several care recipients in our study, divorce occurred after discharge, again leading to severe disadvantages in life and they were met with cultural taboos on divorce within their existing

social network. Participants encountered cultural taboos, as has been described in literature (Furtado et al., 2013; Landau & Hissett, 2008). As a result, the care recipients were left to themselves and could no longer find their way back to healthcare. Providing insights in the consequences of (un)conscious privilege within the context of care networks and into power structures that (re)produce privileged positions within healthcare is necessary to overcome health inequities (Schram et al., 2025). Brown & Jones (2024) specifically advocate for the use of a modified privilege walk within healthcare organizations to promote dialogue about privilege and disadvantage within a healthcare setting. A modified privilege walk can create a safe space to discuss 'privilege, race and racism and their impact on daily life' (p.2). Using privilege walks is not without risk and there should be ample attention to potential harm and emotional distress during an following the exercise (Patel & Kutac, 2024)

The CoP argued that the way aftercare for people with a disability like ABI and migrant background is provided may need to be reviewed given these disadvantages. Additionally, care recipients in our study described that they often do not feel heard or taken seriously by professionals. Furthermore, they often blame themselves for not being heard, which causes them to end up in a negative spiral. Sometimes this can even lead to depression which can be even more disabling than the ABI itself. As care provision is always reciprocal there is a need to understand how barriers and inequalities may prevent access to adequate healthcare. Lequerica and Krch (2014) describe that diversity aspects may complicate interactions between patients and staff and that racist comments or discriminatory actions by professionals occur. Omar et al. (2023) argue that rehabilitation institutions do not always uphold their mandate to provide adequate treatment for minoritised groups. Hengelaar et al. (2024) also show that carers for patients with ABI and a migrant background experience discriminatory practices in collaboration with professionals.

Understanding how coping mechanisms and cultural adaptation strategies of care recipients with a disability and migration background may differ from what health professionals are used to is urgent (Choy et al., 2021). Ethnocentrism often creates a lens through which people view the world and interpret situations according to their own cultural values (Lequerica & Krch, 2014, p. 651). Patel et al. (2021) add that understanding the health literacy levels and circumstances of care recipients is necessary to provide quality care and understand the cultural meanings assigned to ill health. Furthermore, insight into the context surrounding the provision of care is essential when trying to create a partnership, which is the basis for shared decision-making. In order to achieve collaborative partnerships, care recipients and their carers must be able to actively participate within the rehabilitation process (Peoples et al., 2011). This requires professionals to be able to deal with complexity and have critical awareness into how best to respond to the needs of care recipients at any given point in their rehabilitation process. It also requires a greater understanding of how professionals may evaluate and enable care

recipients' readiness and need for power-sharing. Insight into assumptions and moral norms and values underlying this process is necessary to open the possibility for shared decision-making, necessary for adequate collaboration in care networks (Choy et al., 2021).

Ideally policies are developed in more participatory ways (Hankivsky, 2014a, 2020) involving care recipients and their carers in the development of health policy. It is relevant to realise that, with regard to the role DEI plays within collaborative care networks, care recipients and carers experience many disadvantages and negative experiences with the quality of the service, and issues around procedural justice and discrimination. This may lead to mistrust and makes it harder to establish partnerships and voice needs in collaborative networks and policy making. Building trust is thus essential. For care recipients, dealing with the consequences of ABI, the disability comes first. However, from a carer's perspective, it becomes clear that they are often confronted with processes of 'Othering', which they try to hide from care recipients (Hengelaar et al., 2024). Therefore, insights from both care recipients as well as their carers need to be obtained to provide richer and more complete accounts of the problem that needs to be resolved. This offers an in-depth and nuanced understanding of the diverse support needs in healthcare. This may prevent policy development guided by assumptions. Our results show that all too often professionals erroneously believe that choices might be culturally appropriate which in reality they are not. Additionally, Omar et al. (2023) also argue for including voices of minorities in the development of healthcare policies and interventions, and they specifically add the necessity to take an anti-racism lens when doing so.

Methodological considerations

The number of care recipients with a disability and migrant background interviewed was rather small but this is one of the first studies that includes this underrepresented and underserved population. This study can thus be a starting point for further exploration. Recruitment of care recipients was difficult for several reasons. When carers were approached about whether their care recipient would be interested in telling their story, they responded that they were unable to partake in an interview based on language or cognitive impairments. Carers also expressed that they did not want to ask their care recipient, because they did not want to tell their loved ones that they were participating in research into their own carer's experiences. Carers explicitly explained that telling their own story felt like a betrayal of their loved one. Additionally, care and social organisations, as well as the professional network of the authors replied that they did not serve care recipients with a disability and migration background nor believed that care recipients with a disability and migration background would be able to participate in research.

What worked well in the recruitment process included the following: informal conversations with civil society organisations and investing time to get to know and built trust among care

recipients. Several care recipients subsequently agreed to participate in a formal interview. During this interview, they also provided information tailored to them so they could better explain the interview process. Snowball sampling was used amongst care recipients who did respond to the invitation to interview, and they actively supported the recruitment process.

On a critical note, we took care to avoid the specific focus on care recipients with a disability and migration background being counterproductive. Surely, it emphasises categorization of this group and reproduces an essentialised focus on a disability and migration background. Therefore, we took precautions to show within-group differences and highlight both sameness as well as difference amongst care recipients with a migration background. The sample shows within group differences based on age, gender, country of origin and religion. The recruitment started out in a wide variety of organizations to allow for diverse religious background as well as country of origin such as visiting Mosques, Churches, and diverse health and welfare organizations for specific target populations. In this search we also paid attention to a mix of age and gender.

Creating space for the voice of care recipients with a disability and migration background, can contribute to further insights into the diverse experiences and needs of all post-ABI care recipients, including those with a majority background. A strength of this study was the participatory analysis in the CoP. In combination with the data from professionals and carers, vignettes were constructed and brought in for a co-creative reflection in the CoP. This yielded insights into the complexities of DEI in care recipients' experiences. This required ethical work on emotional and relational levels (Groot et al., 2022) to reach the uncomfortable place as personal neutrality is no longer upheld and technical solutions do not work to overcome these epistemological difficulties (DiAngelo, 2015; Zembylas et al., 2014). The CoP meetings with a vast group of dedicated people fostered a reflexive learning process with peers as well as other stakeholders in collaborative care networks.

Conclusion

Our participatory analysis within a CoP with practitioners interested in ABI rehabilitation for care recipients with a disability and migration background was informed by intersectionality theory. On the basis of this study, we conclude that upon discharge home care recipients with ABI and a migration background often run into a lonely state of being with a lack of social support and financial disadvantages. Care recipients seemed to disappear from the healthcare system and were then unable to find their way back, leading to more disadvantages such as having to take care of oneself at home. Negative experiences with the quality of the service, procedural injustice and discrimination further fuels negative experiences and mistrust. Care recipients might benefit from different ways of rehabilitation and aftercare at the community

level. This requires regaining trust and critical awareness amongst professionals as well as healthcare organizations and policymakers and requires a participatory approach to the development of diversity responsive care.

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Intermezzo

Doing justice, is that possible?

I have had several meetings with an organization that supports women who have survived domestic violence, where I met a woman who suffered acquired brain injury as a consequence of domestic violence. Every time I walked into the office of this organization, I immediately felt discomfort. It was not fear or unease with the space itself, but a deep awareness of the contrast between the lives of these women and my own life. They had endured things I hadn't. They had dealt with violence, loss, isolation and trauma. And I arrived with notebooks, research questions and privilege.

But what really bothered me was the language barrier. I could not speak with them directly. Every word went through a translator, and while I was grateful for that bridge, it always felt like a filter. Empathy needs immediacy, and something about the translation process diluted the true connection. I kept asking myself: Who am I to question these women? What right do I have to enter their space and ask them to share their pain with me? And yet they were so open and brave. Their openness exposed a truth that struck me: there was deep injustice in their lives, shaped by poverty, marginalization and violence. But alongside that pain, there was strength. There was so much strength and a resilience that humbled and silenced me.

After almost every interview, every dialogue session, and especially after informal conversations with these kinds of groups, I needed time. Time to realize what I had heard, time to feel what I felt. Time to admit to myself that I did not always know what to do with the sadness, the guilt, the admiration. It was hard to be the outsider. I did not belong to their world, but I felt a deep responsibility to do justice to their stories. Yet the question remained: Can I? Am I even in a position to do so? During the analysis phase, these questions did not go away. Indeed,

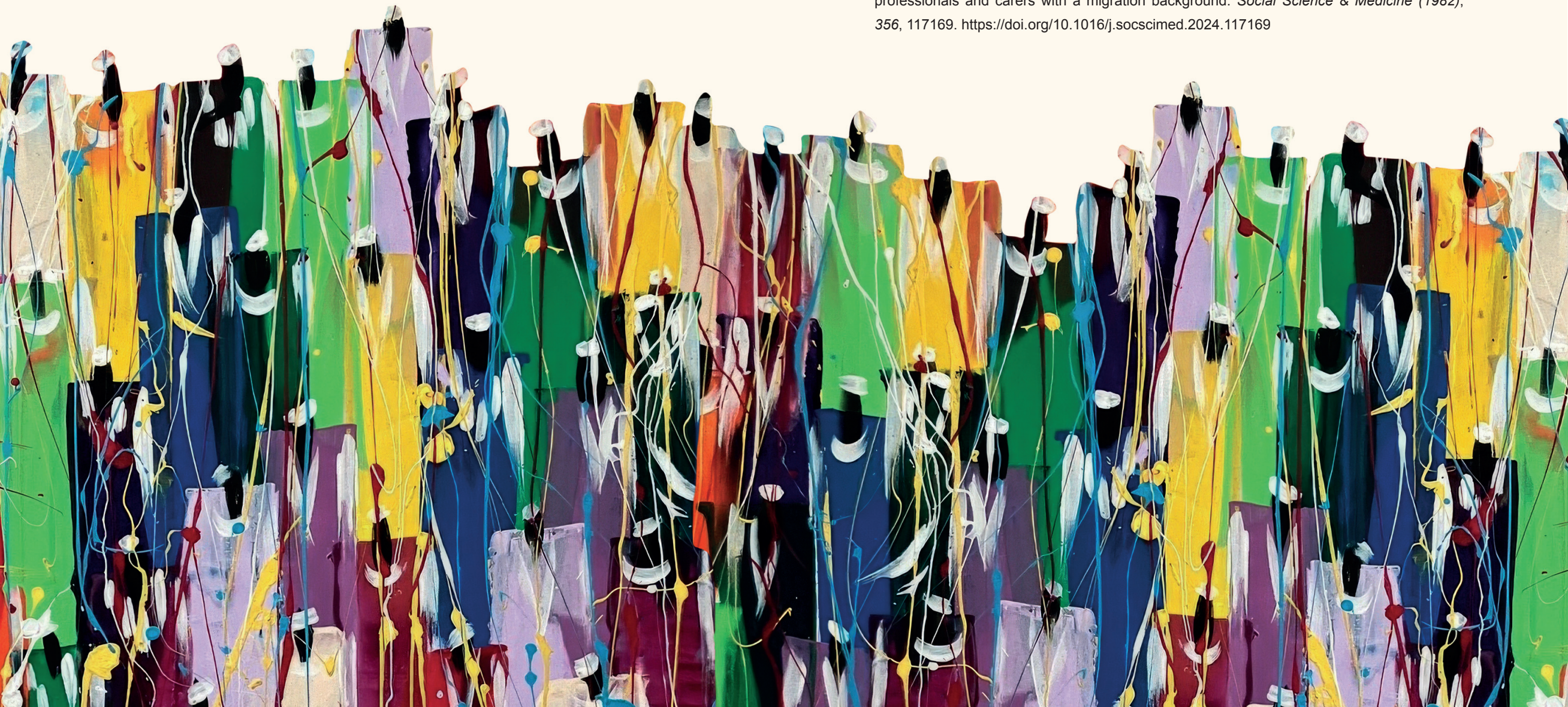
they became louder. I constantly doubted myself. When the women spoke about discrimination in healthcare, their words sounded raw and powerful. But I wondered: Am I interpreting this correctly? Am I just amplifying what I want to hear to make my point? I was afraid of exaggerating the truth in the name of urgency. So I kept returning to the data, sharing doubts with critical friends and letting the community of practice challenge me. I continued questioning whether I was telling the honest story.

That discomfort became fuel. I pushed even harder to reach underrepresented groups. I drew on my experiences in Nepal and Ghana, where creativity was necessary to recruit people and build trust. I used everything I had learned to find ways to connect, even when it seemed impossible. Even as I write this thesis, though, I am not satisfied. The number of participants feels too small. The voice in my head, that old, familiar voice, tells me it is not enough, that I must first prove my worth before I dare to claim anything about the truth. I am learning to silence that voice. I know that I have crossed the boundaries of language, culture and emotion. I have entered spaces where I did not belong, not to claim something, but to listen. Maybe that is enough.

Chapter 5

A sense of injustice in care networks: an intersectional exploration of the collaboration between professionals and carers with a migration background

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Abstract

This study tries to understand the power of knowledge within collaborative care networks to provide insights for designing successful collaboration within care networks by combining intersectionality and epistemic (in)justice. Becoming an informal carer for someone with an acquired brain injury (ABI) causes a dramatic disruption of daily life. Collaboration between professionals and carers with a migration background may result in unjust and unfair situations within care networks. Carer experiences are shaped by aspects of diversity which are subject to power structures and processes of social (in)justice in care networks. In this study, intersectionality was used to both generate complex in-depth insights into the different active layers of carer experiences and focus on within-group differences. Intersectionality was combined with the theoretical concept of epistemic (in)justice to unravel underlying dynamics in collaborative care networks contributing to the understanding that carers with a migration background are often not seen as 'knowers of reality.' This qualitative study conducted in the Netherlands between 2019 and 2022 incorporated three informal group conversations (N = 32), semi-structured interviews (N = 21), and three dialogue sessions (N = 7) with carers caring for someone with an ABI. A critical friend and a community of practice, with carers, professionals, and care recipients (N = 8), contributed to the analysis. Three interrelated themes were identified as constituting different layers of the carer experience: (a) *I need to keep going*, focusing on carers' personal experiences and how experiences were related to carers social positioning; (b) *the struggle of caring together*, showing how expectations of family members towards carers added to carer burden; and (c) *trust is a balancing act*, centering on how support from professionals shaped carers' experiences, in which trusting professionals' support proved challenging for carers, and how this trust was influenced by contextual factors at organizational and policy levels. Overall, the need for diversity-responsive policies within care organizations is apparent. Carers with a migration background need to feel heard so they can meaningfully tailor care to meet recipients' needs.

Introduction

Suddenly becoming an informal carer for someone with an acquired brain injury (ABI) causes major disruptions in daily life (McIntyre et al., 2020). Many carers struggle to accept their changed future, the changed behavior of the care recipient, and the changed rules of reciprocity in their relationship (Pont et al., 2020). Care is provided within large collaborative care networks, and when considering the collaboration between professionals and carers with a migration background it becomes clear that this collaboration often (re)produces inequality (Rønn-Smidt et al., 2020b). Unraveling inequalities is a complex endeavor within public health (McCartney et al., 2019). The present study was informed by intersectionality (Hankivsky, 2014a; Kapilashrami & Hankivsky, 2018; McCall, 2005) to generate insights regarding how carer experiences are socially constructed and power-laden (Zanoni & Janssens, 2015). We combined intersectionality with the theoretical concept of epistemic (in)justice (Fricker, 2007) to capture how dynamics within collaborative care networks contribute to the reality that carers with a migration background are often not seen as knowers of reality (Hengelaar et al., 2021; Mapedzahama et al., 2018; Montero-Sieburth, 2020).

Several studies in diverse fields have used the combination of the two approaches, with limited studies within the healthcare field, e.g. Bacevic (2023); Cummings et al. (2023); Lo (2018); Muntinga et al.(2024); Oliphant (2021); Omran & Yousafzai (2024); Patin et al. (2021); Rekis (2023). Within studies that focus specifically on healthcare, Brown et al. (2023) show that racism is primarily manifested through epistemic injustice as care recipients are disbelieved based on their social identity and Sebring (2021) theorizes medical gaslighting and calls for broader understanding of which structural barriers marginalized people face in accessing healthcare. This body of evidence shows in different fields and at different levels that people belonging to minoritized groups in society are questioned when it comes to their knowledge. However, there are limited studies providing insights in practical implementation in research and additionally research specific to healthcare issues. We aim to contribute to broader theory building on the added value of combining intersectionality and epistemic injustice by providing an in depth empirical exploration of the collaboration in care networks of care recipients with ABI.

ABI is an umbrella term encompassing traumatic brain injury (TBI), when an external traumatic event causes damage to the brain, and non-traumatic brain injury (NTBI), when a disease leads to brain damage. Examples include car accidents, falls, and violence that cause a TBI, or a stroke, tumor, or infection that cause an NTBI. An ABI does not result from congenital disorders, degenerative disorders, or from brain trauma at birth (Goldman et al., 2022). Carers responsible for someone with an ABI experience high carer burden because of the long-term nature of care and the high levels of complex care required (Kavga et al., 2021). Caring for someone with an ABI is also done within larger care networks in which carers collaborate

with different professionals, such as a neurologist, general practitioner, physiotherapist, occupational therapist, (district) nurse, speech therapist, and/or social worker. With a study conducted in Denmark and Australia, Lobo et al. (2021) showed that in the acute care phase, carers felt supported by professionals in the hospital or rehabilitation setting, but that after discharge this professional support was experienced as inadequate. Community services often lack sufficient coordination across a vast variety of involved disciplines, and carers are not well informed about existing community services (e.g., Lobo et al., 2021). Additionally, an international literature review showed that in the home context, carers frequently experienced shared care as ineffective and unstructured (Hengelaar et al., 2018). In the Dutch context of another study, carers often did not feel involved in the care provided in these networks at home (Bussemaker et al., 2022). In a study outlining the developments related to informal care in the Netherlands, it was evident that only half the carers were involved in shared decision-making about provided care and the sharing of care responsibilities (Boer et al., 2020).

From the carer's perspective, the major disruption of daily life following an ABI influences the social, practical, and financial aspects of their daily life (Hart et al., 2018), as well as causing emotional grief and feelings of uncertainty about the course and consequences of their loved one's ABI (McIntyre et al., 2020). Although caring may provide a sense of purpose and a deepened connection with the care recipient, carers may also experience ongoing worry and loneliness. In addition, the loss of participation in meaningful daily activities and occupations further affects carers' health and wellbeing (Kokorelias et al., 2020). In the Netherlands, approximately 3.5% of the population suffers from a type of brain injury, and it can be assumed that this leads to at least an equal number of carers (Bussemaker et al., 2022). The impact of being a carer on the carer's health, participation, and wellbeing is evident, but the degree of influence varies depending on the carer's social positioning (Hengelaar et al., 2021), and adequate collaboration is seen as essential in the process of sharing care with professionals, as the quality of collaboration is of great significance to the recovery of care recipients (Rønn-Smidt et al., 2020). How carers participate in and perceive the collaboration varies substantially, however, and this is subject to many factors, including social identities like gender, age, religion, ability, socioeconomic status, culture, and educational level and their intersections (Hengelaar et al., 2021). These aspects of diversity co-shape the attitudes of carers toward the provided care and their perspective on sharing care with professionals (Wittenberg et al., 2019a). Not knowing what is expected may lead to ambiguity about roles and expectations in the collaboration in the care networks among carers, which can result in feelings of insecurity.

Regarding carers with a migration background, Hamed et al. (2022) reported: "Groups of people who are racialized are considered inferior ... devalued, disempowered and subjected to differential treatment in various institutions" (p. 2). Minority status was negatively associated with health status and disparities in access and quality of care in Akbulut and Razum (2022).

Questions arise about how processes or dynamics within collaborative care networks contribute to inequality, and in what way do the social positions of carers with a migration background in Dutch society matter? In their literature review focusing on migrant health status, Lebano et al. (2020) showed that despite policy ambitions, evidence exists of persistent inequalities in accessing healthcare between migrants and non-migrants. Discrimination has negative consequences for migrant health (Lebano et al. 2020), and a recent study in the Netherlands by Badou et al. (2023) exposed that discrimination occurs within the Dutch healthcare system and government policies are providing little guidance to address discrimination in healthcare organizations.

Hynek et al. (2023) argued that the intersections of being a carer and having a migration background is largely overlooked within public health research. Although they did not find significant evidence in their cross-sectional analysis that being a carer and having a migration background was associated with 'double jeopardy' in daily life in Norway, caution was warranted, as carers with a migration background were underrepresented. International literature reviews (Hengelaar et al., 2021; Shrestha et al., 2023) have reported that, indeed, carers with a migration background are often underrepresented in research on informal care. Nevertheless, carers with a migration background experience higher burden than carers without a migration background. Furthermore, Shrestha et al. reported that (a) the provision of care is gendered, as care is more often provided by women across the globe and also by female carers with a migration background; (b) care is more often shared with family members on the level of sharing caring tasks; and (c) carers with a migration background experience a lack of culturally sensitive support from professionals.

Research focused on collaboration between professionals shows that the above-mentioned production of inequality may stem from (often implicit) bias among professionals that negatively influences collaboration (Drewniak et al., 2017), and that informal carers' knowledge is often downplayed by professionals (Karlsen et al., 2023). The silencing of carer voices hinders adequate collaboration within care networks and overlooks the essential role informal carers play within the public health domain (Mathews et al., 2015). When focusing on carers with a migration background, it becomes clear that their migration background matters in their daily lives, and that being a carer with a migration background also plays a role in collaborative care networks. However, there is a lack of understanding of how dynamics in care networks (re)produce inequalities and how intersections across aspects of diversity play a role in these dynamics. To reform public health in a diversity-responsive way, it is necessary to recognize how social position complicates interactions between stakeholders (Gustafsson et al., 2024).

This study tries to understand the power of knowledge within collaborative care networks to provide insights for designing successful collaboration within care networks by combining

intersectionality and epistemic (in)justice. In an empirical exploration of care networks in the Dutch context, this study sought to understand the relation between social positioning and power of knowledge, within collaboration in care networks of care recipients with ABI from the *carer's perspective*.

Theoretical background

Generally, networks build on the idea of connected nodes where each node represents a stakeholder in the network, like being a carer, care recipient, professional, or for example, another member belonging to the family or social network of either the carer or care recipient. We also took the approach of 'layers,' as each stakeholder has different interests and provides different levels of contribution within the care network which influence carers' experiences in different ways. Figure 1 visualizes a layered care network. To gain insight into carers' experiences per collaboration within care networks, it was necessary to pay attention to the multiple layers within care networks, including the layer of the carer and care recipient, the surrounding social network, and the layer of sharing care with professionals (McPherson et al., 2014). Considering care networks in this way opens the possibility to understand the complexity of carer experiences within care networks because it might enable effective analyses of underlying assumptions and biases present within different stakeholders, which are represented by the different arrows in Figure 1.

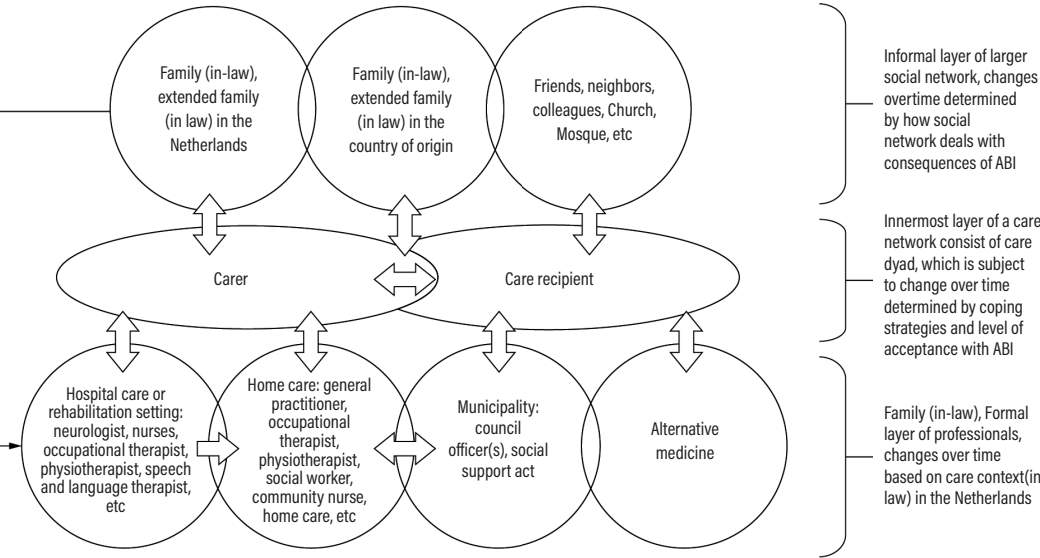


Figure 1. Visualization of layered care network

Within the Dutch context, carers reside in the inmost layer of care networks, which might amplify the complexity of collaboration in these care networks (Duijs, 2023). Due to rising healthcare costs, an aging society, and austerity measures within the Dutch healthcare system, there is a growing awareness within the Dutch government of the necessity to provide informal care. In the changing care landscape, 'good care' does mean good collaboration in care networks to provide good quality care of recipients. Unequal access to healthcare, welfare, and carer support in care networks has appeared related to aspects of diversity, particular for isolated carers, carers living in poverty, or carers unable to speak Dutch (Bussemaker et al., 2022). Carlsson (2023) argued that the care provided is not spatially confined and always embedded within policies and practices that go beyond the home where the care is provided. Therefore, some insight into Dutch policies is necessary, as neo-liberal policies aim to create a society with increased social engagement within Dutch society and are combined with austerity measures to lower healthcare costs (Tonkens, 2018). This hyper-focus on self-reliance and the substitution of formal care by unpaid carers ignores a potential increase of family overload, pressure on the labor participation of carers (and on their employers, such as health and welfare organizations), and, potentially, new safety and health risks related to lower standards of care (Duijs, 2023).

To better understand the role played by diversity in collaborative care networks, we chose to invoke the concept of intersectionality as a theoretical lens. *Intersectionality* helps clarify differences and inequalities within and between groups, as well as the mutual relationships between categories of diversity embedded in a specific context of care networks and can highlight the diversity amongst carers with a migration background. This enabled us to focus not only on differences but in particular on power relations and social injustice, which is necessary because the current research focused on carers with a migration background has mainly focused on cultural sensitivity (Shrestha et al., 2023) or adopted a single-issue approach to uncover discrimination based on, for example, either gender or ethnicity (Badou et al., 2023). Intersectionality fosters responsiveness to diversity by not using a single-issues approach (e.g., gender, migration background, age) or by understanding diversity as additive (such as the added effects of gender + migration), but rather it refers to the interaction between these aspects (gender x migration x age) and how people experience their daily lives at these junctions (Crenshaw, 1991; Hankivsky, 2020). We thus hoped to generate new and more complex in-depth knowledge to both explain the origins and root causes of the experienced lack of support among carers and provide insight into the different processes and dynamics active in carers' experiences (Kapilashrami & Hankivsky, 2018). An intersectionality approach was used to generate insights regarding the interactions between the various aspects of diversity and (dis)advantage in individual lives, social practices, institutional arrangements, cultural ideologies, and the outcomes of these interactions in terms of power, social inequities, and health disparities (Hankivsky 2014).

Power dynamics and social justice within the context of collaborative care networks may relate to fair access to healthcare and the opportunity to be as healthy as possible both for care recipients and carers. We relied on McCartney et al.'s (2019) definition: "Health inequalities are the systematic, avoidable and unfair or unjust differences in health outcomes that can be observed between populations, between social groups within the same population or as a gradient across a population ranked by social position" (p. 28). Additionally, health inequalities might be influenced by policies or actions that adversely affect the societal conditions in which people can be healthy (Levy & Sidel, 2006). As a contested concept, 'power' deserves an explanation as well within the specific context of care networks and how power might come into play (Avelino, 2021). We recognized that *power* plays different roles within care networks, as power is relational and shapes perceptions as well as presuppositions underlying the choices made between stakeholders and might therefore also be oppressive or ignorant (Hancock, 2019; Meyer et al., 2013). Additionally, we framed power as the ability to act and recognize that within care networks it is necessary to understand who is exercising power over whom (*power over*), how actors exercise power to enable or resist change (*power to*), and how actors collaborate in the exercise of *power for/against* change (Avelino, 2021). Specifically, expert power assumed by professionals is a risk within collaborations when professionals determine what is needed by whom and do not question situations unfamiliar to them (Meyer et al., 2013). Within collaborative care networks communication is key, as it is influenced by power structures since power is the capacity to mobilize means to achieve ends (Avelino, 2021).

In the case of carers with a migration background, their concerns are often not heard in care networks. To unpack these dynamics, we chose to additionally make use of Fricker's (2007) theory of *epistemic (in)justice* which occurs when prejudice causes the hearer to question the credibility of the speaker and the reliability of the story (Fricker, 2007; Groot et al., 2022). Prejudice within communication works in two ways: by either assigning more or assigning less credibility to the speakers' testimony based on characteristics such as their social positioning. Fricker (2007) argued that it is the responsibility of the listener to gain access to 'the just story' of the speaker by a correct interpretation of words and body language. Creating such sensitivity is an ongoing process, however, shaped by aspects of diversity and motivational attitudes that are inherited and change over time through lived experiences (Auerback, 2021). Deviation from societal norms may result in a process of being rejected as different (Johnson et al., 2004) within the hierarchy of power and results in situations of oppression (Khrebtan-Hörhager, 2019). In collaborative care networks, there is a risk that professionals only see the generalized 'other' and fail to assess the need of particular carers who, according to professionals, deviate from societal norms. Insights into Othering may help explain the link between minority status and health inequalities (Akbulut & Razum, 2022). Combining intersectionality with epistemic injustice provides more clarity of how epistemic injustice occurs depending on which aspects

of identity and their intersections are attended to (Rekis, 2023). Within care networks, unequal relationships cause tension within the collaboration and may be based in a process of Othering because professionals often follow their own frames of reference and find it challenging to interact with others with a different background (Claeys et al., 2021).

Methodology

The goal of our study was to gain insight into the life-world experiences of carers and draw attention to the concealed and tacit yet crucial work of informal caring and collaboration with professionals. An intersectionality-informed qualitative study design was used by applying an empirical intersectional framework (Hancock, 2019b).

Qualitative methods are appropriate for understanding and describing the experiential knowledge gained from the lived experiences of carers. These methods may help uncover hidden aspects of caring as well as aspects in the collaboration with professionals that are difficult to articulate explicitly, including feelings of social injustice and not being 'heard' (Vanidestine & Aparicio, 2019). We proceeded under the assumption that categories of difference are dynamic productions of individual and institutional factors (Verdonk et al., 2019), while recognizing the interconnectedness of numerous socially constructed identities that collectively shape the lived experiences of individuals and groups (Abrams et al., 2020).

Participants

Diversity among carers with a migration background who are responsible for the care of a person with an ABI was sought through purposive sampling to allow relevant dimensions of diversity to emerge from the data, as these are not predetermined within an intersectionality-informed design (Hancock, 2019b). A within-group intersectional approach was adopted by *not* assuming that all carers with a migration background have similar experiences (Hankivsky, 2020). Twenty-one carers were included to represent a diverse within-group sample of carers with a migration background (Hankivsky, 2014a). To be able to move beyond an essentialized focus on migration background and demographic differences, the diversity of the lived experiences of carers was considered (Bowleg, 2021), resulting in a heterogeneous sample based on carer identified, ethnicity, age, gender, sexual orientation, and religion, as well as carer occupation and relationship to care recipients. Table 1 shows a representation of the sample; the names are pseudonyms.

Table 1. Representation of included participants

Mr. Yildirim	Gender: men (N=8), women (N=13)
Mrs. Zhèng	
Mr. Elmaleh	Sexual orientation: straight (N=20), gay (N=1)
Mr. Chitrit	
Mrs. Metha	Age: ranges between 25-79
Mr. Faya	
Mrs. Ouazzani	Place of residence: urban (N=20), rural (N=1)
Mr. El Din	
Mrs. Sadik	Relationship to the care recipient(s): son (N=4), spouse (N=11), daughter (N=2), brother, spouse & daughter, aunt & uncle, father
Mrs. Sardjoe	
Ms. Silva	
Mrs. Lewandowska	Ethnicity: Dutch-Moroccan (N=5), Dutch - Surinam (N=6), Dutch - Chinese, Lebanese, Polish, Ghanain, Congolese, Aruban, Curaçaoan
Mr. Maduro	
Mrs. Ndongo	
Mr. Autor	Occupation: bus driver, unemployed (N=10), retired (N= 5), care worker (N= 2), social worker, designer, student
Mrs. Leito	
Mrs. Mahabier	
Mr. Beduwaa	Religion: Islam (N=9), Catholic (N=7), Evangelic (N=3), atheist (N=2)
Mrs. Jacobs	
Mrs. Constanica	
Mrs. Juliana	

Data collection

Data collection took place between the end of 2019 and the end of 2022 and followed an iterative process that started with informal group conversations (Green & Thorogood, 2018) with three groups of 8–12 carers (N = 32) not included in the sample illustrated in Table 1. Participant recruitment started by contacting via e-mail and telephone civil society organizations that focus on providing support to informal carers, care recipients with an ABI, or migrant groups. Organizations were chosen based on a mapping of all existing care and welfare organizations within the larger Amsterdam area and the existing network of the authors and the community of practice. Additionally, visits were conducted in person at community centers in Amsterdam, several churches, as well as art-based community projects. In three organizations—a Ghanaian church, an organization supporting domestic violence survivors, and an organization supporting Moroccan older persons—informal conversations were possible with carers. Carers who were present at these organizations were willing to discuss their experiences on the spot but were not willing to take part in a formal interview. The summaries of these informal group conversations were written in fieldnotes and used to substantiate the data analysis.

Semi-structured interviews were conducted with carers (N = 21; Table 1). Recruitment was conducted after the informal conversations, and additional care and welfare organizations outside the larger Amsterdam area were approached. Finally, snowball sampling took place. An interview guide was developed in which the everyday experiences of carers within care networks were the point of departure, starting with the open question: “*Would you mind describing your experiences in caring for [name of care recipient]?*” Questions that framed social categories as separate were avoided (Bowleg, 2021), and instead there was a focus on broader queries. Only when relevant dimensions of diversity emerged was a follow-up question asked about this specific topic, for example, when a carer explained the difficulties in communication between herself and a professional based on language barriers and how she did not feel that her concerns were being heard. Follow-up questions regarding this language barrier and these concerns were asked, like: “*What language did you grow up with? Do you also speak other languages? Are there words or expressions in your own language for your concern? What are those? How would you explain your concern to other, for instance, family or friends?*”

Subsequently, three dialogue sessions were conducted with seven carers to discuss the preliminary analysis of the interviews with additional carers (West et al., 2022) recruited in the same way as the interviewees. The dialogue sessions were used to contextualize the data and strengthen our understanding and interpretation of the data (Groot et al., 2022). Two main topics that emerged from the preliminary analysis of the interviews were part of the dialogue sessions, namely: power dynamics in care networks based on intersecting dimensions of diversity and perceived carer support, focusing on social injustice.

Analysis

The data from the interviews and dialogue sessions were subject to an intersectionality-informed analysis (Stuij et al., 2020). The following steps were taken, including (1) exploring the social categories participants assign to themselves (e.g., when participants mentioned their religious beliefs or sexual orientation in relation to their carer experiences, the specific social categories were coded); (2) linking the social categories to the stories told by the participants; (3) determining the relevant intersections of social categories based on power structures and aspects of social (in)justice; (4) contextualizing the experiences in care networks by analyzing aspects of the socio-cultural, historical, and political context; and (5) creating vignettes to show the interaction of social identity and the context in the experiences of carers in care networks. The vignettes provide insight into the importance of the intersections found in the individual stories to produce a contextualized story.

A community of practice (CoP) was then involved in additional participatory analysis. The CoP consisted of care recipients with an ABI, carers, and professionals (N = 8) and ran parallel

to a larger study aiming to ensure input from representatives affected by this study to create reciprocal learning (Abma et al., 2017; Dedding et al., 2022). By their engagement in the analysis, our results were deepened and strengthened by their perspectives with respect to all forms of knowledge to ensure that the dominant logic that upheld inequalities was not reproduced (Groot et al., 2022). Six meetings were held with the CoP, which were guided by creative hermeneutics (Cardiff & van Lieshout, 2014; Lieshout & Cardiff, 2011). The first meeting included an analysis of diverse cases, aiming to discuss relevant intersections of dimensions of diversity; the second meeting included a presentation of diverse carer groups seen in daily practice and how experiences could be explained from an intersectional perspective; the third meeting was devoted to the concept of intersectionality with regard to participants' own positionality; the fourth meeting involved a group discussion and critical reflection of the group around which and whose perspectives might be missing; finally, the fifth and sixth meetings focused on analysis and discussion of the main themes from the interviews and dialogue sessions.

Ethical considerations

Ethical approval was granted by the Medical Ethics Review Committee of VU University Medical Centre, project number 2017.395. Prior to data collection, verbal consent (informal conversations) or written consent (interviews and dialogue sessions) was provided by all participants. Participants who explicitly indicated that they chose to provide verbal consent and participate only in an informal conversation seemed distrustful of formal procedures and hesitated to sign documents. Salad et al. (2015) explained that it can be common within minority groups on a community level to decline written consent. To increase credibility, data triangulation between the three methods of data collection was used to elicit rich data from different stakeholders' perspectives. For the interviews and dialogue sessions, member checks were carried out, after which two carers provided additional information.

To ensure rigor and establish trustworthiness, a preliminary analysis of the interviews was conducted in close collaboration with a 'critical friend' and co-authors to ensure research triangulation and reflexivity (e.g., Van Wees et al., 2023). A *critical friend* was invited in the analysis because none of the authors had a background in migration, and as this could result in shortcomings in the analysis, we welcomed the critical perspective of someone who could provide insights invisible to the author team. The critical friend identified as bicultural and came from the existing network of the authors with an affinity to engage in research. A reflexivity or positionality statement in and of itself may reproduce racialized power relations, giving the White researcher a legitimizing validity method (Gani & Khan, 2024). However, the assumptions that the researcher's identity has more legitimacy through proximity (migration background) to research participants, like by 'ethnic matching' in interviewing, has also been dismantled

(Ahmed, 2019). With the support of a critical friend, we aimed for critical discussions during the analysis, introspective intentionality, and action that enriched understanding from insights from the critical friend's perspective (Gani & Khan, 2024; Kapinga et al., 2022). As a research team, we understood that our own positionality would influence the conducted research, so a critical reflexive approach was adopted (Lazard & McAvoy, 2020; Verdonk, 2015)

Results

The carers' stories started when they became a carer and the realization they would need to continue being a carer for as long as needed, which stemmed from the carers' stories in general (Kokorelias et al., 2020). Becoming a carer in the Dutch healthcare system sounded daunting, as carers must deal with many different professionals because of the complexity of an ABI. This taxing experience was accompanied by uncertainties about what would happen and fear, grief, and difficulties in accepting that their lives had changed forever. The experiences of the group of carers in this study were amplified by not feeling heard and not taken seriously within the Dutch healthcare system, where they were constantly "reduced" to the category of being a migrant.

Our intersectional analysis of carers' stories showed that Dutch carer experiences in care networks are influenced by underlying intersecting dimensions of diversity as well as contextual factors. When we analyzed carer stories through an intersectional lens, it became apparent that the experiences were multi-layered and associated with a normativity of professionals setting the norm for how carers with a migration background are expected to act within the provision of care and a lack of diversity-responsive care within care organizations. The carer experiences could be divided into three layers: (1) *I need to keep going*, focusing on carers' personal experiences and how experiences were related to their own social positioning; (2) *the struggle of caring together*, showing how expectations of family members towards carers added to carer burden; and (3) *trust is a balancing act*, centering on how the support of professionals shaped carers' experiences in which trusting professional support proved challenging, and how this was influenced by contextual factors on organizational and policy levels.

We noted that layers continuously interacted with each other while shaping carer experiences that impacted the carers' health and perceived wellbeing. Layers were introduced with a composite vignette, which will be explained through an intersectional lens; we then elaborate on our findings and discuss their relation to the literature.

I need to keep going

"We had a very traditional family in which my husband had two jobs as the head of the family,

and I took care of our children and home. It was because of religious reasons that the man provides for the household, but also for financial reasons we needed the two jobs. Now that my husband has suffered a stroke, he is unable to work, and our family is in a very difficult financial situation." (Mrs. Mahabier)

This quotation shows that an intersection of religion and traditional gender roles negatively influenced the everyday life of Mrs. Mahabier and her family. The already difficult financial situation of the family was aggravated after the ABI, and she had to transition from being unemployed to being employed simultaneously as she had to come to terms with the fact that she had become a carer. This created a negative spiral of stress that made it difficult to keep going and care for herself, her husband, and her children. When we considered all of the participants, it became apparent that the carers' social positioning—as people with a migration background—had already caused difficulties in their lives. After becoming a carer for a person with an ABI, life becomes even more difficult, thus a 'double difficulty' is often experienced.

The story of Mrs. Mahabier was similar to those of other carers who were unemployed, and it showed how the difficulties of combining work and care resulted in financial worries. However, this may not be specific to carers with a migration background, as a study found that becoming a carer often negatively influences carers' financial situation (Bussemaker, 2022). However, at the intersection with migration background, financial worries were not solely related to additional healthcare. Retired carer Mrs. Ouazanni moved from Aruba to the Netherlands to provide care for her son who had suffered a brain injury after migrating to the Netherlands for his studies: *"In Aruba, my pension was sufficient, but in the Netherlands, everything is more expensive. I had to sell my house in Aruba, which is giving me sleepless nights. I temporarily moved in with my son, but he was instantly cut off from his welfare. They [the municipality] claimed it was not temporary because they went through the drawers, through my underwear, and claimed I lived there ... so humiliating."* In informal conversations, 10 carers shared that they often encountered difficulties which they related to distrust by professionals because they were not Dutch. For example, they relied on care from different departments of the municipality which, the carers explained, was difficult to navigate especially when different policies contradicted each other. Most of them relied on social benefits that were reduced after they had received financial compensation for their travel expenses as carer. Mr. Yildirim used his small pension; he did not have the possibility of building a full pension to cover the daily expenses as well as the additional costs for professional care for his son due to his migrating to the Netherlands halfway during his working life. The welfare his son had received since his ABI was only sufficient for rent and health insurance. He added that although he himself suffered from financial stress, he felt obligated towards his son.

Carers, specifically carers who identified as Muslim, mentioned that their religion helped them, as it provided them with the strength to keep going: *"Being Muslim, whether you are from Surinam, Morocco or, for example, Turkey, provides us with the strength to deal with everything that is necessary as a carer"* (Mr. Faya). For some carers, their religion provided guidance for accepting their new situation: *"When the faith in your heart is very strong, then you should be patient with everything you experience in life"* (Mr. Emaleh). However, at the intersection of religion and culture, ambiguity was apparent as well, as some carers mentioned that religious beliefs may also be a source of shame within their cultural group: *"The shame of having a daughter with a brain injury is great, and there is not always room to talk about that within our religious beliefs"* (Mr. Maduro). He explained that he once asked the Imam why he was given a child with a brain injury and had been shocked by the answer that he should be happy with the three children that he has and that he would find the strength to care for his daughter.

The relationship between carers and care recipients influences carers' experiences, in which the choice of whether or not to perform certain tasks is placed at the intersection of culture, gender, and family relations. Mrs. Metha was caring for her brother, and she described how, in Hindu culture, you have an obligation to care for your family, but there are limits to what she could provide: *"I have been a nurse for 15 years and have changed so many diapers, but I am unable to do that for my brother; that is not accepted in our culture."* Mrs. Ouazanni also stated that she was not willing to change her son's diapers, but her reason was about "human dignity" in general and did not obviously relate to her culture: *"I am Hindu as well, but for me it has nothing to do with culture. It is about the dignity of my son."* For both carers, their limitations in providing expected care resulted in emotional stress because they had to involve somebody else to provide necessary care.

Mr. El Din provided different insight into how his relationship with the care recipients affected his daily life. He identified his struggles at the intersection of being gay and being a migrant; as he described it, *"I have lost my entire social network since my husband suffered his stroke. This only became evident since the stroke, because before we led very social lives, being gay and all. But when you are unable to attend social gatherings, you are out. Also, we migrated to the Netherlands, so our family is still in Lebanon: They are not around. It is just me and my husband at the moment"* (Mr. El Din).

This first layer reflected the social positioning the carers recognized in their own lives and their openness about already living a difficult life before becoming a carer, which then made their lives even more difficult. Hocking (2021) argued that carers make occupational choices in ways that allow them to maintain a sense of identity acceptable and satisfying to them. The question arises whether that is relevant to carers who do not feel they have a choice but can only focus on moving forward, one day at a time. The endurance carers need to practice to

keep going is evident in informal care research. Studies have shown that becoming a carer is a challenging task, both emotionally and physically, although they often also report positive experiences (Mackenzie & Greenwood, 2012; Sullivan & Miller, 2015). The carers in this study did not express positive experiences even when explicitly asked, which might come from the difficult social position they were already in before becoming a carer. Stenberg and Hjelm (2023) described that the contradiction between the experienced cultural obligation and the preparedness to provide care may lead to carer burden; consequently, carers with a migration background may experience a triple burden of “cultural, social, and often practical barriers” (p. 3). This should be taken into account by other stakeholders within collaborative care networks, as this greatly impacts the way carers with a migration background take part in collaborations.

Additionally, this first layer was overwhelmingly defined by financial worries in relation to caring responsibilities. A recent study revealed that carers in the Netherlands have additional expenses related to their caring responsibilities which put more and more carers in financially difficult situations (Bussemaker et al., 2022). Carers who live in difficult financial situations experience more stress (Grant & Graven, 2018; Lam et al., 2022). Additionally, carers who combine informal care with employment may experience a ‘double burden,’ which often causes severe mental and physical pressure on carers (Detaille et al., 2020). Carers often cope negatively with the experienced burden and stress by placing their own health in second place, which has also been related to care avoidance regarding their own health issues (Cottagiri & Sykes, 2019). This was also the case for the carers with a migration background. Additionally, our carers attributed their financial difficulties specifically to having migrated. For example, as they needed to sell their houses in their country of origin, their financial situation was not prepared for the expenses of the Netherlands and having their pensions cut because they only migrated here halfway into their working life. Another example was when carers applied for social benefits, they were confronted with cuts in benefits because of distrust of council officers of the municipality departments when applying for set benefits. Distrust by the Dutch government in its citizens came to a head in 2014 in the Fraud Act, which encompasses a variety of welfare schemes such as pensions and social benefits. Fraud Act monitoring has been deemed discriminatory by some, as citizens with a migration status and low income were flagged as major risks of fraud (Fenger & Simonse, 2024). We recognized that financial worries not only originated in individual life choices but were also affected by systemic structures and greatly impacted the ability of carers to keep going.

The struggle of caring together

“In the past, families would take care of each other, but that is changing. The world is changing, and everyone is supposed to take care of him- or her-self. When people are willing to help, there can be a quid pro quo for money, and I have no help from my family members. But the main

idea still in organizations here in the Netherlands is that “those foreigners” have family that will provide all the support needed”. (Mrs. Sadik)

This statement was inspired by an encounter between Mrs. Sadik and a professional: With a migration background, she noticed that professionals tended to assume she had a large family to fall back on and share the needed care. Our intersectional analysis revealed a more nuanced reality about how care shared within families is experienced as a struggle, in which reciprocity is a challenge rather than a relief of the burden of care. This experience was echoed by all the other carers in this study. They expressed that the struggle of sharing care with family members increased stress and carer burden. Professional support was not provided partly based on professionals’ assumptions that support was provided by the families of migrant carers even when support was not being provided within carers’ own social environment. The carers felt they were not taken seriously, and that there was no place for their experiences or knowledge.

When the carers’ children were older, generations and biculturality became a relevant intersection. These carers stated that, unlike themselves, their children grew up in the Netherlands and adhered to an individualistic view on life. This meant that, for the carers, they did not want to burden their children: *“We have two children who both have their own families and jobs. I do not want to burden them and ask them to help me with my caring responsibilities, and even though I have brothers and sisters, I am the only one who cares for our brother”* (Mrs. Metha). Additionally, the carers recognized that the possibilities to pitch in might be limited, as their children lived on the other side of the country, and *“because we migrated to the Netherlands, they do not feel connected to the place that we live, so they easily moved away”* (Mr. Chitrit). Carer loneliness, which was expressed by almost all the carers in this study, was evident and contradicted the assumption of professionals that carers with a migration background always rely on the assumed basic cultural value—*you take care of your family*. For most carers, the reason to care stemmed from this value; however, this often did not apply to their own support needs. Mrs. Metha explained that this might be because of generational differences: Because she is of an older generation, she upheld the more traditional cultural values, which were different from her children’s. Mr. Maduro migrated to the Netherlands without his extended family but moved to an area where other people from Surinam lived: *“Luckily the older generation felt responsible to take care of us.”* This shows that intergenerational care might also positively affect carers’ experiences.

Carer stories about sharing care within the extended family revealed an (inter)dependency within the role of families with high—and gendered—expectations, revealing the intersection of family (including in-laws), gender, and religion’s influence on carers’ daily lives: *“We have a big family, especially my family-in-law. They come over all the time, and when they do, they expect to*

be taken care of; that's just the way it is in our culture. Since my husband had a car accident, this did not change. I got burdened by this so much that I had to shut the door on my family. They did not provide support: They only expected me to take care of them" (Mrs. Sadik). Being a daughter-in-law put a lot of strain on Mrs. Sadik, and there were traditional gender roles to adhere to in her situation. Additionally, she also explained that gendered caring responsibilities stemmed from an intersection of culture and religion: *"From a cultural perspective, everyone comes, has dinner, stays the night. Religion teaches us that the bond between family is unbreakable, and that you go and ask what people need if they need help."* Mrs. Leito, who also migrated like Mrs. Sadik to the Netherlands, explained that she adhered more to Dutch cultural values, which provided the legitimacy to say "enough is enough," and predominantly took care of herself instead of her entire extended family: *"But it still hurts because I remember very well that my mother was upset with me when I drew the line in our family."* As the carers themselves got older, they became more open to asking for help, sharing the burden of care within the family. This stemmed from their own worries about who will care for the care recipient when they are gone or unable to provide care due to an illness of their own.

Loneliness was also mentioned by carers whose social network outside the family was severely influenced when they became a carer. Mr. Chitrit explained: *"I do not have a large social group who supports me; I have one friend with whom I share everything, my happiness and sorrows, secrets and thoughts ... [it] is enough. Although I am married, I feel lonely sometimes, but when I am happy, I am able to share my life and caring experiences in general with my close friend, because that is not something you would share with your spouse."* Some carers felt compelled, due to a lack of social support, to confide in strangers on the Internet, who became close friends: *"There you find carers just like you, which is necessary because family and friends do not understand what you feel or what you need. So, this is a tremendous support"* (Mrs. Sadik). They also explained they had not found like-minded carers within the healthcare system or support options from the municipality: *"I finally had the courage to go to a carer support meeting, but I only went once. Everyone was really nice, but they were all retired carers and I need to care for my own children, my husband, our home, and finances"* (Mrs. Juliana). She also explained there was no room to ask questions because her questions were not relevant for the entire group. Thus, space for diverse carer support needs should be created, otherwise some carers will go without support.

In this second layer, carers expressed a deep sense of loneliness at the community level, as they did not feel supported by family and friends. This was contradictory to the assumptions of professionals and caused awkwardness within collaborations where carers were not recognized as *legitimate knowers*, a form of epistemic injustice in which the carers' experiences are not seen as valid (Fricker, 2007). The carers struggled with fulfilling the demands of the different generations in their family, including caring for their children, in combination with

their carer responsibilities. A sense of not "doing right" by anyone prevailed. Studies on the so-called sandwich generation have shown that being caught in this sandwich of care can be emotional, expensive, and even exhausting (Lei et al., 2023; Manor, 2021; Steiner & Fletcher, 2017). Although many carers described a large family, whom professionals assumed could share the care responsibilities, it turned out that carers had many additional responsibilities that involved caring for that large extended family, as well. For daughters or daughters-in-law, it appeared that the assumed cultural values of caring for each other did not always apply in the carer's situation. This gendered caring can put significant strain on carers to comply with their responsibilities within their own family as well as in their family-in-law (del Pino-Casado et al., 2012; del Río-Lozano et al., 2013; Tannenbaum et al., 2016). This is especially worrisome in light of Williams et al.'s (2017) findings, which showed that women experienced more physical health issues when providing informal care. This layer also suggests an obligation of care organizations and policymakers have to create space for individual carer support needs. Carer loneliness increased when they did not feel like they belonged within existing carer support systems because there was no space for their specific situation.

Trust is a balancing act

"I am not asking the impossible: I found out that it is normal to have a yearly check-up after a stroke, and when I asked why my son is not receiving that, the doctor just looked at me like, "What are you complaining about? For him that's not necessary." I just think, "well, I do not have money, so apparently, I do not have the right to a yearly check-up." When we first entered the roller-coaster of having a brain injury, I fully trusted the professionals with the expectation that they would do what's best. Now over 5 years, trust has turned into distrust, and we still have a lot of issues". (Mrs. Sardjoe)

Mrs. Sardjoe explained that where she comes from, direct payment for care is necessary when you cannot pay, and you will not receive care. It took her awhile to realize that in the Netherlands she has health insurance, which made her realize, *"I was just not taken seriously as a migrant with my questions. I often have the feeling that my questions take up too much time or are deemed unnecessary, and as I am asking about things that are apparently common knowledge for the Dutch, they [the professionals] often stand up in the middle of my questions to escort me to the door"* (Mrs. Sardjoe). This quotation illustrates how the intersection of being a migrant with a difficult financial situation fueled the perception of Mrs. Sardjoe that she does not belong in the Dutch healthcare system. Additionally, it showed her unfamiliarity with the Dutch healthcare system and her dissatisfaction that there was no time to tell her entire story, and both factors contributed to the development of her distrust towards professionals.

Per the interviews as a whole, the carers mainly expressed frustration when speaking about their experiences of collaborating with professionals. Some carers discussed their inability to trust

the care provided by professionals, and some carers wondered whether they were considered “unworthy” of receiving care. Both issues created a difficult starting point for collaboration in care networks. Our intersectional analysis revealed how the carers felt powerless when sharing care with professionals, and that unjust situations arose when the carers did not feel heard.

The carers felt a need to keep an eye on professionals, and they expected that when, for example, a care plan was made in consultation with them, the professionals would uphold that care plan; yet, especially with regard to religion-specific values, *“we need to constantly check whether or not my daughter is fed halal food, or no alcohol for that matter: That is a big task”* (Mr. Maduro). They felt they could not discuss care that fit with their cultural or religious beliefs with care organizations: *“My brother called me up to say that they [the nurses] wanted to take him to church because it’s Easter, but he does not want to, and they made him go anyway. He’s a Muslim and they do not believe that because he’s from Surinam”* (Mrs. Metha). There was no room for religious or cultural commemorations outside the dominant culture, so Ramadan or Ketu Koti was not widely celebrated. In institutions, the health professionals did not even ask and only reasoned from their own cultural perspectives. In some carers’ experiences, there was not even room for using their own language: *“We were hopeful that [when] another woman from Surinam came to stay in the ward, that meant that my daughter was not the only Hindu anymore and [she would] be less lonely. Well, they hit it off immediately, but in the next care meeting we, as a family, got reprimanded. The team explained that they were talking in their own language, which bothered the other residents, and, if I would be so kind to ask her to speak only Dutch”* (Mrs. Mahabier). For the carers, it was difficult to watch the effect this had on the care recipients, and they described a feeling of powerlessness.

Several carers provided examples of discriminatory actions of professionals during their caring experiences. Mrs. Sardjoe’s son was living in a care facility, and she told a story that highlighted the disregard for her son and the danger of stereotypical assumptions: *“My son is wheelchair-bound because of his ABI. A group of residents was wheeled outside to enjoy the nice weather, and my son was placed in the only completely sunny place around the table. Being from Morocco, we can take the heat pretty well; however, we enjoy the heat most often in the shade. He got such a bad sunburn that he had blisters on his skin. When I complained about this situation, the response I got was that they assumed he was unable to get a sunburn based on his skin color. No apology or promise that it would not happen again followed”* (Mrs. Sardjoe). Mrs. Lewandowski explained that her husband was being reduced to a “single category” and not seen as a person, which had a dehumanizing effect and deeply influenced her wellbeing: *“My husband is the only person of color on the ward and, for convenience, was often called ‘the black one’ by one of the care workers.”* She explained that this had a negative impact on her husband’s self-esteem and on her trust in the care organization, especially when she was not being taken seriously or not believed when she confronted the team with this. Carers lost trust in professional support in

situations like these, but especially in the process after reporting a negative situation and not being taken seriously.

When all the above-mentioned situations were brought to the attention of care management, it became clear, according to the carers, that the professionals protected each other by saying that their colleague probably did not mean it, which made it even more painful for the carers involved. They often felt they were not being heard: *“Our concerns are not heard, and the doors close quickly”* (Mrs. Sadik). Not being heard by care management or involved professionals contributed to the perception of unequal access to healthcare. The carers explained how this was amplified by a lack of diversity lenses in organizational policies: *“When I worked as a nurse, we had protocols for everything as a guide for how to handle certain situations; you would imagine that there would be such a protocol for discriminatory actions”* (Mrs. Sardjoe). The great dependency on professionals triggered in the carers a feeling of running into a wall and created an obvious sense of insecurity. The power structures underlying this dependency provided the conditions for injustice in the provided healthcare, as professionals could neglect to listen or act upon a request or complaint. An unequal situation emerged because of the lack of faith in there being room to discuss discrimination, according to carers. Rather than a means of support, sharing care with professionals felt like a burden to the carers in this study. In one extreme example, a carer’s frustrations ran so high they took it out on the care recipient in an abusive way. The carer in question explained that her misuse of power with her care recipient stemmed from the carer’s position of helplessness; this is never justified, but it can happen when feeling overburdened takes center stage.

Regarding the level of sharing care with professionals, the carers expressed frustration and described a lack of trust felt towards professionals. This lack of trust emerged over time with the realization that they and their care recipients were subject to a process of *Othering* and, in particular, when there was no space for practicing cultural or religious beliefs. ‘White ignorance’ may explain the processes shared in these stories of experiences, as most often carers encountered professionals who belonged to the majority White group in the Netherlands. *White ignorance* manifests when White people do not know something and in particular are unaware of not knowing because of their position in society (Mills, 2015); it may exist in many different forms, including the “absence of belief” where, for example, first-hand knowledge from victims of racism is not seen as a source of evidence, which again questions the victims’ legitimacy as knower (Bain, 2023). Othering is powered by processes of racialization, and within carers, experiences of racialization can be overt when professionals make choices, based on their position of power within care networks (Akbulut & Razum, 2022), that deny care recipients or carers specific activities or opinions based on their cultural or religious beliefs. However, discrimination within care networks is more covert and not directly visible when a comparison between people or groups takes place. Ahlberg et al. (2019) argued, that is instrumental to make

it overtly visible in healthcare as discrimination is the critical determinant of health inequalities. For carers, experienced racialization can be an 'energy draining device' (Ahmed, 2019) that results in carer burden in their everyday lives and can even result in the reduced wellbeing of care recipients if the burden becomes too high to provide necessary care.

The carers' lack of trust was magnified by the fact that, when concerns were expressed, they did not feel heard, and their concerns were diminished into something irrelevant. This form of *testimonial injustice* can be seen within the one-on-one relationships between carers and professionals, but it was also visible at organizational levels when complaints were dismissed by care management, when the benefits of carers were reduced by a lack of coordination between departments of the municipality, or, for example, by the lack of existing policies regarding diversity-responsive care. Tronto (2010) argued that caring institutions have the responsibility to acknowledge problems that must be taken care of. When tensions arise because some are heard and *others* are not, the concept of 'privileged irresponsibility' may help explain destructive underlying processes (Van Nistelrooij & Visse, 2019). *Privileged irresponsibility* means that the needs of the *other* are ignored or denied when professionals might not recognize the needs because they themselves are exempt by their privilege from considering these needs. In care networks, this requires challenging the taken-for-granted social position of privilege of a majority group of professionals, as this majority group fails to acknowledge the exercise of power, thus maintaining—and reproducing—their taken-for-granted positions of privilege (Zembylas et al., 2014). Unconscious bias might be underlying, but in reality, a gap in the provision of healthcare is created, and professionals are responsible to identify this. Finally, feeling silenced had a major impact on the health and wellbeing of carers in this study, which could in extreme situations derail informal care in ways that harmed both care recipients and carers (Isham et al., 2020), and, possibly, also the professionals.

Discussion

To overcome social and epistemic injustice in care practice, this study has identified a need to move beyond cultural limitations towards adopting a broader diversity-sensitive scope. The essentialization of culture—or even pathologizing culture—as the only explanation is not enough to understand reality. Additionally, there is a need to move beyond sensitivity to an awareness of differences and similarities between people without assigning a value to them. It is important to create space for responsiveness (Muntinga et al., 2016), where there is room for adaptation to a specific situation in which knowledge is adapted. This probably necessitates creating space for carers with a migration background and giving them opportunities to introduce their own frames of references into care networks and express their knowledge and support needs.

Our intersectional analysis resulted in three different layers that showed there is a need for diversity-responsive carer support in which open dialogue about expectations, needs, and wishes is essential, in which the carer can be an equal partner in the conversation and where healthcare professionals show reflexivity towards care provision within these care networks. However, we are well aware of the dilemma of categorizing carers into groups for research purposes while, on the other hand, trying to make a case against categorization into groups. Thus, we tried to focus on providing insight into within-group differences. In showing how the group of carers with a migration background had heterogeneous experiences (although some might adhere to similar social categories), we hoped to clarify that recognizing carers' contexts is vital, as this approach is underrepresented in mainstream research. Additionally, since ours was a qualitative study, the main limitation is that the findings are not widely generalizable and applicable to other groups of carers with a migration background. Yet, the 'thick description' of the studied context enables readers to transfer our findings from the studied context to their own in some cases. In 'naturalistic generalization' (Abma & Stake, 2014), if one were to transfer lessons learned from this study of the practice of social categories of carers, the specifics of the context as well as critical reflection on one's own positionality should be considered.

Intersections of aspects of diversity discussed in the results were assigned and recognized by the carers themselves and reflected the lived experiences of carers with a migration background. Critiques on intersectional analysis include that social positioning is often assigned by researchers (Aldrin Salskov, 2020; Davis, 2020), which undermines the original intentions of an intersectional approach to illuminate discriminatory situations (see Crenshaw in Lutz et al., 2016). The intersectionality approach enabled the coloring-in of themes with a deeper layer of power visible in socially unjust situations in collaborative care networks. Discriminatory practices were experienced by carers in collaboration with professionals in extramural care or institutionalized within care organizations or governmental regulations and manifested in experienced loneliness due to social isolation in care responsibilities and high carer burden.

The use of intersectionality in combination with the concept of epistemic (in)justice as an analytical framework was a strength of this work. It revealed the influence of intersecting aspects of diversity (Stuij et al., 2020) by uncovering in-depth insights in the power of knowledge within care networks influenced by Othering and epistemic injustice. Sebring (2021) argues that these practical insights are particularly useful in transforming health care systems where lived experiences are seen as legitimate. Our results show that for minoritized care recipients, and their cares, this is often not a realistic expectation as their lived experiences are not seen as valid. Brown et al. (2023) show that racialized care recipients are not being believed and are often not taken seriously and their lived experiences are not taken as a starting point for changing health care but in minoritized care recipients are requested to embrace white normativity and with that disregard their own lived experiences (Brown et al., 2023). Not being

heard is also mentioned in studies focusing on carers without a migration background (e.g. Bussemaker et al., 2022), but Lagewaard (2021) argues that the social position of people with a migration background aggravates processes of epistemic injustice and may lead to deep disagreement between individuals.

Healthcare organizations should therefore facilitate dialogue between professionals regarding assumptions about carers and care recipients and should also focus on creating safe spaces for carers to speak their minds. Brown et al. (2023) additionally argue for explicitly guiding minoritized care recipients within dialogue processes as lack of trust may stand in the way of their ability to participate in dialogue. Our results might also encourage and challenge organizations and professionals to answer questions like “for which group(s) is our help or support accessible? And would this exclude groups with different needs?” Sometimes making room for diversity requires letting go of protocols or rules that create unequal outcomes or inequities. We recommend going a step further by also explicitly addressing discrimination and racism within care organizations and by healthcare providers in community healthcare.

Evidence of discrimination within the Dutch healthcare system exists, although the related research did not focus on the experiences of carers (Badou et al., 2023). Experiences of racism within healthcare contexts relate to unmet needs, loss of trust in healthcare professionals, and delays in seeking healthcare (Hamed et al., 2022). Explicitly addressing racism is necessary even in the Netherlands—one of the first European member states to pass anti-discrimination laws reinforced since 1994 (Agyemang et al., 2007). However, although racism exists within the Dutch public space, it only recently gained recognition in formal conversations to address structural forms of racism (Ghorashi, 2023). Interventions like anti-racism training may perhaps result in a better understanding of racism in healthcare contexts (Hamed et al., 2022), although more knowledge is needed about interventions' impacts. Also, future informal care research should focus on the Dutch healthcare system to better capture the contextual nature of racism (Pattillo et al., 2023).

On a policy level, it would make sense to explore which groups are not yet being reached, and how that can be changed, using the intersectionality-based policy analysis framework developed by Hankivsky (2020). In organizations, how can leaders make room for different views and unmet needs in provided care? By questioning each other and challenging policies on these issues, organizational stakeholders can discuss how best to match the situations and wishes of people within a specific care system, in which, of course, those seeking care and the informal caregivers themselves remain the people who know best how to meet their needs. It would be beneficial to focus further research on the perspectives of care recipients with a migration background to uncover their experiences in the collaboration within care networks.

It is therefore of vital importance to not assume that people with a migration background are “hard to reach” but instead to reflect on how the chosen methodology and the social position of researcher often creates an us-versus-them binary that can impede contact (Abma, 2019).

Conclusion

Within care networks, the carers with a migration background in this study were often confronted with *Othering*, which is fueled by racialization. When brought to the attention of professionals or care management, *testimonial injustice* occurred, creating a space where migrant carers did not feel heard and lost trust in care organizations. Additionally, the carers felt confronted with a misfit between care provision and the needs of carers, as well as a lack of flexibility in regulations and by those applying them to meet needs. Migrant carers should not be essentialized to their migration background or to the cultural group with which they identify. The three layers of carer experiences presented in this study publicize the need to gain a diversity-responsive, nuanced, and contextualized understanding of carer needs within care networks. These three layers also highlight the need to proactively gain additional insight into carers' and care recipients' frames of reference regarding provided care. We urge care organizations to put diversity-responsive policies into practice to ensure that healthcare focuses on critical reflexive practices, to understand the epistemic injustices that might occur within care networks, to create communicative spaces within organizations where carers with a migration background feel heard and are given opportunities to meaningfully participate in the care necessary for care recipients.

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Intermezzo

Being an occupational therapist myself

As an occupational therapist, I have worked with clients with acquired brain injury in several settings. One day, I was called into the office of my boss. He asked me to explain why I had not completed my required number of home visit hours. I explained that I had two families on my caseload that needed more time, which meant that I would be able to visit fewer families that week. My boss asked me to explain why I thought these families needed more time. I began talking about a family that had just been placed in our municipality after spending years in an asylum centre. This family had multiple care needs, including a child with cerebral palsy and a father who had suffered a stroke, and they needed some peace and quiet to settle in their own home. The first time I visited their home, conversation was minimal; the family was acclimating, and I was offered tea, then I had to rush to my next appointment. So, I decided to clear my schedule to visit them shortly thereafter. The conversation with my boss ended with him saying that this was not a valid reason to take more time, which left me confused and angry

When working in primary care, I hardly had any contact with carers. They were there in the background and made things possible, but they were not seen as part of the rehabilitation process, as I now think they should be. I did not ask any questions about it then: It was just how things were done. The same was true for clients and carers with a migration background: They were largely absent from my practice, or to be honest, they were invisible in it. This ties in with a comment made by many professionals, “We don’t see them [care recipients and their carers with a migration background] in our practice” or “I think you only see them in other neighbourhoods or cities”. These questions make me wonder why this is the case and what our professional responsibility is.

Being an occupational therapist myself also presented a barrier to reaching participants, which was something I was not prepared for before starting this research. During a group conversation, I was confronted with negative comments, with some carers explicitly stating that they did not want to participate in a follow-up interview, because they did not want to tell their story again to a professional who did not understand them. An uncomfortable feeling crept up on me. I wonder: How can I

understand carers if I have never been one? How can I talk about migration experiences if I have not experienced them myself? How can I challenge a system that I am part of as a professional? Building trust with participants was not quick or easy. Many carers were understandably hesitant to talk with me, a researcher from the healthcare system they distrusted. Some saw me as someone from the medical world who represented professionals, which gave me “authority” in various ways. Over time, through informal conversations, community connections and a lot of listening, that trust began to grow.

Chapter 6

Deconstructing the Self-Other binary in care networks by unravelling professional' perspectives through an intersectional lens

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Abstract

In many western countries informal care is conceived as the answer to the increasing care demand. Little is known how formal and informal caregivers collaborate in the context of an diverse ageing population. The aim of this study was to gain insight in how professionals' perspectives regarding the collaboration with informal carers with a migration background are framed and shaped by intersecting aspects of diversity. We used an intersectionality informed qualitative design with informal conversations (N=12) and semi-structured interviews (N=17) with healthcare professionals working with clients with Acquired Brain Injury. Two critical friends were involved in the analysis which was substantiated by a participatory analysis with a community of practice. We identified four interrelated themes: (a) '*The difficult Other*' in which professionals reflected on carers with a migration background causing 'difficulties'; (b) '*The dependent Other*' refers to professionals' realization that 'difficulties' are intensified by the context in which care takes place; (c) in '*The uncomfortable self*' professionals describe how feelings of insecurities evoked by the Other are associated with an inability to act 'professionally'; and; (d) '*The reflexive self*' shows how some professionals reflect on their own identities and identify their blind spots in collaboration within a care network. These themes demonstrate the tensions, biases and power imbalances between carers and professionals, which may explain some of the existing health disparities perpetuated through care networks.

Introduction

In many western countries the informal carers are considered essential to face the increasing demand of care in an ageing population (Kruse et al., 2021). Informal care refers to carers who in contrast to professional- or formal carers belong to the existing social network of the care recipient, e.g. family, friends and/or neighbors, and provide unpaid care to someone with long-term health and/or welfare needs. The context of this study is the Netherlands, where the numbers of carers has risen to 5.5 million in 2019 due to the changes in health policies by strengthening the focus on the self-reliance of citizens and their social networks (Boer and Plaisier 2020, p.7). Informal care often occurs within larger care networks in which collaboration with different professionals is necessary, referring to care in the home context as well as within institutional settings. In the Netherlands, carers often reside in the inmost layer of these care networks together with the care recipient. Due to rising healthcare costs, an aging society, and austerity measures within the Dutch healthcare system, there is a growing need for informal care (Carlsson, 2023). Even though the provision of informal care can be a positive experience for carers, the hyper-focus on informal care often ignores carers' potential overload and pressure on their labor participation as well as safety risks and lower standards of care (Boer & Plaisier, 2020) Currently, one out of ten feels overburdened (Badou et al., 2023).

The existing literature on the collaboration between professionals and informal carers in diverse networks shows that a 'partnership approach' contributes to quality care within care networks and to the wellbeing of informal carers (Hengelaar et al., 2018). This requires an open dialogue between all actors, about the mutual understanding of expectations and assumptions regarding collaboration, roles and needs. However, such partnerships can be difficult to achieve in practice due to the complex contexts surrounding the collaboration and a lack of awareness about the role that underlying intersecting aspects of diversity play in shaping expectations and assumptions within care networks (Hengelaar et al., 2023). Aspects of diversity such as gender, age, ability, religion, culture, geography, ethnicity, education level, socioeconomic status simultaneously and in interaction shape everyday experiences and further complicate the collaboration between professionals and informal carers in diverse care networks (Choo & Ferree, 2010).

In this study, we focused on professionals' experiences of collaborating with carers who migrated to the Netherlands and act as a proxy for their care recipients with acquired brain injury. Migration to the Netherlands has been shaped by the country's colonial history, economic factors such as labor migration, as well as by political choices and public policies (Manning, 2022). Carers with a migration background cannot be categorized as one homogeneous group and multiple within group difference exist – their backgrounds may be European or from other

continents with differing ethnicities, educational levels may vary as well as for example religious affiliation or income level. They do share higher risks of discrimination in society as well as within health care settings. Our earlier study showed that carers experienced a sense of injustice after experiences of discrimination, leading to unmet needs of care recipients and carers themselves, and a loss of trust in healthcare professionals (Hengelaar et al., 2024). Additionally when zooming in on this collaboration it can be seen that carers with a migration background report lower levels of wellbeing when they are misunderstood within care situations or when they encounter racism within care networks (Paine et al., 2020). According to Shepherd et al. (2019) different studies in the field of public health indicate that particular cultural groups are often underserved, experience negative treatment and/or treatment outcomes (p. 2). There is a need to further understand the contextual nature of this process (Pattillo et al., 2023), as professionals' perspective on their collaboration with carers with a migration background is largely understudied (Hengelaar et al., 2023).

There are indications that these negative experiences and outcomes of the care for people with a migration background and informal carers are related to the context and social position of professionals. Claeys et al. (2021) show, for instance, that professionals take their own frame of reference as a starting point during care planning and often encounter difficulties empathizing with other frames of reference. This might stem from the fact that professionals sometimes experience dealing with diversity as stressful (Carpentier et al., 2008) and often find it easier to provide care to someone who has a similar background (Rønn-Smidt et al., 2020b). Berdai-Chaoui (2020) adds that professionals caring for people with a migration background appear to do so in a rather ethnocentric and essentialist context and are often unaware of the complex reality of care. This results in increased informal care burden and might contribute to ineffective care in care networks (p.8). This phenomenon can be explained by professionals' positionality in that specific care situation, showing the impact of personal and professional identities in a specific situation, based on for example age, gender, and professional training (Windsong, 2018). An analysis of positionality can show how personal and professional identities influence and potentially bias or strengthen their understanding of the collaboration (Rudman, 2018) and provide insight in how unconscious bias might create unfair systems of power in care networks (Paine et al., 2020).

This study aims to explore diverse professional perspectives on and experiences in collaboration with carers with a migration background in care networks around care recipients with acquired brain injury ABI in order to expose aspects of power and injustice in care networks. We deliberately chose to focus on professionals working in care networks around a care recipient with acquired brain injury (ABI) - the leading cause of disability worldwide (Sharma & Lawrence 2014) - because care recipients with ABI require long-term complex care, provided at home where care networks often consist of different professionals (Achilike et al., 2020). This

study is part of a larger research project where the experiences with the collaboration in care networks is central and the perspectives of professionals, informal carers and care recipients are explored. The stories of informal carers and care recipients are of equal importance and will be featured in two different studies. We focus here on the perspectives of professionals. Our study builds further on the notion that the social position of professionals influences the collaboration with informal carers, and aims to explore the experiences of professionals in 'diverse' care networks by explicitly paying attention to how systems of power play a role in these care networks (Aguayo-Romero, 2021).

Theoretical background

To understand professionals' perspectives within diverse care networks, it is essential to gain insight in how their perspectives are framed and shaped by intersecting aspects of diversity as well as situational and contextual factors (Windsong, 2018). Within public health there is a longstanding commitment to understand how individual and structural identities, characteristics and patterns shape health and wellbeing (Merz et al., 2023). Social categories and structures as well as individual identities create the conditions in which people live and influence their health and well-being (Sabik, 2021). An intersectionality approach, originally coined by black feminist legal scholar Kimberley Crenshaw, may offer insight in the interactions between the various aspects of diversity and (dis)advantage in individual lives, social practices, institutional arrangements, cultural ideologies and the outcomes of these interactions in terms of power, social inequities and health disparities (Hankivsky 2014). This study 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) and serves as a critical praxis focusing on (in)equality and social (in)justice in care networks (Merz et al., 2023).

By doing so, intersectionality is understood as challenging health inequalities and structural disadvantages within care networks (Hengelaar et al., 2023; Merz et al., 2023). Inequalities are not merely differences but unfair disparities, and might stem from the process of Othering in which people who are constructed as deviating from a fictitious societal norm are identified as being different, creating an us versus them mentality (Brons, 2015; Leyerzapf et al., 2020). Othering is a process that ascribes inferior characteristics to minority groups and to people deviating from social norms in order to establish and ideology of superiority of majority groups. Othering is identified by Claeys et al. (2021) as a key concept underlying difficult communication and potential conflicts within care networks, especially when care is provided to care recipients with an ethnic minority background. Leyerzapf (2020) shows that the denial of underlying in- and exclusion mechanisms within Dutch health care are linked to white innocence (Wekker,

2016) and white privilege (DiAngelo, 2015). An analysis of processes of Othering requires a critical examination the taken for granted social position of privilege of professionals (Tronto, 2010; Zembylas et al., 2014).

Methodology

In this study an intersectionality informed qualitative design was used (Hancock, 2007; Hankivsky, 2014a; Hunting, 2014). From an epistemological standpoint we recognize that power is relational which shapes perceptions as well as presuppositions which are context based and incorporate time contingency (Hancock, 2019b; Meyer et al., 2013). Using intersectionality as a way of thinking recognizes the interconnectedness of numerous socially constructed identities which collectively shape the lived experiences of individuals and groups (Abrams et al., 2020). Additionally, since the larger research project follows is a Participatory Action Research (PAR), we have taken measures to ensure the inclusion of stakeholders in every step of the research process (Abma et al., 2017), which stems from the epistemological belief that knowledge is embedded in social relationships and is most influential when produced collaboratively (Fine, 2010).

Data collection

Two methods of data collection were used in order to elicit rich data from different perspectives, to ensure rigor and establish trustworthiness. These are visualized in figure 1. Firstly, informal conversations were conducted with professionals in twelve health and/or welfare organizations who support carers. These professionals were social workers, community nurses or community coaches. The purpose of these informal conversations was to: (a) recruit participants for this and other sub-studies; (b) use their expertise to inform the interview guide for the additional interviews, and: (c) substantiate the data analysis and strengthen our understanding and interpretation. Secondly, seventeen semi-structured interviews were conducted with various healthcare professionals.

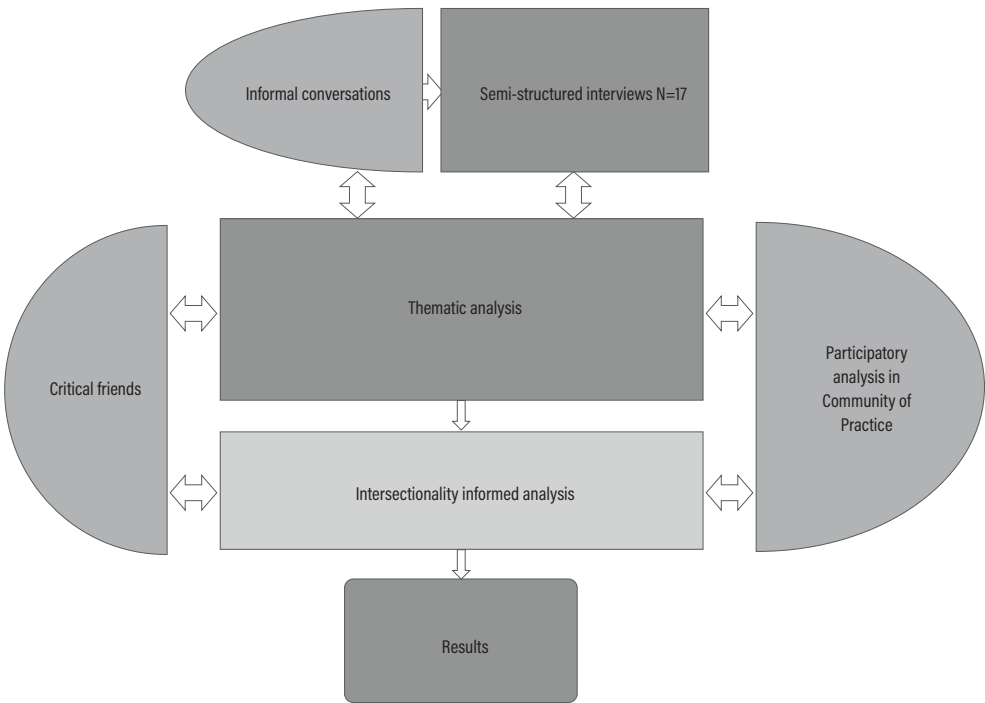


Figure 1. Visualization of data collection and analysis

Everyday experiences of professionals in care networks with carers with a migration background were central in the interview guide and open questions were used, example questions from the interview guides are shown in table 1. Questions that frame social categories as binary or provoke an essentialized understanding of said categories were avoided (Bowleg, 2008).

Table 1. Example interview guide

➤ Can you describe your experiences in collaborating with carers with a migration background? ➤ How are the care responsibilities arranged? ➤ What goes well and what needs to be improved? ➤ What does it mean for you to collaborate with carers with a migration background? ➤ What is important for you in the collaboration with carers with a migration background?
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Sample

Sampling was done purposively to include a diverse set of healthcare professionals working with carers with a background of migration (Green & Thorogood, 2018). From an intersectional perspective this allows thinking beyond existing categories of difference (Hunting 2014, p.8),

meaning that we did not start with predetermined categories of difference within the group healthcare professionals working with carers with a background of migration. As a starting point for sampling we focused on majority Dutch professionals working with carers with a migration background. Recruitment was done via email, telephone and via informal conversations with key figures in healthcare- and carer support organizations, starting with the existing network of the authors after which snowball sampling was used (Green & Thorogood, 2018). For this study, we were particularly interested in the perspective of Dutch majority professionals. During informal conversations it became clear that professionals with a background of migration themselves wanting to share their experiences, they argued that too often they collaborate in care networks with carers with a migration background that is not always similar to their own background, and were therefore included. These collaborative networks provided positive and complex experiences they wished to share, as eloquently described by Ahmad (2022). Therefore, we did invite a diverse group of professionals along-the-way (emergent sampling) (Green & Thorogood, 2018; Hancock, 2007). A description of the characteristics that were identified by the participants as relevant during the interviews is presented in table 2.

Table 2. Intersectional visualization of sample

Participant	Profession	Place of Residence	Ethnicity	Age	Place of work	Gender
I1	Policy Officer	Urban	Dutch	63	Municipality	Woman
I2	Policy Officer	Urban	Dutch	52	Municipality	Woman
I3	Policy Officer	Urban	Dutch	34	Policy Advisory organization on informal care	Man
I4	Community Nurse	Urban	Dutch-Peruvian	36	Care organization also providing home care	Woman
I5	Community Nurse	Urban	Dutch-Surinam	53	Care organization also providing home care	Woman
I6	Community Nurse	Urban	Dutch	46	Care organization also providing home care	Woman
I7	Occupational Therapist	Urban	Dutch	25	Rehabilitation Centre	Woman
I8	Occupational Therapist	Urban	Dutch-Armenian	48	Rehabilitation Centre	Woman
I9	Occupational Therapist	Urban	Dutch-Turkish	41	Nursing Home	Woman
I10	Occupational Therapist	Urban	Dutch	32	Nursing Home	Woman
I11	Occupational Therapist	Urban	Dutch	27	Care organization also providing home care	Woman
I12	Occupational Therapist	Urban	Dutch	46	Primary care practice	Man
I13	Occupational Therapist	Urban	Dutch	38	Primary care practice	Man
I14	Creative Therapist	Urban	Dutch-Surinam	42	Care organization also providing home care	Woman
I15	Social Worker	Urban	Dutch-Afghan	36	Policy Advisory organization on informal care	Woman
I16	Social Worker	Urban	Dutch	47	Rehabilitation Centre	Woman
I17	Director	Urban	Dutch	55	Care organization also providing home care	Man

Analysis

Analysis consisted of a thematic analysis (Clarke & Braun, 2017) and a secondary intersectionality informed analysis (Stuij et al., 2020). Researcher triangulation was a priority to ensure rigor and establish trustworthiness, therefore the analysis was substantiated by the involvement of two critical friends and a participatory analysis in a community of practice (CoP) (see figure 1). Two critical friends were involved during the preliminary analysis (Blake & Gibson, 2021), both of them identified as bicultural, and provided different perspectives as they were able to look from a distance to the data and the analysis, yet also providing additional insights in what it means to have a migration background.

Interview transcripts and fieldnotes from informal conversations were, in constant comparison, subject to a thematic analysis, following the steps of Clarke & Braun (2017). Subsequently, a round of intersectionality-based analysis was performed, which allows for analyzing complexity, the interaction between individual and institutional levels as well as focusing on power structures and social injustices. Based on Stuij et al. (2020), Hunting (2014) and McCall (2005), an intersectional informed coding scheme was developed (see table 3). This intersectional analysis deepens the thematic analysis by zooming in on the social locations participants assign to themselves (Stuij et al., 2020). Within the themes, identified in the thematic analysis, we: (a) searched for social categories participants assigned to themselves; (b) analyzed which intersections of social categories came forward as relevant within the data; (c) focused on processes of social injustice and power structures within the stories of the participants, and finally; (d) searched for aspects of relevance mentioned with regard to the socio-cultural, historical and/ or political context in which the provided care took place, in order to expose aspects of power and injustice in care networks.

Table 3. Intersectionality informed coding scheme (Stuij, et al 2020; Hunting 2014; McCall 2005)

(1) Which social categories do the participants assign to themselves?	e.g. gender, age, disability, family relations, ethnicity, religion, urban/rural, SES, occupation, education level.
(2) Which intersections of social categories come forward as relevant within the data?	linking social categories to the stories told by the participants
(3) Which aspects of social and societal injustice come forward in the data? Which forms of power, power structures, power inequities detected in the interview data?	This can be examples from both justice and injustice. What is used as the norm? Which assumptions, prejudice, norms and values come forward? How does the collaboration take place and can tensions be detected?
(4) Which aspects of the socio-cultural, historical and or political context come forward?	Locally, nationally and of in the country of origin? Which assumptions, prejudice, norms and values come forward?

A Community of Practice (CoP), running parallel to the larger research study, was involved in additional participatory analysis aiming to ensure input from representatives that are impacted by this study (Abma, 2020). The CoP consist of care recipients with an ABI, carers and different

professionals (N=8) with their engagement in the analysis, the results are deepened and strengthened by their perspectives with respect to all forms of knowledge to ensure that dominant logics that uphold inequalities will not be reproduced (Groot et al., 2022). Five meetings were held with the CoP guided by creative hermeneutics (Cardiff & van Lieshout, 2014): (1) a group discussion of relevant themes from the thematic analysis; (2) an unraveling of our own pre-assumptions towards the topics; (3) reflections on the CoP members positions in everyday life; (4) a group discussion about the CoP members perspective on collaboration in care networks, what do they recognize in their daily practice and; (5) mind-mapping the connection between the thematic and intersectional analysis in order to define the final results.

Results

We explored professionals' perspectives on the support of and collaboration with carers with a migration background. The analysis shows that professional perspectives are complex and layered and that underlying social categories influence their daily practice. Four main themes are identified: (1) *'The difficult Other'* which refers to professionals' perspective on the difficulties they encounter within care networks which they attribute to the 'Other'; (2) *'The dependent Other'*, showing professionals' understanding of difficulties as intensified by the care context, resulting in a state of dependency of the Other; (3) *'The uncomfortable self'*, with professionals describing how insecurities evoked by the Other lead to an inability to act 'professionally'; and; (4) *'The reflexive self'* with professionals reflecting on how their personal and professional identities were implied in complex and diverse care networks.

A Self-Other binary becomes visible within the results. In the interviews, we identified a 'Self' presented by professionals either with or without a background of migration and an 'Other' which, according to the participating professionals, represent carers with a migration background and occasionally also the care recipients. The first three themes are based on the stories of Dutch professionals belonging to the white majority. Within these themes it can be seen that the intersection of being Dutch/white and professional becomes problematic when white privilege is not noticed or confronted and opportunity arises to attribute the underlying reasons to the Other. These themes focus on the uncovered aspects of social injustice and/or underlying power inequities within the collaboration. Within the fourth theme relevant intersecting social categories identified by participants themselves become visible and are therefore only explicitly mentioned within this theme.

The difficult Other

When asked about their experiences in collaboration with carers with a migration background, participants presented most carers with a background of migration they come in contact

with as 'complex' or 'difficult' based on 'their' cultural background and identified them as 'the Other'. During the informal conversations professionals recognized great willingness to provide informal care which professionals attributed to the non-Dutch cultural background of carers. Pre-assumptions of professionals about care attitudes in different cultures became visible; a Dutch policy officer for example describes *'with non-western clients that's the way it is in their culture'* (I2) and a Dutch community nurse explained *'there is more a We-culture, family takes care of the support needs'* (I6). Professionals experience this emphasis on family care often as causing difficulties especially within larger families, where it is often unclear to them who is the actual carer providing care and who is the spokesperson. A Dutch policy officer explains that within her care organization, *'it is difficult, especially in Muslim families that there is one person appointed as primary carer who is the contact person with the professionals, and not necessarily the person providing the actual care. Often the father, brother or uncles are the primary spokes persons and the daughters-in law the actual carers'* (I3).

When the division of responsibilities within families is unclear to professionals, miscommunication between professionals and carers may occur, in particular when family members have diverging ideas on caring responsibilities. Professionals attribute this to different levels of acculturation in the Netherlands society. For example a Dutch social worker finds *'dealing with the struggles within the family stressful when carers are not accustomed to the Dutch norms yet'* (I16). Additionally, conflicts between professionals and carers emerged when gender roles within families skewed the division of care responsibilities within families. A Dutch occupational therapist describes an example of a Somalian carer who suffered severe carer burden due to lack of care division of care within the family: *'She has a big family. Her nephews and uncle came by every week to visit the nursing home, but they did nothing. They are not allowed to [based on their cultural background]. Only women from the family are allowed to help'* (I11). Such care division is experienced as difficult when this does not align with professionals own personal values. It is not the particular situation or family, but the generalized culture that is perceived as problematic in these cases.

Furthermore, participants assume that the intersection of ABI with a minoritized cultural background creates a particular vulnerable position for carers in society. Several participants explain how families cope with the invisible consequences of ABI, which proved difficult in some cultural groups. A Dutch care organization director described that *'in some cultural communities there is a lack of knowledge and understanding'* (I17). This lack of knowledge and understanding may result in a lack of acceptance by the community, which in turn leads to social isolation of carers. The social isolation of carers is exacerbated by carers not reaching out to healthcare professionals out of loyalty to the care-recipient. A Dutch occupational therapist experienced that, *'[They] do not want to ask for help as they feel ashamed they are unable to provide the care themselves'* (I12), as there may be a cultural obligation to take care of your family. A community

nurse notices that *'they [carer with a background of migration] never reach out. In all those years working in primary care I only had one carer who came [after discharge] out of her own will to ask for help'* (I6). Again, the cultural difference of carers is perceived as the underlying problem for health professionals to offer support in the home context. On top of that, difficulties are linked to unrealistic expectations of carers towards professionals and care organizations: *'They demand too much'* (I8). Consequently, these 'demands' result sometimes in irritation and feeling annoyed towards carers. A social worker gives an example: *'They expect that we do everything for them, that is just not the way it works here'* (I16). This mismatch impacts the relationship between the professionals and the carers as many participants feel a lack of appreciation by carers and care recipients.

The dependent Other

In the Dutch context of care, a norm of self-reliance and person-centered care exists that assumes that everyone is capable of self-reliance or active control over their care situation. In our informal conversations, professionals recognized that this 'difficult Other' does not readily fit within this existing norm, and that this mismatch may create a 'dependent Other'. Professionals attributed this dependency to health illiteracy of carers of certain cultural groups' and to carers' care attitudes which make it difficult for professionals to adequately support the carers. A Dutch community nurse explains: *'They just don't know the way in the swamp of different laws and regulations which are carried out by different organizations'* (I6). The bureaucracy and lack of knowledge to navigate the system renders carers dependent on professionals who invest extra time or on knowledge in their own social network. Knowing the way is based on coincidentally having a professional within your care network who bridges the gap to the home context, often this is not the case which has the worrisome effect that carers are often invisible with the Dutch healthcare system.

Especially after discharge carers become invisible within the Dutch healthcare system, A Dutch occupational therapist explains that this is worrisome *'because at home the confrontation with the limitations of an ABI become visible and it hits that the situation is vulnerable and there are many struggles, so that's the moment carers reach-out, but not carers with a background of migration'* (I12). Some participants realize that non-western carers are dependent on the possibilities of the healthcare system. They express feeling friction as they realize how carers do not fit the rigid and standardized way of working. Nevertheless, responsibility is however placed on the Other as participants argue that carers with a background of migration have learned to be helpless. A Dutch informal care policy officer talked about the responsibility of carers and how this contradicts with her own views on care responsibilities and self-control: *'I noticed that a lot of non-western carers have learned to be helpless. I believe that we are in full control of our actions. Your decision-making skills should not be influenced by your faith or any*

culture, only then can you cultivate your own values and beliefs. I feel strongly that everyone has the same chances in life and that you paddle your own canoe. I try to encourage carers to do so but it does not always pan out the way I've hoped' (I1). Putting emphasis on self-reliance, which is a deeply Western individualized cultural belief, placing the 'blame' of not fitting in completely on the shoulders of the dependent 'Other' is overlooking the unequal position of carers with a background of migration and not recognizing the need for rapprochement within care networks as a responsibility of everyone, contributes to inadequate collaboration within care networks.

During the interviews participants expressed their struggle with the fact that the dependent Other does not readily fit within the system. Standardization of care interventions form a juxtaposition with the need for person-centered care in which the uniqueness of each person is seen as essential. This is an impossible situation based on previous observations that carers often do not know their way in the health care system. Additionally participants describe that carers also do not have equal opportunities to access healthcare. Professionals recognize that carers and by proxy care recipients may not have the means to access healthcare after an ABI. For example, participants mention that the lack of supplementary insurance is a struggle for carers with a background of migration: *'They do not have the financial means for this kind of insurance'*. But without this form of insurance additional but necessary care needs to be paid out of pocket, and this is often not possible, which again leads to skewed access to healthcare services.

The dependent Other also becomes visible in the lack of access to professional translators within the healthcare system. As participants mention language as the main barriers within the collaboration, a Dutch-Surinamese creative therapist tells that: *'When I think of non-western clients I think of the language barrier, in addition to the language barriers from the ABI such as aphasia'* (I12). There is a large need to have contact with carers who speak Dutch or work with a translator, placing responsibility for unequal access to care on carers as a translator is *'not always readily available'* (I7). However, participants also express that there is a gap in health care: *'It's not okay when people do not understand you! or 'nobody talks about their fears, anger or sadness in a second languages'* (I16).

Struggles between professionals and carers also emerge when family norms and values of caring for someone interfere with care provision. A Dutch occupational therapist explains, *'I always put a large emphasis on the self-reliance of the care recipient, with the aim of not losing more function after the brain injury than is already lost'* (I7). This focus often leads to debates between professionals and families as families tend to take over all activities, keeping the care recipient dependent of the carer. A Dutch social worker provides an example where care recipient expectations did not fit within Dutch Social Support Act: *'A woman from Egypt only*

has her son here in the Netherlands. Due to incontinence as a consequence of her ABI, she has severe bedsores and is unable to take care of her house. She explicitly does not want her son to take care of the house because he is a man' (I16). This mismatch impacts the relationship between professionals and carers as such a statement by care receivers may cause professionals to experience a lack of appreciation by carers and care recipients.

Dependency is seen in the role of the carer themselves, as they do not have a formal place in the care network. Carers depend on professionals, organizations or policy to assign them a place in the care network. 'Sometimes participants ask questions to the carer, 'how are you holding up, do you manage with work or do you also focus on yourself?' (I10). But in many organizations participants are not required to discuss care or choices with a carer, 'this is the responsibility of the care-recipient' or 'they need to give consent to talk to the carer, which proves difficult sometimes with an ABI (I6). For the interviewed professionals, this was stressful as they felt caught in the middle when trying to meet the expectations of the care recipient and carers. Care was constrained by the possibilities of the care context.

The uncomfortable self

Collaborating with a carer with a non-majority cultural background may lead to feelings of insecurity and stress. A Dutch occupational therapist explains 'I have stress when I do not know what to do, do I need to take off my shoes? May I refuse more coffee? When I am with a Dutch family I ask, but here I do not' (I13). Unfamiliarity with gender roles in different cultures makes participants uncertain about their possibilities as a professional, a Dutch community nurse asks: 'Are we allowed to wash a man when only his wife is allowed to see him naked?' (I16). Insecurities are also observed in the discomfort surrounding terminology when talking about carers with a migration background, such as 'foreigners', 'immigrants', 'westerners versus non-westerners', 'them and they', pointing towards a lacking vocabulary for speaking about diversity issues. Professionals' discomfort could be literally observed during the interviews in actual physically retreating bodily posture when discussing the matter, or accompanying it with laughter.

Uncertainties might stem from the topic's political sensitivity, a fear of doing or saying something wrong, or even be viewed as a racist. Racism or discrimination was mentioned by two participants who wanted to make abundantly clear that they themselves were not discriminating. A Dutch occupational therapist expressed that cultural differences are a struggle for her for example when carers present as victims and lack self-reliance and place their locus of control outside themselves. She described her feeling, 'dammit again a Moroccan who believes that she is a victim...I do not want to deal with that anymore' (I12). Another extreme example was given by a Dutch social worker, who described a complex situation in dealing

with a care recipient who called her a racist, after which she called the police department to report him: 'Dutch people never say they get discriminated against, this always concerns someone with a different culture. I feel that this is learned behavior and I believe that when you are firm and do not tolerate being called a racist this will not happen again' (I16). Both professionals expressed a justification for their comments with a reflection that this is not a discriminatory way of thinking.

When speaking about lack of self-confidence, a shift in the professionals' reasoning becomes visible in their stories. All participants comment on the role of diversity, and argue that carers are the same, to justify their earlier comments on the difficult Other. For example a Dutch occupational therapist argues; 'occupational therapy is aimed at the individual and has therefore nothing to do with diversity' (I11) or a director of a care organization explains his worldview 'person is a person to me no matter if they look different' (I17). With this sudden turn, professionals completely negate the role that aspects of diversity play when their reflections, assumptions and predefined expectations could not be reconciled with their professional identity.

The reflexive self

Some participants reflect on their personal and professional identities and how these relate to their work. In general, collaboration with carers with a migration background is perceived by some participants as fun or a learning opportunity. A policy officer likes to submerge herself in different cultures: 'I like to learn from different culture' (I2). Some participants explain how cultural differences are a struggle for them, for example when carers take on what they perceive as 'an attitude of victimhood'. Thereby several participants reflected on their own role with differences in care networks, and recognized the need to be open minded and the necessity to ask questions and to not make quick assumptions. A Dutch occupational therapist reflected: 'I realize that I have blind spots... I need to make contact first before going further in the process' (I13). Often, participants realize that there is a need to let go of the expert opinion and first, learn from different cultures. A Dutch Afghan social worker recognizes the need to be open minded and not assume to quickly: 'Know that knowledge is power but that you do not know everything even though you are the professional' (I15).

Subsequently, some participants identified within their own identity, two intersecting aspects of diversity as relevant regarding the professional perspective: being an educated professional on the one hand, and seniority within the workforce or having a migration background themselves on the other hand. Senior professionals sometimes recognized that reflection is required on the validity of their knowledge. This Dutch-Peruvian community nurse explained how she falls back on her work experience when trying to work in a partnership with carers: 'Throughout the years as a nurse I have learned to perceive people as my partner, being the

professional who thinks they know best will do more harm than good in my opinion' (I5). A Dutch-Turkish occupational therapist who for years works in the same culturally diverse community adds to this by explaining that she does not have a manual to fit every person. To her, person-centered care has added value and she explicitly mentions the autonomy, or power of doing things differently every time.

Some participants mention how having a migration background as a professional was helpful in itself when supporting carers. A Dutch-Peruvian community nurse explains: *'I am from Peru myself and I speak several languages. So I am able to communicate with them on their level'* (I4). They found it easy to build trust, which is necessary for carers to be open about their situation and support needs. This is not always the case. A Dutch-Afghan therapist explains that to her, sharing an assumed similar background with care recipients can also be burdensome: *'I often go on home visits where people have the same cultural background as me. They put an extreme pressure on me by saying things like... 'I am so happy that you understand me completely'... while I have no idea'* (I15). The participant is annoyed having to explain over and over again that she does not understand everything, and this has a major impact on work pressure and pleasure. Thus, although professionals' migration backgrounds may be an added value, they are not automatically so. And finally, although people may share group memberships, stereotypical assumptions and expectations can also be applied to professionals by care recipients and carers.

Discussion

This study gains insight in diversity in care networks by exploring professionals' experiences in collaboration with informal carers with a migration background. We will now discuss how the four themes help to understand the complex reality of this collaboration, which is influenced by professional and personal identities and the context in which care is provided. We will also argue that our intersectional analysis offers an explanation for the health inequalities found by other scholars who studied diverse networks and discuss what is needed to overcome these inequalities.

Our intersectional analysis reveals a dynamic process of feeling, thinking and acting in professionals' description and understanding of their collaboration with informal carers with a migration background. Professionals' experiences are influenced by aspects of diversity of both the diverse Other as well as the diverse self, which is captured in the four themes: (1) *'The difficult Other'*, (2) *'The dependent Other'*, (3) *'The uncomfortable self'* and (4) *'The reflexive self'*. The four themes are interrelated, and can be seen as part of what Brons (2015) denotes as a dialectic process in which Othering is the 'simultaneous construction of the self and the other in mutual and unequal opposition through identification of (un)desirable characteristics. This

opposition sets up a superior Self in contrast to an inferior Other, but that is nearly always left implicit' (p.70)

The process of Othering becomes explicit and visible when professionals identify the Other as (1) difficult when problems arise within the collaborative network, and (2) dependent when they do not fit within the structures and norms of the Dutch healthcare system. This identification as the difficult Other is based on intersecting aspects of diversity such as culture, family systems, and gender roles, and associated stereotypical assumptions. These assumptions are often taken-for-granted and highly unconscious among professionals, and so are their normative persuasions of how carers and their care recipients should behave according to the dominant societal norms and policy regimes. In such a situation it is hard to build a relationship and attend carefully to the specific needs of the carer and the particulars of the situation. This is in line with Alpers (2018) who argues, from a care recipient perspective, that Othering might lead to distrust within care relations, and a recent study of Claeys et al. (2020) who show that professionals are 'likely to portray their own frame of reference and find it challenging to show empathy with patients with a different background' (p. 484). Moreover, there is the risk that professionals from their perceived superiority will use their expert power to determine what is needed by whom. If professionals only see the generalized Other they may not assess and offer what is needed by the particular informal carer(s) in a diverse care network, which may lead to health inequalities. In this study, we see how the process of Othering offers an explanation of these undesirable outcomes, and that Othering needs to be addressed to avoid health inequities and related negative influences on health outcomes.

Misunderstandings and conflicts within care situations become visible, within the 'Dependent Other' as professionals narrate about their struggles in the collaboration that derive from this dependency. Tensions and conflicts arise when carers with a migration background do not readily fit within the Dutch healthcare system, which is set by neoliberal health and welfare policy. This finding is in line with Peacock et al. (2014) who argue that the experienced dependency can be the result of internalized neo liberal discourse. Neo-liberal policies have an aggravating effect of the 'access to healthcare services for groups that are already experiencing difficulties' (Sakellariou & Rotarou, 2017, p. 7). Othering is then often used to serve to 'both position the self in a safe and defensible space and to endeavor to make sense of what is felt to have changed in the wider world' (Peacock et al., 2014). The dependent Other is a construction in opposition to and harnesses the independent professional as neutral Self, and this Self-Other binary prevents a mutual partnership between professionals and informal carers.

Subsequently, insecurities and stress are observed amongst professionals within the collaboration with carers with a migration background which is captured in the 'Uncomfortable Self'. Prejudices of professionals about other cultures and habits of carers create tensions

and barriers within the collaboration. This also works the other way around, when informal carers have different expectations of the provided care, which may lead to distrust fueled by preconceptions of professionals (Alpers, 2018). Within the 'Uncomfortable Self' it is recognized that professionals do not question situations that are unknown to them as they have the feeling they are required 'to know as the expert' professional. This is also observed by Claeys et al. (2020) who identify fear amongst professionals to be seen as racist, which prevents them to 'communicate and act in a spontaneous way' (p. 4). Instead of defining oneself as all-knowing and superior to the Other, professionals may redefine their identity to develop a more caring and fruitful relationship with informal carers (Abma et al., 2020). The Self-Other binary can only be deconstructed by reframing the identity of the professional and the relationship as being deeply interdependent and interconnected. Only, then a partnership approach can start to develop among professionals and carers in a diverse network.

The 'Reflexive Self' describes professionals who reflect on their own identity and its impact on their daily practice. Reflexivity towards the role of diversity and participants' own identity shows a level of sensitivity necessary to overcome social injustice recognized in the participants experiences. Namely, being sensitive towards carers allows them to speak their mind, recognize multiple truths within a care network and create a space where the other is also heard especially those who are not typically acknowledged and heard as an 'expert' in their role. This requires that all stakeholders in care networks, at personal, professional and organizational levels, enter into a multicultural dialogue (Hankivsky, 2014b). The lack of reflexivity may reinforce unchallenged assumptions about the Other (Hunting, 2014). Professionals often do not recognize the need for help as they simply do not recognize the signs that an informal carer is in need, or they lack knowledge about the cultural background of the informal carer. In order to widen access to healthcare, there is a need to be sensitive for blind spots, based on personal identity and social position. Letting go of the illusion of being all-knowing and that all tensions can be technically solved, the reflexive practitioner starts from a more humble attitude, acknowledging the wisdom of informal carers and their longstanding relationship with the client (Agner, 2020). Changing how professionals communicate can alter power dynamics and reconfigure healthcare practices.

Strengths and limitations

The use of intersectionality as an analytical framework in the secondary analysis is a strength in this work showing the implicit influence of contextual factors and intersecting aspects of diversity becomes explicit (Stuij et al., 2020). As seen in the results of this study the original themes are colored by a deeper, otherwise invisible layer, of diversity and power. Additionally, the data collection and analysis of the dataset consists of 17 interviews, 12 informal conversations within health and welfare organizations, a CoP and two critical friends in order

to create a strong sense of data- and researcher triangulation. Although some participants had little contact with carers with a migration background data saturation was still met. One of the limitations of this study is the fact that some of the included participants had limited contact in their work with carers with a migration background.

Implications

From the professional perspectives it becomes evident that an interrelated process of Othering, including the construction of a Self-Other binary, plays a role in diverse care networks, which offers an explanation for health inequalities that have been evidenced. From the professional perspective the collaboration in these networks is loaded with tensions and misunderstandings. It would be beneficial to focus further research on the perspectives of carers with a migration background and care recipients and uncover their experiences in the collaboration within care networks.

An intersectional approach can be helpful to understand the Self-Other binary that appears within collaborative care networks surrounding care recipients with ABI. The rather essentialist perspective of professionals on carers with a background of migration may be broadened when an intersectional perspective is introduced. Such a perspective may help professionals to gain knowledge and insight in differences and inequalities within and between groups of carers they collaborate with, now often in general referred to as 'them' or using broader overarching terms. Additionally, an intersectional perspective may provide insight in the intersections of diversity categories that are embedded in a specific context of care networks. This may help to highlight and understand the diversity amongst carers with a migration background. Professionals may then be able to move beyond an essentialized view on 'cultural difference' when working with carers and by proxy care recipients with a background of migration.

Within educational programs and within practices there is a need to explore how reflexivity can become an essential competence of what it is to be a professional to ensure equal access to healthcare. 'Reflexivity can help transform the collaboration when people involved bring critical self-awareness, role-awareness, interrogation of power and privilege, and the questioning of assumptions and 'truths' to their work' (Hankivsky, 2014, p.10). Reflexivity is the process of engaging in self-reflection about who we are as professionals and how subjectivities and biases guide and inform daily practices (Lazard & McAvoy, 2020). Reflexivity requires one to enter into what Donald Schon (1987) calls a 'swampy lowland', that is the uncomfortable place where technical solutions do not work, because of uncertainties and ambiguities and where one is involved on a personal level. Here the comfortable shield of professional neutrality can no longer be upheld, which often causes emotional pain, moral uncertainty and existential unrest. No need to say professionals rather avoid such a place, and often have the privilege to

do so because they do not regularly have to reflect on their cultural background as they are not confronted as being different (DiAngelo, 2015; Verdonk, 2015).

Therefore the integration of reflexive practices in healthcare curricula is needed as diversity responsive care requires a critical investigation of oneself as professional. This reverses the traditional way in which the Self-Other binary is approached (Leyerzapf et al., 2020). Instead of studying the Other, the Self becomes object of scrutiny.

Conclusion

The collaboration between professionals and informal carers with a migration background is subject to and reinforces underlying power structures and aspects of diversity. A process of Othering and Self-Other binary becomes visible in unequal relationships and tensions within the collaboration. Amongst participants, levels of insecurity emerged when a variation of action was needed, which did not belong to the core competencies of their profession, which fueled the feeling of not being an adequate professional. Being reflexive as a professional and letting go of the illusion of being all-knowing and in control of confusing situations will allow for the identification of blind spots and power asymmetries within the collaboration. We would therefore call upon educational curricula and professionals to invest in the integration of reflexive practices through participatory action research, unsettling the Self-Other binary by a critical scrutiny of oneself as part of an interconnected and interdependent care network.

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Intermezzo

Diversity is not an afterthought: It requires an ongoing process of learning

I am sitting in a small lecture room with students, and our discussion revolves around our perspectives on collaboration with carers with a migration background. One of the students has written down her thoughts, but she hesitates to share her perspective. When I ask her why she is hesitating, tension fills the room. She goes on to say that she feels ashamed of her reflection, because it made clear to her that she grew up in a context where people with a migration background were viewed in a negative way. As a lecturer, I wonder if I should protect this student. Her comments are vulnerable, and I also worry that her fellow students feel disrespected by her. What sticks with me is a comment from one of her fellow students with a migration background: She views the reflection in a positive way, because it has become a topic of conversation that was necessary for change.

During this PhD project, I worked with nineteen occupational therapy students, at both the bachelor's and master's level, who each brought their own questions, assumptions and identities into the research. Writing positionality statements became a central part of their projects, not as a formality but as a living exercise in critical reflexivity. We did not do this work in isolation. Every student had the opportunity to express their reflections in a guided dialogue, and it was there, in the conversation, that the most meaningful learning occurred. These were not easy dialogues. It was a matter of trial and error for all of us. As their lecturer, I had to adjust my approach for each group; there is no one-size-fits-all when it comes to creating safe and honest learning spaces. Yet something stuck. Many of these students now continue to engage with diversity, equity and inclusion (DEI) work in their workplaces. Some stay in touch. We share resources, stories and frustrations. Perhaps most importantly, we continue the dialogue. Besides academic and professional publications, ongoing discussion is, for me, one of the most powerful outcomes of this research.

That same need for dialogue became painfully clear during a training session I co-facilitated for policymakers in municipalities. We brought forward an intersectionality-informed perspective that encouraged participants to think critically about who was included, and who was not, when developing care policies. It quickly became clear that "diversity" in policy often meant a narrow focus: carers with Moroccan or Turkish background. Other populations

were completely overlooked. One policymaker even admitted, "We never really considered other groups; it just didn't occur to us." Then someone added, "We never hear from male carers, especially not men with a migration background. I assume they just do not provide informal care." That assumption hit hard. These were quiet, revealing moments of new awareness. Not every space welcomed this kind of critical engagement. When I was asked to design a training for health professionals on informal care, I was excited: Finally, a session that emphasized learning with carers and thinking in networks! It aligned perfectly with everything I advocate for. But when I suggested integrating diversity into the training content, I was met with resistance: "Let's just focus on carers first," someone said, "before we get into diversity issues." That moment stayed with me.

Why is "diversity" seen as something extra, as something optional? Why is it seen as something we can postpone until later, until the "real work" is done? This mindset suggests that the "real work" is neutral or universal, when in fact it is already shaped by dominant norms and requires us to examine our own positions and privileges, not just our professional roles. When we treat diversity as secondary, we fail to recognize that it is integral to the quality, equity and relevance of the work itself, particularly in fields like healthcare, education and social services.

Chapter 7

General Discussion



It is only human to make assumptions about others who you are not familiar to you (Fiske et al., 2007; Schwartzman et al., 2023). This becomes problematic, however, when such assumptions (un)consciously hinder quality care for people whose lived realities do not readily align with existing dominant norms in our healthcare system. In this PhD thesis, I explored how aspects of diversity shape collaborative care networks surrounding persons with acquired brain injury (ABI) at the intersection with having a migration background. The following research question was the starting point for this PhD thesis:

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

In this general discussion, I elaborate on the main findings and overarching lessons learned by synthesizing diverse stakeholder perspectives. I discuss methodological considerations and elaborate on implications for policy, practice, education, and further research.

Main findings

The results from the different chapters unveil inequity in collaborative care networks and show that power dynamics hinder collaboration between professionals and carers with a migration background, thus standing in the way of diversity-responsive care. Collaborative care networks are multi-layered and centre the caring relationship between the care recipients and carer, and may further consist of family (in law) in the Netherlands and the country of origin, and for example friends, neighbors, colleagues, Church or Mosque, and diverse professionals, alternative medicine practitioners, and the larger healthcare system (see Figure 1, Chapter 5). How diversity shapes the collaboration across these different layers is captured in five overarching themes: (1) disconnection in collaborative care, (2) Othering in care networks, (3) epistemic injustice in care networks, (4) an intersectional perspective in care network, and (5) critical reflexivity and ongoing dialogue. Across all five overarching themes, stakeholder positionality emerges as a critical factor shaping care attitudes, decisions in care, and relationships between professionals and carers with a migration background. Positionality informs how stakeholders navigate and contribute to care networks.

Central to this PhD thesis were the experiences of care recipients and carers with a background of migration, as well as healthcare professionals. While having a migration background is often assumed to be a primary axis of diversity by professionals, care recipients and carers rarely framed it as the most decisive factor influencing their experiences. When having a migration background was referenced by care recipients and carers, this was always in intersection with other aspects of diversity. Nonetheless, across all layers, having a migration background was

consistently experienced, by care recipients, carers and professionals alike, as complicating the collaboration. It affected not only how professionals approached treatment and formed assumptions, but also the way in which collaboration took place within care networks (Chapters 2 and 4–6).

Disconnection in collaborative care

In this PhD thesis, a persistent mismatch was observed between the perspectives of care recipients, carers and professionals on what constitutes adequate collaboration, expectations are part of those perspectives, and as a result, they lead to misalignment in practices (Chapters 4–6). While professionals often cite trust, clear communication and recognition of carer knowledge as essential components of collaborating in a partnership (Chapter 2), these elements are too often lost in interactions with carers with a migration background. Carers described that they experience distrust, not only towards individual professionals but towards the healthcare system as a whole. Communication with professionals was also frequently described by carers as unclear, contradictory or inconsistent, which left carers uncertain about what to expect and unclear about their roles. This ambiguity generates ongoing feelings of insecurity and exclusion amongst carers (Chapter 5). Assumptions and (un)conscious bias based on aspects of diversity shaped professional decision-making in care networks and often do not take the lived experiences of care recipients and carers into account (Chapters 4–6). In addition, care recipients with a migration background reported that a lack of understandable information by professionals complicated their access to adequate care, especially upon discharge home (Chapter 4).

While Dutch policy recognizes carers as essential partners in care networks, this study has shown that there is a gap between this anticipated situation and the actual collaboration taking place. When professionals struggle to adopt a true partnership, they fall back on the role of being an expert and attribute less value to the knowledge of care recipients and carers. This results in an insufficient and unstructured way of collaborating, in which care is provided in fragmented unity. Collaboration in practice often takes a complementary form in which carers are turned into quasi-professionals. Informal care provision in care networks is essential, but guidelines on how to put this into practice are lacking. At the intersection of informal care and a migration background, it becomes clear that, for some professionals, cultural differences within care networks contributed to stressful experiences and were identified as complicating the collaboration (Chapter 2). At this intersection, it also became clear that when collaboration is experienced as difficult by professionals, accountability takes over. Accountability then emphasizes a focus on measurable outcomes, efficiency and compliance with protocols and guidelines to enhance transparency and quality of care. As an unintended result of this reflex,

carers and care recipients with a migration background may become invisible, because they do not fit in standard categories or procedures, so their needs may be overlooked, misinterpreted or excluded (Chapter 6).

Recent literature has identified both contributing and hindering factors for building a partnership approach in care networks with carers, but there remains a significant gap in the literature when it comes to the specific experiences of carers with a migration background. In line with the findings in Chapters 4–6, Claeys et al. (2025) and Shrestha et al. (2023) recognize that a mismatch in collaboration adds to the experienced burden of carers, while an additional layer of difficulty, rooted in a lack of diversity-responsive care, is added at the intersection with a migration background to the experiences of carers. While other studies focussing on informal care without the specific focus on the intersection with a migration background, such as Wittenveen et al. (2021), underscore that carers in general often do not feel recognized as partners by professionals. Groenvynck et al. (2021) emphasize that carers must feel a sense of agency and be given time and support to build relationships within care networks. Similarly, Hoek et al. (2021) and Hovenga et al. (2022) underline that trust and open communication are vital pillars for any functional partnership. A consistent message across the literature is that professionals must not only collaborate effectively with carers but also with each other to contribute to adequate collaboration in care networks. However, as Woldring et al. (2023) point out, disagreement and uncertainty about how and by whom collaboration should be led continue to complicate such collaboration. Wittenberg et al. (2024) further warn that professionals frequently fail even to acknowledge carers as legitimate partners, thus undermining the foundation of any intended collaboration. Dohmen et al. (2025) identify structural hierarchies within care networks as a major barrier, with professionals often clinging to authoritative roles rather than engaging in genuine shared decision-making. This hierarchical dynamic is particularly damaging when combined with Kremer's (2025) observation that the Dutch healthcare system is least trusted by those who rely on it most. This points to a systematic mismatch between what carers need and what the system delivers. It is also imperative that professionals know each other and that carers and care recipients feel empowered to share care with professionals (De Coninck et al., 2023). Indeed, Stewart (2018) highlights that for collaboration to work within care networks communication between different professionals is essential.

While these insights are critical for improving collaboration in partnerships in general, they become even more urgent when considering the disconnection in the collaboration experienced by carers with a migration background. It is essential to recognize that if partnerships are to be equitable and adequate, the unique challenges faced by carers with a migration background must be addressed head-on.

Othering in care networks

Othering is a process where a division is created between people, Us versus Them, in which someone (i.e. the Other) is treated differently or seen as inferior because they do not belong to the dominant group (Akubulut & Razum, 2022; Jacob et al., 2020). In this study, Othering was explicitly recognized by care recipients and carers when facing the assumptions and (un)conscious bias from professionals they experienced. They were aware that they are treated differently because they belong to a minority population (Chapters 4 and 5). Carers explicitly emphasized having to deal with discriminatory practices based on their cultural and religious backgrounds. Carers with a migration background reported feeling a strong sense of injustice when collaborating with professionals; they often had to confront stereotypical assumptions and were frequently reduced to a single aspect of diversity – namely, their migration, cultural or religious background. These experiences felt deeply dehumanizing for carers. They faced professional normativity that dictated how they were expected to behave within care networks, which undermined the possibility of an equal partnership in the collaboration. When professionals gain insight into othering, space could be created where carers and care recipients with a migration background could meet each other and share common experiences, thus contributing to a sense of belonging in the Dutch healthcare system and regaining trust that is lost by negative experiences (Chapter 5).

Insecurities, frustration and stress regarding the collaboration with carers with a migration background were observed among professionals, which complicated collaboration in care networks (Chapter 6). Professionals experienced difficulties empathizing with carers and care recipients with a migration background when they did not have a similar background. However, the challenges professionals faced in the collaboration were attributed by professionals to carers with a migration background, while ignoring their own professional role within the difficult collaboration. Othering can be observed in this process, as carers with a migration background were labelled as difficult by professionals based on their non-majority status and divergence from societal norms. Carer experiences and knowledge were dismissed or undervalued, and professionals made assumptions based on stereotypes, ignoring differences amongst carers with a migration background. This study identified Othering as a main contributor to miscommunication and conflicts within collaboration. The fact that carers were labelled as the other by professionals came to the fore in the participatory analysis in the Community of Practice (CoP), and it is necessary to note that professionals themselves seemed unaware of this process in practice (Chapter 6).

The process of Othering can be seen as a power dynamic within care networks because it involves drawing boundaries between a perceived dominant group (self) and those labelled as different (other). This distinction is not neutral and emphasizes a power dynamic which

contributes to health inequity. A self–other binary unfolds in which professionals' sense of self, rooted in their own personal frame of reference and professional identity, is taken as the starting point for collaboration. Professionals tended to position their own worldview, with accompanying personal values, as the norm – that is, as the default perspective on collaboration. As a result, the views, experiences and contexts of carers with a migration background were perceived as different, unfamiliar and even problematic (Chapters 5–6). This finding highlights the importance of paying attention to providing insights to professionals about (un)conscious Othering and the consequences for health and wellbeing of carers who are at the receiving end of this process.

Being subject to the process of Othering greatly affects health and wellbeing. Othering is an exclusionary mechanism and a humiliating practice that creates a situation in which care recipients and carers feel that they do not belong in the healthcare system (Subramani, 2024). Having access to healthcare positively influences people's sense of belonging (Calvo et al., 2017; Hammell, 2014). Leyerzapf (2019) revealed that the process of Othering is omnipresent within healthcare, as well as in healthcare educational programmes, which highlights the need to bring Othering into the conversation to create a more just and inclusive approach to care provision (Alpers, 2018). Gangarova et al. (2025) highlight that making the process of Othering visible in healthcare practices may open up a dialogue about experiences of racism of care recipients and carers with a migration background. Additionally, deconstructing the sense of self in relation to the other is necessary to open space for constructive dialogue focussing on change (Akbulut & Razum, 2022; Leyerzapf et al., 2020), thus preventing the reproduction of otherwise negative experiences (Roberts & Schiavenato, 2017). Although the process of Othering is put in practice by individual professionals, it is not solely their individual responsibility to change: policies and healthcare systems need to assess how categorization of certain groups may be stigmatizing and may be subject to structural Othering (Jacob et al., 2021). While the existing literature has mainly focussed on experiences of people subject to Othering, two studies were found that examined professional perspectives. Claeys et al. (2021) identified Othering as an example of micro-racism that is (un)consciously put in practice by healthcare professionals in the field of dementia care. Leyerzapf et al. (2020) argue that a self–other binary may be a way for professionals to reproduce and maintain the position of power by placing themselves at the top in the hierarchy of care networks.

Epistemic injustice in care networks

Epistemic injustice is form of injustice in which someone is wronged based on their capacity as a knower (Fricker, 2007, 2018). In this study, epistemic injustice became visible when the knowledge of the care recipient and carer was not acknowledged but rather downplayed and silenced by professionals. It also appeared when assumptions of prejudice by professionals

were challenged by care recipients and carers, they did not feel heard or taken seriously by professionals and professional attitudes often remained unchanged (Chapters 4–5). When carers brought discriminatory practices to the attention of professionals or to a higher management level within healthcare organizations, their experiences were often dismissed, which created very painful situations. Epistemic injustice is a harmful power dynamic in the collaboration, because professionals can decide whose experiences or knowledge is true and should be considered and whose can be dismissed. This power dynamic results in health inequity and puts quality care under pressure (Chapter 5). Epistemic injustice contributed to a sense of distrust in professionals and the Dutch healthcare system as a whole, ultimately leaving carers feeling powerless when sharing care with professionals. Carers felt a great dependency on professionals, which created a sense of insecurity (Chapter 5). Care recipients' accounts of epistemic injustice were evident, when the assumptions of professionals were challenged by care recipients, but professionals' assumptions did not change. This is alarming because care recipients argued that choices about their care were often made based on the assumptions of professionals (Chapter 4). Being silenced greatly affects the health and wellbeing of both care recipient and carer because it is a contributor to stress and experienced burden. Although it is the individual responsibility of care recipients and carers to speak up and let their voice be heard, there is also a responsibility on the receiving end to listen. (Un)conscious bias can contribute to significant gaps in healthcare provision, and there is a clear professional responsibility to recognize and address these situations (Chapters 4 and 5).

Communication is essential in healthcare, particularly when language barriers exist. Peled (2018) highlights the importance of language to articulate care needs, illness beliefs and care attitudes; being unable to articulate this well and being heard has a detrimental effect on quality care. Even when there is little or no language barrier present, Fricker's concept of epistemic (in)justice is evident in the experiences of carer and care recipients in care networks, as prejudice from professionals causes them to question the credibility and reliability of the stories of care recipients and carers based on their identity (Fricker, 2007; Kidd et al., 2017).

Prejudice within communication works in two ways – by assigning either more or less credibility to the testimony of the speaker based on characteristics such as their social positioning (Garry et al., 2017). Fricker (2007) argues that it is the responsibility of the hearer to gain access to “the just story” of the speaker by a correct interpretation of words and body language. Creating such sensitivity is an ongoing process shaped by aspects of diversity and motivational attitudes that are inherited and change over time through lived experiences (Auerback, 2021). There is a responsibility on the level of healthcare organizations, as well as among individual professionals, to address situations of epistemic injustice (Nielsen et al., 2025). Michaels (2021) argues that it is also necessary to reflect critically on how evidence-based guidelines might be based on bias and thus create situations of epistemic injustice. To achieve this in practice,

healthcare organizations and professionals need to have insight into (un)conscious bias, epistemic privilege (Carel & Kidd, 2014) and Tronto's (2010) notion of privileged irresponsibility (Bozalek & Zembylas, 2023; Zembylas et al., 2014). The concept of privileged irresponsibility suggests that people who benefit from a privileged position can remain unaware of inequities experienced by others, and accountability may be deflected by relying on claims of professional neutrality or institutional protocols (Bozalek & Zembylas, 2023).

An intersectional perspective in care networks

Despite the growing emphasis on person-centred care in Dutch healthcare policy, this PhD thesis has shown that current informal care or ABI research, policy and practice often lack responsiveness to the diverse care needs of care recipients and carers with a migration background. The collaboration between professionals and carers in care networks is uncharted territory for using an intersectional perspective, and aspects of diversity are largely understudied in informal care research. That is, there is an overall lack of understanding of diversity in an intersectional way (Chapter 3). In this study, intersectionality was used as an empirical and theoretical lens to provide insights into the layered complexity of care networks. Intersectionality proved to be of added value, as it helped illuminate diversity within the group of care recipients and carers with a migration background as well as to unveil the role of power dynamics and revealed health inequities in care networks (Chapters 4–6).

In this study, intersectionality exposed Othering and epistemic injustice as power dynamics at play in care networks. In the power hierarchy present in care networks, carers do not have a formal place and are dependent on professionals to allow them a place in the care network. Carers often feel powerless in the face of professionals' expert authority, and this dependency creates feelings of exclusion and insecurity. These existing power dynamics reveal inequities that are caused by a failure to accommodate difference in care networks. This results in the fact that, in practice, carers with a migration background experienced sharing care with professionals not as helpful but as a burden (Chapters 3–6). Power dynamics are discussed indirectly within recent research (Chapter 3), but, in practice, taking power into consideration becomes obvious, as who can decide how the collaboration takes place and who has the final say is a matter of power. There should, ideally, be space for different perspectives, care needs and attitudes within the collaboration (Chapter 5).

This study has also shown the need to acknowledge sameness and difference within the group of care recipients and carers with a migration background on the levels of research, policy and practice. On the level of informal care research, diversity is frequently approached as a single-issue category, with gender being the most studied dimension. However, when intersectional studies are conducted, they uncover important within-group differences, such as the combined

influence of religion, gender roles and bicultural identities, in carer experiences (Chapter 3). In practice, care recipients and carers are also met with generalized cultural assumptions of professionals, and these assumptions fail to capture the complexity of their lives and with that their care needs. Adequate collaboration requires moving beyond surface-level "cultural sensitivity" to deeper diversity-responsive practices. Care recipients and carers expressed that having to deal with the consequences of an ABI is difficult enough without having to deal with being reduced to being a migrant (Chapters 4 and 5). Care recipients' daily lives are coloured by their social position. This study showed that based on the context of the included care recipients, the intersections of migration and disability and gender, class, education level, culture or family relations were relevant for their experiences (Chapter 4). Carer stories conveyed that the intersection of religion and traditional gender roles affect daily lives. The intersection of religion and culture both helped and hindered carers and is therefore not unequivocal. Culture, gender and family relations were also identified as an important intersection that influenced the relationship between carers and care recipients (Chapter 5). Insights into these within-group differences are necessary to develop more diversity-responsive healthcare policies (Chapters 3–6). This study has demonstrated that using an intersectional lens makes it possible to explore who is being reached by current policies and, importantly, who is being left out. Exclusionary mechanisms in policy or a lack of diversity-responsive guidelines may lead to professionals feeling insufficiently competent in working with carers from migration backgrounds. Some also noted that they rarely encounter carers with a migration background, further reflecting systemic barriers that exclude them from care networks (Chapters 3 and 6). By embracing intersectionality, professionals and policymakers can challenge (un)conscious assumptions, recognize both difference and sameness, and create conditions for genuine partnerships (Chapters 4–6).

In line with this study, Carbado et al. (2013) argue for expanding the scope of intersectionality to better capture the full range of intersecting power structures in society. In line with this, this study adopted an intersectional lens enabling an analysis of care networks as relational spaces shaped by the social positions of stakeholders (Crenshaw, 1991; Hankivsky, 2020; Stuij et al., 2020). Research has increasingly focussed on the experiences and needs of care recipients and carers with a migration background. This PhD thesis contributes to this emerging field by offering insights into collaborative care networks to support the development of diversity-responsive practices, which have begun to be addressed by other scholars and practitioners. For instance, the Pharos project *Taking Care of Caregivers* highlights the experiences of migrant carers for people with dementia (Ahmad et al., 2020). Pijpers and Carlsson (2018) explore outreach to older migrants, while Pijpers et al. (2022) advocate for intersectional policy at the municipal level. Organizations like the Knowledge Platform Inclusive Society (KIS.nl) and the National Network for Inclusive Care (NNIZ.nl) promote inclusion as a key value

for healthcare. Samra and Hankivsky (2021) and Sharma (2019) emphasize the importance of using intersectionality to challenge power dynamics in medical institutions. Despite these valuable and necessary developments, healthcare policy often remains narrowly focussed on cultural diversity, with limited attention to broader intersecting aspects of diversity (Badou et al., 2023; Peñuela-O'Brien et al., 2023; van Loenen et al., 2022).

Recent studies support the arguments of this study by offering additional intersectional insights into within-group differences among carers. For example, Wittenberg et al. (2019) show how carers' social identities shape collaboration with professionals. Zarzycki et al. (2022, 2023) highlight the cultural motivations behind caregiving and how these may shift as care recipients move through healthcare systems, thus challenging assumptions of familial care. Zygouri et al. (2021) expose how gendered stereotypes disadvantage women and call for research on intersecting factors like age, ethnicity and class. Unson et al. (2023) note racial disparities in carer stress and health; they also advocate for a greater focus on male caregivers, a gap addressed by Van Wees et al. (2023). Starosta et al. (2023) reveal health inequities in mortality and rehabilitation access after ABI, especially among those with language barriers or lower socio-economic status. At the network level, Ho et al. (2023) stress the need to recognize diverse caregiving structures, while suggesting care plans should accommodate shared responsibilities among family or friends. Waling et al. (2022) document how older lesbian and gay carers face stigma and barriers in accessing care, thus paralleling the experiences of carers and care recipients with a migration background discussed in this PhD thesis. Insights from these studies once again highlight the importance of healthcare policy and practice that benefit diverse populations in the broadest sense possible.

Critical reflexivity and ongoing dialogue

This study has shown that professionals remained largely unaware of the impact of their own social positioning on the provided care and their role within the collaboration. It became apparent that if professionals were aware of their own social positioning, they were more sensitive towards carers with a migration background and created space for diverse care needs (Chapter 6). Becoming aware of the influence of your own social positioning in everyday practice requires ongoing critical reflexivity. The participatory analysis in the CoP revealed that critical reflexivity is something that requires follow up supervised dialogue. Through dialogue, the choices, underlying norms and values, perspectives on the collaboration and preferences of all stakeholders became visible, which is a prerequisite for a needs-based approach and a true partnership. This is a personal learning process which can only take place in reciprocity with the other stakeholders in care networks. This learning process was put in practice within the CoP, in addition to meetings with critical friends (n=3) and students (n=19) who participated in the sub-studies.

The learning process started with the creation of a social identity map by everyone involved, which was followed by a dialogue about the disadvantage and privilege we might experience based on our social position (Jacobson & Mustafa, 2019). Everyone involved also wrote one or more positionality statement(s), which were then discussed within the CoP or with the students or critical friends involved at that moment. This was part of a first exploration after which this reflexivity focussed on the topic at hand – that is, we discussed our perspective on informal care and collaboration and explored how our social position influenced our perspective. In this phase, power dynamics were addressed by making them visible through creative methods such as actually visualizing power hierarchies. The meetings with the CoP, students and critical friends were guided by creative hermeneutics (Cardiff & van Lieshout, 2014) and appreciative inquiry (ICPHR, 2021), which contributed to a positive and safe space for all stakeholders involved that allowed for reciprocal learning. During data collection, the participatory analysis in the CoP, preliminary analysis with the critical friends and the supervision of students, ongoing dialogue took place in which we consequently asked ourselves how our perspectives were formed and influenced by our social position. It was recognized that this learning process is necessary for every professional to be able to provide diversity-responsive care. Chapters 4–6 show that there is no quick fix available, as there is always the possibility for unfamiliar situations to present themselves. Professionals are responsible for choosing to aim for diversity-responsive care despite the barriers that exist in the healthcare system; there is an individual responsibility to add this to one's own professional development. However, it is up to the healthcare organizations to support individual professionals as well as providing communicative spaces within their organization with the necessary resources (Chapters 2–6).

In principle, professionals want to do the right thing. Reflection is part of current healthcare education curriculum and healthcare practice and aims mainly to help professionals determine a course of action within care (Pollard, 2015). However, reflection often does not occur, given the focus on professionals' and students' social position, with the accompanying privilege and disadvantage and their impact on care attitudes and choices. Recent research has also highlighted the importance of reciprocal learning to turn critical reflection into action by emphasizing reflexivity. Learning together makes (un)conscious privilege or bias visible, which is necessary for behaviour to change (de Bruijn, 2025): "Reflexivity can help transform collaboration when people involved bring critical self-awareness, role-awareness, interrogation of power and privilege, and the questioning of assumptions and 'truths' to their work" (Hankivsky, 2014, p.10).

Methodological considerations

There are several methodological considerations to discuss. The migration-first approach taken in this PhD thesis allowed for research with participants who are often underrepresented

in research. However, this choice coincided with the realization that there is a need to focus on within-group differences and not have an essentialized perspective on migration. Using intersectionality as a theoretical and empirical approach allowed for responsiveness to the intersections between aspects of diversity and how people experience their daily lives at these intersections (Crenshaw, 1991; Hankivsky, 2020). Taking an intersectional approach was necessary because there is a need to embrace diversity and move beyond a simplistic representation of society, which risks leaving associated health inequities unseen (Bakkum et al., 2023). The carers and care recipients who took part in the empirical studies of this PhD thesis, as well as in the CoP, self-identified by their migration background – for example, by mentioning that they are proud of a certain heritage or culture. Although carers and care recipients self-identified as having a migration background, all words have meanings rooted within historical contexts, and it is essential to expose the underpinning world views to expose bias and prejudice in care networks. Taking a migration-first approach requires sensitivity and respect. This PhD thesis also demonstrated the value of combining intersectionality with epistemic injustice to better understand communication in care networks and how care recipient and carer knowledge is recognized by professionals. This aligns with Kidd et al. (2017) and Rekis (2023), who argue that this combination offers insights into the varied ways epistemic injustice is experienced. Using intersectionality within occupational science is relatively recent and studies mainly focus on the intersection of gender and race in relation to studying meaningful daily activities (Reid et al., 2025). Using an occupational focussed perspective in combination with intersectionality can further enrich our understanding of how social positions shape meaningful activities and participation in everyday life.

There has been an ongoing national and international debate about the terminology for describing diverse populations with a migration background respectfully. In the Netherlands, the term *person with a migration background* was introduced in 2016 to replace the words *allochtoon* and *autochtoon* (de Ree, 2016), and in 2022, the terminology transitioned to a division between born in the Netherlands and naming a country of origin (CBS, 2021). This is, however, still distinction that is not informative and may lead to stereotyping and evoke negative associations (Bovens et al. 2021). The question also arises: until which generation is it significant to identify a migration background? The narratives of people with a migration background in particular contribute to reinforcing social hierarchies within Dutch society, highlighting an *us-versus-them* mentality, even when social policies seek to address social problems that are experienced by particular groups (Akbulut & Razum, 2022; Helberg-Proctor et al., 2017). This occurs without assuming that care recipients and carers with a migration background are vulnerable by definition (Kremer, 2023). At the start of my PhD research, the research population was defined as *having a non-Western migration background*. In hindsight, this definition implies a rather essentialized view of the research participants. Over the course

of the project, the terminology was changed to *carers with a migration background*, with an explicit focus on within-group differences in the group of carers with a migration background. Therefore, in the empirical studies the concept of migration background was used, but within the data collection and analysis emphasis was placed on relevant intersecting aspects of diversity that emerged in the stories of the participants. Still, the terms care recipients and carers with a migration background are not neutral, and it remains to be seen if there can even be a term that is relatively neutral, if exclusion, discrimination and racism continue to exist. However, it is essential to study experiences that are understudied in public health research to aim for a more inclusive approach to care provision.

Following a PHR design provided an insightful process of participatory learning in a CoP with stakeholders involved in care networks. The CoP meetings showed that it was beneficial to engage in reciprocal learning with care recipients, carers and professionals. The combination of stakeholders required complex analysis, but it also provided deep insights into how diversity and power are active in care networks and simultaneously provided a learning process for the included stakeholders. The CoP concluded that educators, students, professionals, carers and care recipients need to go through a learning process to be able to provide diversity-responsive care. Although a PHR design was used in this PhD thesis, the question arises if the measures taken to ensure participation were sufficient. A community of practice was involved, critical friends were involved in the empirical chapters and stakeholders from care networks were involved in the development phase of this research, but is that PHR? It would have been beneficial for stakeholders to be actual co-researchers in the sub-studies of this PhD thesis. This would have required a different method of grant application to be able to provide them with financial compensation for their work. Additionally, the stakeholders should be involved in the dissemination of research results, through either academic or practice-oriented modes of dissemination. Dissemination of the results was part of the CoP dialogue, and we spoke about implications for practice and education. However, the CoP members were not actively involved with the dissemination of results.

The empirical studies in this PhD thesis were completely rooted in qualitative research, which provides an in-depth understanding of relevant social positions of diverse stakeholders and their experiences in care networks. The research methods used find their origin within the Western world, and to be receptive to decolonial tendencies within research, it would be beneficial to learn from indigenous forms of evaluation to produce research whose voice is heard and whose voice represents world views that are not Western (Smith, 2022). Over the course of my PhD research, critical reflexive practices were put into practice and positionality statements were written by myself, the members of the CoP and the students involved, as well as critical friends. Providing reflexive positionality statements could, however, be open to criticism. Gani and Khan (2024) argue that it must be remembered that positionality statements were founded

for the White researcher to better conduct research on the non-White other, albeit in a more ethical way, as the origins of reflexivity as a methodology in anthropology emerged from the practice of studying the “native other”. It is thus necessary to recognize that a declaration of privilege can reproduce power hierarchies and reinforce colonial practices. Acknowledging privilege does not prevent someone from taking up space, seeking validation or performing allyship in ways that leave power structures intact and continue to sideline marginalized voices. Humility is therefore necessary when rethinking knowledge and reflecting how my own views and approaches may be influenced by stereotypes and pre-held assumptions. Humility is necessary to recognize that the personal crosses boundaries with the academic within research, and this requires ethical work on behalf of the researcher, especially when doing research which is participatory in nature (Groot & Abma, 2024). Ethical work may be invisible; however it is needed to avoid epistemic injustice within participatory research and ensure meaningful participation, especially of voices that are underrepresented within research (Groot et al., 2022).

The ethical principles of PHR research established in previous research (Abma et al., 2018; Centre for Social Justice and Community Action & National Coordinating Centre for Public Engagement, 2022; ICPHR, 2021) were rigorously followed. The CoP meetings adhered to mutual respect, and there was a place for knowledge from care recipients, carers and professionals. When situations arose in which different perspectives emerged, we collectively tried to explore the value of those different perspectives and embrace the opportunity to learn. Equity and inclusion were sought by actively trying to include the voices of care recipients and carers with a migration background, as they are often ignored in informal care research. Participants in informal conversations, the members of the CoP, critical friends and students were not, however, actively involved in the data collection of the different sub-studies. There was democratic participation in the preparation stage of, for example, demarcating the research topic or developing an interview guide. They were also actively involved in the participatory analysis of the data. Learning together was central to the meetings of the CoP, critical friends and students. The participatory analysis was a shared process; however, the dissemination of the findings was driven by the research team. In future projects, I would like to explore the possibilities of data collection and dissemination of findings together.

Implications for policy

An important finding from this study is that current policies in healthcare do not provide professionals with the tools and guidance to collaborate adequately with carers with a migration background. Informal care policy should be developed that emphasizes a partnership approach, in which professionals and carers collaborate with and complement each other. It is important to note that an integral part of informal care policy should additionally focus on supporting

carers. Healthcare organizations frequently do not have the resources to dedicate time for professionals to support carers, which results in carer support being offered only if there is time left after attending to care recipients. Lack of support by professionals greatly affects the health and wellbeing of carers, and the impact of providing care by carers should always be considered alongside other interests. Carer support should be formally embedded within care schedules by allocating time specifically for carer support. For example, multidisciplinary care meetings should include dedicated segments to address carer needs, as well as coordination of the collaboration between professionals and carers. In addition, care pathways should integrate check-ins with carers as part of routine assessments to ensure that their well-being and capacity to continue providing care are monitored and supported proactively. Additionally, informal care policy should have an interprofessional character and should be developed for healthcare professionals as well as social workers, as too often a lack of coordination between professionals negatively affects the collaboration in a care network.

While evidence-based approaches and following guidelines are standard in professional care networks, this study has shown that, in practice, policy often overlooks diversity and power dynamics and does not take an intersectional perspective. Pharos, Movisie and Mantelzorg.nl (n.d.) provide insightful guidelines and tools to collaborate with carers both with and without migration background, which should be taken into account in healthcare policy development. Additionally, healthcare policy should represent the knowledge of professionals as well as care recipients and carers from diverse backgrounds. Kremer (2023) argues that the person-centred and tailor-made approach emphasized in healthcare policy would allow for diversity-responsive care in practice. I would argue that an intersectional perspective should be used to analyse which stakeholders are represented in current policy, as well as where current policy may have blind spots and if current person-centred care is meeting the diverse needs it implies.

So, who is not benefiting from policy or might even be at a disadvantage within our healthcare system? Hankivsky et al. (2014) provide an intersectionality-based policy analysis framework which can be useful for analysing current policy within healthcare. Policymakers should adopt diverse strategies and go out of their way to include voices that are not traditionally heard in policy development. Policy developed from an intersectional perspective could guide all stakeholders to take diversity and power (which is often the invisible actor in care provision) into account and rethink how to better understand each other. This would ultimately improve collaboration through socially relevant, inclusive and effective policy solutions.

Finally, it became apparent in this study that there should be specific policy on how to deal with situations of discrimination, as these appeared in all stakeholder perspectives in the three empirical studies. Recent studies conducted in the Netherlands (Badou et al., 2023; van Loenen et al., 2022) have also shown that discrimination exists within our healthcare system, although

they did not specifically include informal care practices. When developing anti-discrimination policy, it is essential to include minority voices in policy development. Adequately dealing with situations of discrimination and having care recipients and carers feel heard is essential for quality care. Within these policies, specific attention should be given to the prevention of discrimination and providing an environment in which building trust is central. Noteworthy here is the useful framework developed by Van Marlen et al. (2023) for using intersectionality as a basis for assessing current policies and developing anti-discrimination policies in the future.

Implications for practice

Implications for practice are evident in all chapters and the main findings. As in the implications for policy, a true partnership approach should be pursued in practice by diverse professionals, rather than simply working alongside a carer or emphasizing carers take over tasks from professionals. This first and foremost requires that professionals recognize carers' experiences and knowledge. Critical reflexive practices should be put in practice in care networks, because they are necessary to unveil inequity in care networks by addressing and understanding the Othering and epistemic injustice that may occur by refocussing the process of Othering to the reflexive self. Critical reflexivity should not be a standalone exercise and should be followed by ongoing dialogue. This is not a simple task. It requires an ongoing process of reciprocal learning which can take place in communicative spaces.

In the context of care networks, a communicative space is a space where all stakeholders involved can participate in dialogue to create a mutual understanding of care needs, expectations and responsibilities. A mutual understanding does not mean that there needs to be consensus, but rather that insight into differences is necessary. Different forms of knowledge should be recognized, including the lived experiences of care recipients and carers, as well as experiences of professionals. Insight into power dynamics is a pre-requisite for enabling genuine dialogue and should be explicitly addressed. A communicative space may allow for acknowledging multiple truths and the possibility of moving forward together. This safe space should be facilitated for carers to speak their minds (Chapters 2 and 4–6), after which, professionals may evaluate and enable carers and care recipients' readiness and reflect on power-sharing. In practice, professionals should additionally be trained in, for example, inclusive interviewing techniques and shared decision-making that incorporates carer perspectives. The steps taken in the CoP based on using creative hermeneutics and appreciative inquiry, described in the different chapters, are fruitful steps to facilitate dialogue in communicative spaces which can be taught to professionals. Team-based supervision sessions could be organized that include reflections on how carer knowledge was or was not integrated into recent care decisions.

Healthcare organizations should adequately facilitate communicative spaces in both space and time for these additional necessary activities. Working with guidelines and evidence-based work are key components in care networks from a professional perspective. Diversity and power are not captured in these guidelines; it is, however, essential that they become a part of it. A needs-based approach is necessary, as well as a realization that there is no one-size fits all solution. Rather, there needs to be space to ask what is needed. Practically, this means healthcare organizations should institutionalize reflexive team practices, such as regular dialogue groups or conducting privilege walks or cultural humility workshops that bring assumptions and biases to the surface. Care organizations should support long-term implementation of participatory tools like identity mapping and positionality workshops as part of continuing professional development. Managers should also be trained to create environments where staff are encouraged and rewarded for engaging in this reflexive work.

Van Kemenade et al. (2022) argue that collective reflexivity is essential for the development of integrated care. It can foster trust amongst diverse stakeholders and enhance perspectives for multiple truths (Lips et al., 2024). Understanding how the coping mechanisms and cultural adaptation strategies of care recipients with a disability and migration background may differ from what health professionals are used remains urgent (Choyet et al., 2021). To achieve collaboration in true partnerships, care recipients and carers must be able to participate actively within the rehabilitation process (Peoples et al., 2011). This requires professionals to be able to deal with complex and diverse realities in differing care networks (Rønn-Smidt et al., 2020) and have critical awareness into how best to respond to the needs of care recipients and carers at any given point in their rehabilitation process.

Implications for education

There are several implications to put forward for educational programmes. First, what it means to become a carer and provide informal care should be part of educational curricula for healthcare and social work professionals. There should be specific focus on possible positive and negative aspects of caring and the impact on everyday life and the caring relationship with the care recipient and larger social network, with an emphasis on sameness and differences within carer experiences. Sameness and difference should be integral with the use of diverse examples, cases, literature (e.g. Claeys et al., 2025; Franzen et al., 2021; Giesbrecht et al., 2021) and (guest) lecturers in the educational programmes of allied health professions and social work. From my own practice experience, I recognize the added value of using diverse cases of lived experiences and inviting diverse carers, like Kofi and Ama, into the educational programme to tell their story to upcoming professionals. There should also be specific attention to the impact of the larger healthcare system, including guidelines and policy with a focus on understanding who benefits and who is excluded. Additionally, educational curricula should

specifically focus on teaching upcoming professionals what it takes to work in partnership with carers. Highlighting first and foremost the need to recognize carers in their role and carers' own support needs, as well as truly inviting them to participate in shared care (McPherson et al., 2014; Westerling et al., 2024; Wittenberg et al., 2024). This would be beneficial for all stakeholders involved, as research has shown that coordinating care between professionals, amongst each other and with carers diminishes conflicting ways of working and is thus a responsibility of all professionals involved (McPherson et al., 2014; Westerling et al., 2024). This includes building trust and communication, which are essential components of the care process, and having insight in one's own assumptions and biases towards carers in general

Critical reflexive practices should also be an integral part of every healthcare and social work curriculum to contribute to true partnerships by overcoming processes of Othering and epistemic injustice. To facilitate diversity-responsive care in the practice context, it should be a prerequisite for students, before they become practitioners, to go through a learning process focussing on the use of self as well as one that focusses on making visible the invisible processes active underneath care provision. Working on diversity, equity and inclusion or proposing critical reflexive practices is often met with resistance on the level of lecturers and not among students per se. There is of course a need to have educators on board, as they are part of these critical reflexive practices and the supervised dialogue necessary. Indeed, not having to reflect regularly about their social positioning as they are not confronted with being different may be part of the educator's privilege (DiAngelo, 2015; Verdonk, 2015). Muntinga et al. (2016) argue that critical reflexive practices are essential within healthcare education for upcoming professionals to understand their own background and its role within care provision. Schuitmaker-Warnaar et al. (2021) argue that critical reflexive practices are essential when the care needs of certain populations are not met, especially in cases where inequality exists. They highlight that reflexive practices should be an integral part of healthcare policy. In line with this study, Dawson et al. (2022) advocate for critical reflexivity to be recognized as a key skill for healthcare professionals to provide a safe space for care recipients and carers with a migration background, one that should be added in current healthcare curricula as well as social work. Integrating critical reflexivity in education curricula also requires communicative spaces where resistance to deal with diversity can be explored. This is a learning process that requires awareness, time and the personal commitment of educators and students.

Implications for further research

Further research informed by intersectionality would be beneficial within care networks. This PhD thesis researched perspectives of diverse stakeholders; however, the included stakeholders did not belong to the same care networks. Following care networks as a whole and taking a care network journey as a research approach (Davies, et al., 2023) may fill in some

of the remaining blanks. Central within a care network journey should be an observational approach, as aspects of power and inequity are often left unsaid and difficult to uncover within conversations. Observations within the different settings encountered by care recipients and carers should be followed by individual interviews and dialogue sessions including diverse stakeholders, as exploding process of power and inequity together would yield even richer results (Abma et al., 2018).

Participatory research within healthcare settings, as well as within healthcare and social work educational programmes, should be actively promoted to deepen our understating of inclusive healthcare practices. Such research should prioritize the co-construction of knowledge by bringing diverse professionals and carers together, enabling stakeholders collaboratively to explore the complex dynamics of power and diversity that shape care but are often overlooked by existing guidelines and conventional evidence-based practice. To strengthen the evidence for inclusive healthcare provision in a meaningful way, it is essential to engage with a broad spectrum of participants, including care recipients, carers, professionals from diverse disciplines, educators and students. Research exploring the added value of creating spaces where critical reflexivity is used to challenge the self-other binary should also be conducted. By doing so, we can better understand how professional identities are constructed and thus prepare future professionals to engage ethically and empathically in increasingly diverse care networks.

Within the implications, there is a large focus on critical reflexivity and creating communicative spaces, which require extra time, space and financial means from the organizations and stakeholders involved. In times of tremendous staff shortages and austerity measures, it would be of interest to research if putting diversity-responsive care into practice would result in more time for professionals and carers to spend on the actual provision of care in a cost-effective way. For example, recent research from the World Economic Forum (2025) into women's health has shown that research into closing the gender gap on the levels of treatment efficacy, care delivery, data and funding could "unlock 75 million disability-adjusted life years annually and 1 trillion in annual global GDP" (p. 4). Further research could explore whether inclusive healthcare provision would perhaps yield economic benefits besides the overall benefits of quality care and wellbeing for all stakeholders involved.

Conclusions

In sum, this PhD thesis unveiled the complex and often unjust dynamics between professionals and carers with a migration background in collaborative care networks surrounding care recipients with an ABI. Diversity shapes collaboration in care networks in several ways. First, stakeholder positionality plays a crucial role in shaping care attitudes, decisions and relationships. Second,

there is a persistent disconnection in the collaboration between professionals and carers with a migration background, which is rooted in misaligned expectations, unclear communication and the (un)conscious bias of professionals. Third, Othering is identified as a pervasive, often (un)conscious process within care networks that reinforces power imbalances and disadvantages of care recipients and carers with a migration background. Fourth, epistemic injustice in care networks silences the voices of care recipients and carers with a migration background, thus reinforcing professional authority and undermining trust and quality of care. Addressing these challenges requires a shift towards diversity-responsive care that acknowledges carers as equal partners and confronts structural barriers within collaborative care networks. This entails a structural and professional commitment to recognizing and valuing diverse knowledge, challenging bias and fostering truly inclusive communication and decision-making. It also requires both individual awareness among professionals and structural changes in healthcare systems to dismantle exclusionary norms and foster equitable, inclusive collaboration. An intersectional approach in this study proved essential for uncovering how stakeholders' social positions shape experiences within care networks and contribute to health inequities. To foster equitable collaboration, professionals and policymakers must move beyond generalized notions of cultural sensitivity and actively address the structural and relational power imbalances that disadvantage care recipients and carers with a migration background, while also addressing diversity in the broadest sense in policy and practice. Ongoing critical reflexivity, grounded in dialogue and reciprocal learning, is essential to uncover and address power dynamics, Othering and epistemic injustice within care networks. Creating communicative spaces where diverse forms of knowledge are valued enables more equitable, inclusive collaboration and supports the development of diversity-responsive care. Building on these insights, sustainable change in healthcare requires commitment from policymakers, educators and professionals to embed diversity-responsive practices throughout all levels of care and in the educational programmes for healthcare professionals and social work. Embracing critical reflexivity and intersectionality not only challenges existing power imbalances but also fosters shared understanding of how adequate collaboration should be put in practice, essential for effective partnerships. By prioritizing inclusive policies, education and research, the healthcare system can better meet the complex and varied needs of care recipients and carers alike. Ultimately, this comprehensive approach can contribute to more equitable, compassionate and adequate care for diverse populations.

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Summary

The central focus of this PhD thesis is to critically understand how intersecting aspects of diversity shape the collaboration between professionals and carers in care networks surrounding care recipients with acquired brain injury and a migration background, with a focus on uncovering underlying power dynamics 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.

Chapter 1 elaborates on the background and methodology of this PhD thesis. People who have suffered some form of acquired brain injury, must reconcile immense changes to their daily lives and often have to accept that they have become recipients of care provided by others. Care is provided in care networks where professionals collaborate with informal care. 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. In addition, Dutch government policy emphasises the provision of informal care for people with health and welfare needs in their own living environment, however within current informal care policy there is little attention for carers and care recipients with a migration background. Carers providing informal care for someone with an acquired brain injury 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. Additionally, amongst carers with a migration background 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. However, carers with a migration background face significant barriers in accessing adequate care, due to insufficient communication and distrust in professionals. 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. Participatory Health Research is the research design used in this PhD thesis. Participation of care recipients with acquired brain injury, carers with a migration background and professionals, was sought after through the involvement of the community of practice, critical friends and students from the occupational therapy program, as well as the participants of the different sub studies. An intersectional approach was used as theoretical underpinning, providing 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. 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 people's lived experiences. In doing so, intersectionality is

understood to challenge health inequities and structural disadvantages within care networks.

Chapter 2 explores the collaboration between professionals and informal carers, through literature review and thematic synthesis. Aiming to better understand experiences of professionals in the collaboration with informal caregivers and to further understand their perspective, to strengthen care networks in the future. PubMed, Medline, PsycINFO, Embase, Cochrane/Central and CINAHL were searched systematically which resulted in the identification of 2828 articles, using specific key words, inclusion criteria and methodological appraisal, twenty-two articles were used for thematic synthesis. Working in collaboration with informal carers requires professionals to adopt a different way of functioning. Specific attention should be paid to the informal carer, where the focus now is mainly on the care recipient for whom they care. This is difficult to attain due to different restrictions experienced by professionals on policy and individual levels. Specific guidelines and training for the professionals are necessary considering the current policy changes in the Netherlands, where an increased emphasis is placed on informal care structures within the Dutch healthcare system.

Chapter 3 explores, through a scoping review, how dimensions of diversity across their intersections are currently represented in informal care research. Key terms 'informal care' and 'intersectionality' were used for a search in PubMed, PsychINFO, Cochrane Library and CINAHL, resulting in 342 articles. Following PRISMA 28 articles were selected for inclusion in the scoping review. All 28 studies were analyzed based on a for this scoping review created intersectionality informed coding scheme. The scoping review revealed that aspects of diversity are largely understudied in informal care research, in particular across their intersections and from a critical perspective. This intersectional informed analysis revealed that when studying diverse caring experiences, the use of an intersectional perspective provides a nuanced understanding of these experiences. Adopting an intersectional perspective ensures that not only different categories or social identities of caregivers are included in future studies, but the mutual relationships between these categories embedded in their specific context are actually studied.

Chapter 4 explores care recipients' perspectives on the provided care in the care networks aiming to provide a contextualized understanding of the complexity through the added value of the individual experiences. Nine semi-structured interviews were conducted with care recipients with acquired brain injury at the intersection with a migration background. In addition, a secondary stakeholder analysis was conducted amongst the professionals, carers, and care recipients who were part of the community of practice or participated within the other studies belonging to this PhD thesis. An intersectionality lens was applied to understand the power dynamics in the experiences as expressed in the interviews and stories. Using vignettes of care recipients' experiences, the results present the following intersectional mechanisms

that reproduce health inequities: (1) navigating diversity, (2) gender-related loneliness, (3) hidden challenges, and (4) challenging assumptions. Upon discharge home care recipients with ABI and a migration background fall into a lonely state of being, often with a lack of social support and experience financial difficulties. Care recipients disappear out of the healthcare system' sight and are unable to find their way back. They are met with a lack of diversity responsive care, care recipients must deal with stereotypical assumptions of professionals and when these assumptions are challenged, care recipients are met with epistemic injustice. Diversity responsive healthcare begins with a critical awareness of health inequities and the underlying mechanisms among professionals, healthcare institutions, and policy.

Chapter 5 sought to gain insight into carer experiences with care networks around care recipients with ABI. Specifically aiming to expose aspects of power and social injustice in care networks. An intersectionality informed qualitative study design incorporated three informal group conversations (N=32), semi-structured interviews (N=21) and three dialogue sessions (N=7) with carers caring for someone with an ABI. Three interrelated themes were identified as constituting different layers of the carer experience: (a) I need to keep going, focusing on carers' personal experiences and how experiences were related to carers social positioning; (b) the struggle of caring together, showing how expectations of family members towards carers added to carer burden; and (c) trust is a balancing act, centering on how support from professionals shaped carers' experiences, in which trusting professionals' support proved challenging for carers, and how this trust was influenced by contextual factors at organizational and policy levels. Carers were met with Othering and discriminatory situations. When this was brought to the attention of professionals, carers were met with epistemic injustice. The need for diversity-responsive policies within care organizations is apparent. Carers with a migration background need to feel heard so they can meaningfully tailor care to meet recipients' needs.

Chapter 6 explores diverse professional perspectives on and experiences in collaboration with carers with a migration background in care networks around care recipients with acquired brain injury. An intersectionality informed qualitative design was used with informal conversations (N=12) and semi-structured interviews (N=17) with healthcare professionals working with clients with Acquired Brain Injury. The results show four interrelated themes: (a) 'The difficult Other' in which professionals reflected on carers with a migration background causing 'difficulties'; (b) 'The dependent Other' refers to professionals' realization that 'difficulties' are intensified by the context in which care takes place; (c) in 'The uncomfortable self' professionals describe how feelings of insecurities evoked by the Other are associated with an inability to act 'professionally'; and; (d) 'The reflexive self' shows how some professionals reflect on their own identities and identify their blind spots in collaboration within a care network. These themes demonstrate the tensions, biases, and power imbalances between carers and professionals, which may explain some of the existing health inequities perpetuated through care networks.

Chapter 7 contains the general discussion which zooms in on overarching lessons learned, methodological considerations and implications for policy, practice, education and research. The different chapters unveil inequity in collaborative care networks and show that power dynamics have a hindering effect on the collaboration between professionals and carers with a migration background, standing in the way of diversity-responsive care. How diversity shapes collaboration in care networks is discussed in five overarching themes; (1) Disconnection in collaborative care, highlighting a persistent mismatch between the perspectives of care recipients, carers and professionals on what constitutes for adequate collaboration, often leading to misalignment in expectations and practices, complicating collaboration in a true partnership; (2) Othering in care networks, Othering was explicitly recognized by care recipients and carers in facing the assumptions and (un)conscious bias from professionals they had to deal with. They were aware that they are treated differently because they belong to a minority population. Carers explicitly emphasized having to deal with discriminatory practices, based on their cultural and religious backgrounds. In addition, when challenges in the collaboration where experienced by professionals were they attributed by professionals to carers with a migration background, ignoring their own professional role within difficult collaboration; (3) Epistemic injustice in care networks, epistemic injustice became visible when care recipient' and carer' knowledge was not acknowledged but downplayed and silenced by professionals; (4) An intersectional perspective in care networks, by embracing intersectionality, professionals and policymakers can challenge (un)conscious assumptions, recognize both difference and sameness amongst care recipients and carers with a migration background, unveil power dynamics within the collaboration which lead to health inequity. All necessary to create conditions for genuine partnerships; and (5) Critical reflexivity and ongoing dialogue, is required to enable an inclusive way of collaboration. This is an ongoing process of learning that needs to take place in reciprocity between care recipients, carers, and professionals. Building on these insights, sustainable change in healthcare requires commitment from policymakers, educators, and professionals to embed diversity-responsive practices throughout all levels of care and educational programs of healthcare professionals and social work. Embracing critical reflexivity and intersectionality not only challenges existing power imbalances but also fosters shared understanding of how adequate collaboration should be put in practice, essential for effective partnerships.

Samenvatting

Centraal in dit proefschrift staat het kritisch begrijpen van hoe aspecten van diversiteit, in wisselwerking met elkaar, de samenwerking tussen professionals en mantelzorgers beïnvloeden binnen zorgnetwerken rondom cliënten met een niet-aangeboren hersenletsel en een migratieachtergrond. De focus ligt hierbij op het zichtbaar maken van onderliggende machtsdynamieken, met als doel bestaande ongelijkheden aan te pakken. Dit proefschrift beoogt inzicht te verschaffen in de ervaringen van cliënten, mantelzorgers en professionals in diverse zorgnetwerken, en zo bij te dragen aan een meer inclusievere vorm van samenwerking in zorgnetwerken.

Hoofdstuk 1 gaat in op de achtergrond en methodologie van dit proefschrift. Mensen met niet-aangeboren hersenletsel worden geconfronteerd met ingrijpende veranderingen in hun dagelijks leven en raken vaak in meer of mindere mate afhankelijk van zorg door anderen. Deze zorg wordt verleend binnen zorgnetwerken, waarin professionals samenwerken met mantelzorgers. Mantelzorgers van mensen met niet-aangeboren hersenletsel ervaren een hogere zorglast dan mantelzorgers van mensen met andere aandoeningen, mede vanwege het langdurige en complexe karakter van de zorg. De Nederlandse overheidsbeleid legt veel nadruk op de inzet van informele zorg voor mensen met gezondheids- en welzijnsbehoeften in hun eigen leefomgeving. Hoewel het belang van een goede samenwerking tussen professionals en mantelzorgers duidelijk is, wordt in bestaand onderzoek en mantelzorgbeleid onvoldoende aandacht besteed aan de ervaringen van mantelzorgers met een migratieachtergrond. Onder mantelzorgers met een migratieachtergrond bestaat een urgente behoefte aan professionele ondersteuning, aangezien zij een verhoogd risico lopen op overbelasting. Tegelijkertijd ervaren zij aanzienlijke barrières bij het verkrijgen van passende zorg, onder andere door gebrekkige communicatie en een gebrek aan vertrouwen in professionals. Professionals geven aan zich vaak onvoldoende toegerust te voelen om mantelzorgers en cliënten met een migratieachtergrond adequaat te ondersteunen. Specifiek beleid en gerichte interventies ontbreken grotendeels.

Voor dit proefschrift is participatief actieonderzoek gehanteerd als overkoepelend onderzoeksdesign. De participatie van cliënten met niet-aangeboren hersenletsel, mantelzorgers met een migratieachtergrond en professionals werd nagestreefd via betrokkenheid van de community of practice, critical friends en studenten van de opleiding ergotherapie, evenals de deelnemers aan de verschillende deelstudies. Een intersectioneel perspectief vormde de theoretische basis van dit onderzoek. Dit perspectief biedt een kader om te begrijpen hoe verschillende dimensies van diversiteit in interactie met elkaar patronen van (on)gelijkheid creëren in het leven van mensen, in sociale normen, culturele overtuigingen en institutionele structuren. Het maakt zichtbaar wat de gevolgen van deze interacties zijn op het gebied van macht, sociale ongelijkheid en gezondheidsverschillen. Dit proefschrift

beperkt zich niet tot culturele verschillen, maar onderzoekt juist de invloed van meerdere, elkaar kruisende aspecten van diversiteit in zorgnetwerken. Het intersectionele perspectief helpt om de diversiteit van mantelzorgervaringen te erkennen en is ingezet om ongelijkheid en machtsstructuren binnen zorgnetwerken aan zichtbaar te maken.

Hoofdstuk 2 onderzoekt de samenwerking tussen professionals en mantelzorgers aan de hand van een literatuurstudie en thematische synthese. Het doel is meer inzicht te krijgen in de ervaringen en perspectieven van professionals, om zo toekomstige zorgnetwerken te versterken. Systematisch literatuuronderzoek in PubMed, Medline, PsycINFO, Embase, Cochrane/Central en CINAHL leverde 2828 artikelen op. Na selectie op basis van trefwoorden, inclusiecriteria en methodologische beoordeling, werden uiteindelijk 22 artikelen opgenomen in de thematische synthese. Samenwerken met mantelzorgers vraagt van professionals een andere benadering, waarbij specifieke aandacht voor de mantelzorger nodig is, iets wat nu vaak onderbelicht blijft door de focus op de client. Dit is lastig vanwege belemmeringen op beleidsmatig en individueel niveau. Richtlijnen en training zijn noodzakelijk, zeker gezien de beleidsveranderingen in Nederland waarbij informele zorg een centralere rol krijgt.

Hoofdstuk 3 verkent via een scoping review hoe dimensies van diversiteit en hun onderlinge verwevenheid momenteel worden gerepresenteerd in mantelzorgonderzoek. Met de zoektermen 'mantelzorg' en 'intersectionaliteit' werden 342 artikelen gevonden in PubMed, PsychINFO, Cochrane Library en CINAHL. Volgens PRISMA-richtlijnen werden 28 artikelen geselecteerd. Deze studies werden geanalyseerd met een speciaal voor deze review ontwikkeld coderingsschema gebaseerd op intersectionaliteit. De review toont aan dat diversiteitsaspecten grotendeels onderbelicht blijven, met namen in hun onderlinge samenhang en vanuit een kritisch perspectief. Een intersectionele benadering biedt een genuanceerd begrip van zorgervaringen, doordat het niet alleen afzonderlijke sociale identiteiten onderzoekt, maar ook hun onderlinge verwevenheid in hun context.

Hoofdstuk 4 onderzoekt het perspectief van cliënten op de geboden zorg binnen zorgnetwerken. Het doel is een contextueel begrip te verkrijgen van de complexiteit aan de hand van individuele ervaringen. Er werden negen semigestructureerde interviews gehouden met cliënten met niet-aangeboren hersenletsel en een migratieachtergrond. Daarnaast werd een secundaire stakeholderanalyse uitgevoerd onder professionals, mantelzorgers en cliënten die betrokken waren bij de community of practice of andere studies binnen dit proefschrift. Op basis van clientvignetten werden vier intersectionele mechanismen geïdentificeerd die bijdragen aan het in stand houden van gezondheidsongelijkheid: (1) omgaan met diversiteit, (2) gender gerelateerde eenzaamheid, (3) verborgen uitdagingen, en (4) het ter discussie stellen van aannames. Na ontslag uit het ziekenhuis vallen mensen met niet-aangeboren hersenletsel en een migratieachtergrond vaak in een sociaal isolement, met onvoldoende steun en met

financiële problemen. Ze raken uit beeld van het zorgsysteem. Diversiteit responsieve zorg ontbreekt, en cliënten worden regelmatig geconfronteerd met stereotype aannames van professionals. Wanneer zij deze ervaringen willen bespreken, ervaren zij epistemisch onrecht. Kritische bewustwording van gezondheidsongelijkheid en onderliggende mechanismen is een noodzakelijke eerste stap, richting diversiteit responsieve zorg, voor professionals, instellingen en beleid.

Hoofdstuk 5 richt zich op de ervaringen van mantelzorgers. Een intersectioneel geïnformeerd kwalitatief onderzoek werd uitgevoerd via drie informele groepsgesprekken (N=32), semigestructureerde interviews (N=21) en drie dialoogsessies (N=7). Drie thema's kwamen naar voren als lagen van de mantelzorgervaring: (a) *Ik moet door*, over persoonlijke ervaringen en sociale positie; (b) *De worsteling van samen zorgen*, over hoe familieverwachtingen de zorglast vergroten; en (c) *Vertrouwen is balanceren*, over de invloed van professionele steun. Het vertrouwen in professionals bleek kwetsbaar en afhankelijk van organisatorische en beleidsmatige contexten. Mantelzorgers rapporteerden uitsluiting en discriminatie. Bij het melden hiervan ervoeren zij epistemisch onrecht. De noodzaak van diversiteit responsief beleid binnen zorgorganisaties is evident. Mantelzorgers met een migratieachtergrond moeten zich gehoord voelen om zorg passend mogelijk te maken.

Hoofdstuk 6 onderzoekt perspectieven van professionals. Een intersectioneel kwalitatief onderzoek werd uitgevoerd met informele gesprekken (N=12) en semigestructureerde interviews (N=17). Vier thema's kwamen naar voren: (a) *De moeilijke Ander*, waarin professionals reflecteerden op de problemen in de samenwerking; (b) *De afhankelijke Ander*, waarbij zij erkenden dat deze moeilijkheden mede voortkwamen uit de zorgcontext; (c) *Het ongemakkelijke zelf*, waarin gevoelens van onzekerheid en handelingsverlegenheid aan bod kwamen; en (d) *Het reflexieve zelf*, waarin sommigen hun eigen identiteit en blinde vlekken onderzochten. Deze thema's maken spanningen, vooroordelen en machtsongelijkheid zichtbaar die bijdragen aan gezondheidsongelijkheid binnen zorgnetwerken.

Hoofdstuk 7 bevat de algemene discussie en bespreekt de belangrijkste inzichten, methodologische overwegingen en implicaties voor beleid, praktijk, onderwijs en onderzoek. Uit de hoofdstukken blijkt dat er sprake is van structurele ongelijkheid in zorgnetwerken en dat machtsdynamieken de samenwerking tussen professionals en mantelzorgers met een migratieachtergrond belemmeren. De invloed van diversiteit op samenwerking wordt geanalyseerd aan de hand van vijf overkoepelende thema's: (1) Verbinding ontbreekt in de samenwerking, door een mismatch in verwachtingen en opvattingen; (2) Uitsluiting in zorgnetwerken, door (on)bewuste vooroordelen en discriminatie; (3) Epistemisch onrecht, waarbij kennis van mantelzorgers en zorgontvangers niet serieus wordt genomen; (4) Intersectioneel perspectief, dat aannames doorbreekt en machtsdynamieken blootlegt; en

(5) Kritische reflectie en dialoog, als fundament voor inclusieve samenwerking. Duurzame verandering in de zorg vereist inzet van beleidsmakers, opleiders en professionals om diversiteit responsieve zorg structureel te verankeren. Door kritisch te reflecteren en intersectionaliteit te omarmen, ontstaat een gedeeld begrip over wat adequate samenwerking betekent, essentieel voor effectieve en inclusieve zorgnetwerken.

About the Author

Rieke van Dijk – Hengelaar was born on 28 July 1984 in Sneek, the Netherlands. She received her HAVO diploma from Katholiek Gelders Lyceum Arnhem in 2002. In 2007, she obtained her Bachelor of Science degree in Occupational Therapy from HAN university of applied science in Nijmegen, based on her bachelor thesis titled '*Play as key to development for children with cerebral palsy in Nepal*'. After completing her bachelor's degree, she has worked as an occupational therapist in acquired brain injury rehabilitation in different settings, including a stroke unit in the hospital, a rehabilitation center, and primary care, until 2013. Additionally, she still is involved with the NGO Sama Nepal which focusses on inclusive education for children with special needs in Nepal, and was involved with HoopsCare, an NGO in Ghana that promotes participation through sports. Parallel to her clinical work, she served as a lecturer at HAN university of applied science from 2007 to 2009, teaching courses on evidence-based practice and neurorehabilitation. She later earned a second Bachelor of Science degree, in Anthropology and Sociology, from the Radboud University in Nijmegen. Her thesis was titled '*Social discourse on participation of people suffering from polio in Ghana*'. In 2013, she obtained her Master of Science in Development Studies from the Radboud University, based on her master thesis '*Caregiver wellbeing in Nepal explored through an intersectional lens*'. That same year, she began teaching in the Bachelor of Science in Occupational Therapy program at the Amsterdam University of Applied Sciences (AUAS). Before starting as a lecturer, she obtained her BEQ qualifications. Within the bachelor program at AUAS, she contributed to curriculum development, served on the curriculum committee, coordinated alumni relations, taught in year 1, 2 and 3 and was part of the organization committee for the Occupational Science Europe Conference held at AUAS in 2019. She currently supervises and examines bachelor thesis projects. Additionally, she works as a coordinator for diversity, equity and inclusion within the Faculty of Health, Sports and Physical Activity at AUAS. Since 2018, she also serves as a lecturer within the Master of Science in Occupational Therapy program at AUAS. In this role, she teaches qualitative and participatory research methodologies and supervises and examines master thesis projects. Between 2021 and 2024, she contributed as a lecturer within a PhD course 'Intersectionality & I' at AmsterdamUMC VUmc location. She has also delivered guest lectures at institutions including the Cohehre academy, Movisie, Dutch Brain Injury Association, occupational therapy program at HOgent in Gent Belgium, the interprofessional master's program at HAWK Hildesheim in Germany, the occupational therapy program at Stellenbosh University in South Africa, and at the European Centre for Social Policy and Research. In 2017, she began a pre-PhD trajectory, which resulted in funding and ethical approval for her PhD research. She has presented her PhD research, through workshops and oral presentations, at numerous national and international conferences; European Forum on Primary Care (EFPC) in Riga and Porto, European Network of Occupational Therapy in Higher

Education (ENOTHE) in Nijmegen, Zagreb and Oviedo, Council of Occupational Therapy for the European Countries (COTEC) in Galway, World Federation of Occupational Therapy (WFOT) in South Africa, the Other conference in Durban South Africa, Intersectionality and Health conference in Gent, OT-Europe conference in Krakow, International Conference on Integrated Care in Dublin and Odense, Occupational Science Europe (OSE) in Hildesheim, Amsterdam, online and Odense, the European Social Work Conference in Amsterdam, and conference of the Dutch occupational therapy association, and of the Dutch sociology association.

PhD portfolio

A total of 27,5 ects of PhD-training were obtained in the following courses:

Intersectionality & I - Department Ethics, Law and Humanities, Amsterdam Public Health Research Institute, Amsterdam UMC, location VUmc (3 ects)

Gender & Migration – Radboud University (2 ects)

International migration: theories, causes and consequences – Malmö University (7,5 ects)

Research Integrity - Department Ethics, Law and Humanities, Amsterdam Public Health Research Institute, Amsterdam UMC, location VUmc (2 ects)

Qualitative Research Methodology - Department Ethics, Law and Humanities, Amsterdam Public Health Research Institute, Amsterdam UMC, location VUmc. (4 ects)

Participatory Action Research – School for Participation in Amsterdam (3 ects).

Narrative Methodology – Karolinska Institutet (4 ects)

Writing a scientific article - Department Ethics, Law and Humanities, Amsterdam Public Health Research Institute, Amsterdam UMC, location VUmc. (2 ects)

List of publications

Hengelaar, A. H., Verdonk, P., Hartingsveldt, M. V., & Abma, T. (2025). Experiences of Disadvantage and Privilege of Care Recipients With a Migration Background in Acquired Brain Injury Rehabilitation: An Intersectional Analysis. *Health & Social Care in the Community*, 2025(1). <https://doi.org/10.1155/hsc/9074966>

Hengelaar, A.H., Van Hartingsveldt, M., Abma, T., & Verdonk, P. (2025). Deconstructing the Self-Other Binary in Care Networks by Unravelling Professional' Perspectives through an Intersectional Lens. *Health Care Analysis*. <https://doi.org/10.1007/s10728-024-00504-z>

Hengelaar, A.H., Verdonk, P., van Hartingsveldt, M., & Abma, T. (2024). A sense of injustice in care networks: An intersectional exploration of the collaboration between professionals and carers with a migration background. *Social Science & Medicine* (1982), 356, 117169. <https://doi.org/10.1016/j.socscimed.2024.117169>

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Hengelaar, A.H., van Hartingsveldt, M., Wittenberg, Y., van Etten-Jamaludin, F., Kwekkeboom, R., Satink, T., 2018. Exploring the collaboration between formal and informal care from the professional perspective-A thematic synthesis. *Health Soc.Care Community* 26 (4), 474–485. <https://doi.org/10.1111/hsc.12503>

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Pijpers, R., Wittenberg, Y., Hengelaar, R., Scherpenzeel, R., & de Bruijn, I. (2022). Inclusieve mantelzorgondersteuning: wat is dat en hoe ga je er mee aan de slag? *Movisie*. Available from <https://www.movisie.nl/inclusieve-mantelzorgondersteuning>

Wittenberg, Y. & Hengelaar, R. (2022). Ruimte voor diversiteit. *Samenwerking mantelzorgers en professionals*. *Vakblad Sociaal Werk*, (23)6, 16-18. <https://doi.org/10.1007/s12459-022-1520-y>.

Hengelaar, R. & Wittenberg, Y. (2022). Heb oog voor diversiteit onder mantelzorgers. *Sociale Vraagstukken*. Te raadplegen op <https://www.socialevraagstukken.nl/heb-oog-voordiversiteit-onder-mantelzorgers/>

Engelen, A-M., Regina Silva, C., Zango Martin, I., Gracia Cloete, L., Schiller, S., Nyirankumbuye Kagwiza, J., Hengelaar, R., & Celik, Z. (2020). Community development in occupational therapy education: learning from global experiences. In S. Saúde , M. A. Raposo , N. Pereira , & A. I. Rodrigues (Eds.), *Teaching and learning practices that promote sustainable development and active citizenship* (pp. 276-305). IGI Global Publishing. <https://doi.org/10.4018/978-1-7998-4402-0>

Hengelaar, R. & van Gils, A., (2017) Context. In: *Grondslagen van de ergotherapie*. le Granse, M., van Hartingsveldt, M. & Kinébanian, A. (eds). 5e druk ed. Houten: Bohn Stafleu van Loghum, p. 205-218.

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