Unveiling inequity: diversity and power in collaborative care networks

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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.

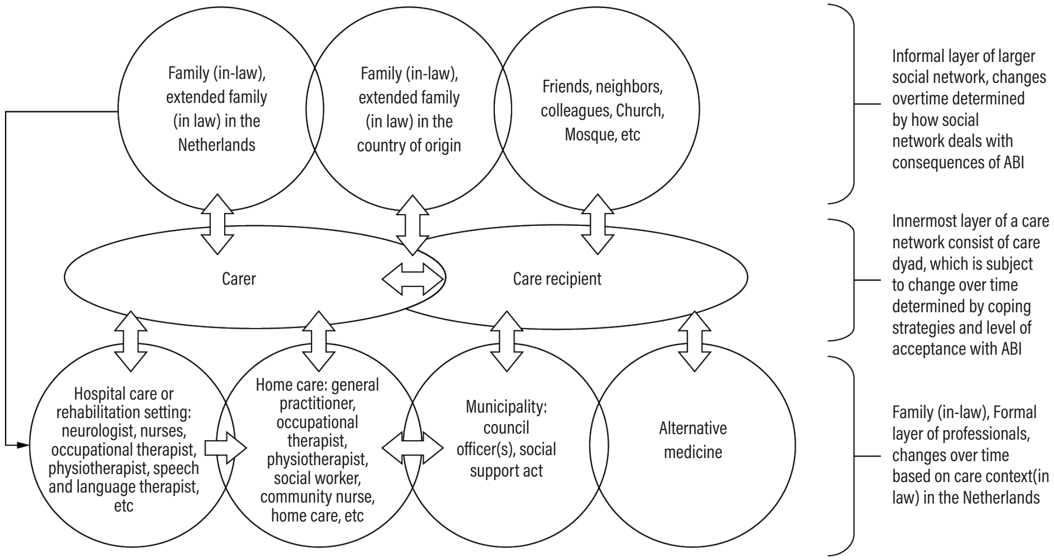

Figure 1. Visualization of layered care network

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 × migration × 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 heterogenous 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. Constancia	
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 Netherland 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 Keti 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 O*thering* 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 O*thering*, 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.

References

Abma, T. A. (2019). Dialogue and deliberation: New approaches to including patients in setting health and healthcare research agendas. Action Research, 17(4), 429–450. https://doi.org/10.1177/1476750318757850

Abma, T. A., Cook, T., Rämgård, M., Kleba, E., Harris, J., & Wallerstein, N. (2017). Social impact of participatory health research: Collaborative non-linear processes of knowledge mobilization. Educational Action Research, 25(4), 489–505. https://doi.org/10.1080/09650792.2017.1329092

Abma, T. A., & Stake, R. E. (2014). Science of the Particular: An Advocacy of Naturalistic Case Study in Health Research. Qualitative Health Research, 24(8), 1150–1161. https://doi.org/10.1177/1049732314543196

Abrams, J. A., Tabaac, A., Jung, S., & Else-Quest, N. M. (2020). Considerations for employing intersectionality in qualitative health research. Social Science & Medicine, 258, 113138. https://doi.org/10.1016/j.socscimed.2020.113138

Agyemang, C., Seeleman, C., Suurmond, J., & Stronks, K. (2007). Racism in health and health care in Europe: Where does the Netherlands stand? The European Journal of Public Health, 17(3), 240–241. https://doi.org/10.1093/eurpub/ckm040

Ahlberg, B. M., Hamed, S., Thapar-Björkert, S., & Bradby, H. (2019). Invisibility of Racism in the Global Neoliberal Era: Implications for Researching Racism in Healthcare. Frontiers in Sociology, 4, 61. https://doi.org/10.3389/fsoc.2019.00061

Ahmed, S. (2019). What's the use? On the uses of use. Duke university press.

Akbulut, N., & Razum, O. (2022). Why Othering should be considered in research on health inequalities: Theoretical perspectives and research needs. SSM - Population Health, 20, 101286. https://doi.org/10.1016/j.ssmph.2022.101286

Aldrin Salskov, S. (2020). A Critique of Our Own? On Intersectionality and "Epistemic Habits" in a Study of Racialization and Homonationalism in a Nordic Context. NORA - Nordic Journal of Feminist and Gender Research, 28(3), 251–265. https://doi.org/10.1080/08038740.2020.1789218

Auerback, R. (2021). Just How Testimonial, Epistemic, Or Correctable Is Testimonial Injustice? International Journal of Philosophical Studies, 29(4), 559–576. https://doi.org/10.1080/09672559.2021.1997394

Avelino, F. (2021). Theories of power and social change. Power contestations and their implications for research on social change and innovation. Journal of Political Power, 14(3), 425–448. https://doi.org/10.1080/2158379X.2021.1875307

Bacevic, J. (2023). Epistemic injustice and epistemic positioning: Towards an intersectional political economy. Current Sociology, 71(6), 1122–1140. https://doi.org/10.1177/00113921211057609

Badou, M., Cadat-Lampe, M., Felten, H., Kros, K., Yohannes, R., Zemouri, C., & de Zwart, O. (2023). Verkenning Discriminatie en Racisme in de zorg. Movisie.

Bain, Z. (2023). Mills's account of white ignorance: Structural or non-structural? Theory and Research in Education, 21(1), 18–32. https://doi.org/10.1177/14778785231162779

Boer, A. de, Klerk, Mirjam de, Verbeek-Oudijk, Debbie, & Plaisier, I. (2020). Blijvende bron van zorg: Ontwikkelingen in het geven van informele hulp 2014-2019. Sociaal en Cultureel Planbureau. https://www.scp.nl/publicaties/publicaties/2020/12/09/blijvende-bron-van-zorg

Bowleg, L. (2021). Evolving Intersectionality Within Public Health: From Analysis to Action. American Journal of Public Health, 111(1), 88–90. https://doi.org/10.2105/AJPH.2020.306031

Brown, C. E., Marshall, A. R., Snyder, C. R., Cueva, K. L., Pytel, C. C., Jackson, S. Y., Golden, S. H., Campelia, G. D., Horne, D. J., Doll, K. M., Curtis, J. R., & Young, B. A. (2023). Perspectives About Racism and Patient-Clinician Communication Among Black Adults With Serious Illness. JAMA Network Open, 6(7), e2321746. https://doi.org/10.1001/jamanetworkopen.2023.21746

Bussemaker, J., Bogaerts, G., Dannenberg, E., Hillhorst, P., Ismaili M'hamdi, H., Kraaij-Dirkzwager, M., Kremer, J., Leerink, B., Ouwehand, A., van der Steen, M., & Driessen, S. (2022). Anders leven en zorgen: Naar een gelijkwaardig samenspel tussen naasten, vrijwilligers en beroepskrachten. Raad voor Volksgezondheid en Samenleving.

Cardiff, S., & van Lieshout, F. (2014). Het kritisch-creatief hermeneutisch data-analyseraamwerk: Analyseren met in plaats van voor participanten. KWALON, 19(2). https://doi.org/10.5117/2014.019.002.030

Carlsson, H. (2023). Migrants' pathways to aged care: The role of local relationships of care in facilitating access for super-diverse older populations. Ageing and Society, 43(7), 1502–1529. https://doi.org/10.1017/S0144686X21001240

Cebrián, G., Grace, M., & Humphris, D. (2015). An Action Research Project for Embedding Education for Sustainable Development in a University Curriculum: Processes and Prospects. In W. Leal Filho, L. Brandli, O. Kuznetsova, & A. M. F. do Paço (Eds.), Integrative Approaches to Sustainable Development at University Level (pp. 707–720). Springer International Publishing. https://doi.org/10.1007/978-3-319-10690-8_48

Claeys, A., Berdai-Chaouni, S., Tricas-Sauras, S., & De Donder, L. (2021). Culturally Sensitive Care: Definitions, Perceptions, and Practices of Health Care Professionals. Journal of Transcultural Nursing, 32(5), 484–492. https://doi.org/10.1177/1043659620970625

Cottagiri, S. A., & Sykes, P. (2019). Key health impacts and support systems for informal carers in the UK: A thematic review. JOURNAL OF HEALTH AND SOCIAL SCIENCES. https://doi.org/10.19204/2019/kyhl11

Crenshaw, K. (1991). Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color. Stanford Law Review, 43(6), 1241. https://doi.org/10.2307/1229039

Cummings, S., Dhewa, C., Kemboi, G., & Young, S. (2023). Doing epistemic justice in sustainable development: Applying the philosophical concept of epistemic injustice to the real world. Sustainable Development, 31(3), 1965–1977. https://doi.org/10.1002/sd.2497

Davis, K. (2008). Intersectionality as buzzword: A sociology of science perspective on what makes a feminist theory successful. Feminist Theory, 9(1), 67–85. https://doi.org/10.1177/1464700108086364

Davis, K. (2020). Who owns intersectionality? Some reflections on feminist debates on how theories travel. European Journal of Women's Studies, 27(2), 113–127. https://doi.org/10.1177/1350506819892659

Dedding, C., Groot, B., Slager, M., & Abma, T. (2022). Building an alternative conceptualization of participation: From shared decision-making to acting and work. Educational Action Research, 1–13. https://doi.org/10.1080/09650792.2022.2035788

del Río-Lozano, M., García-Calvente, M. del M., Marcos-Marcos, J., Entrena-Durán, F., & Maroto-Navarro, G. (2013). Gender Identity in Informal Care: Impact on Health in Spanish Caregivers. Qualitative Health Research, 23(11), 1506–1520. https://doi.org/10.1177/1049732313507144

del-Pino-Casado, R., Frías-Osuna, A., Palomino-Moral, P. A., & Ramón Martínez-Riera, J. (2012). Gender Differences Regarding Informal Caregivers of Older People: Gender Differences in Caregiving. Journal of Nursing Scholarship, 44(4), 349–357. https://doi.org/10.1111/j.1547-5069.2012.01477.x

Detaille, S. I., De Lange, A., Engels, J., Pijnappels, M., Hutting, N., Osagie, E., & Reig-Botella, A. (2020). Supporting Double Duty Caregiving and Good Employment Practices in Health Care Within an Aging Society. Frontiers in Psychology, 11, 535353. https://doi.org/10.3389/fpsyg.2020.535353

Drewniak, D., Krones, T., & Wild, V. (2017). Do attitudes and behavior of health care professionals exacerbate health care disparities among immigrant and ethnic minority groups? An integrative literature review. International Journal of Nursing Studies, 70, 89–98. https://doi.org/10.1016/j.ijnurstu.2017.02.015

Duijs, S. (2023). Hora Est: The Caring Class: Precarization of paid care workers in long-term care and its relation to health, an intersectional perspective. Podium voor Bioethiek. https://research.vu.nl/en/publications/the-caring-class-precarization-of-paid-care-workers-in-long-term-

Fenger, M., & Simonse, R. (2024). The implosion of the Dutch surveillance welfare state. Social Policy & Administration, 58(2), 264–276. https://doi.org/10.1111/spol.12998

Fricker, M. (2007). Epistemic injustice: Power and the ethics of knowing. Oxford University Press.

Gani, J. K., & Khan, R. M. (2024). Positionality Statements as a Function of Coloniality: Interrogating Reflexive Methodologies. International Studies Quarterly, 68(2), sqae038. https://doi.org/10.1093/isq/sqae038

Ghorashi, H. (2023). Taking racism beyond Dutch innocence. European Journal of Women's Studies, 30(1_suppl), 16S-21S. https://doi.org/10.1177/1350506820978897

Goldman, L., Siddiqui, E. M., Khan, A., Jahan, S., Rehman, M. U., Mehan, S., Sharma, R., Budkin, S., Kumar, S. N., Sahu, A., Kumar, M., & Vaibhav, K. (2022). Understanding Acquired Brain Injury: A Review. Biomedicines, 10(9), 2167. https://doi.org/10.3390/biomedicines10092167

Grant, J. S., & Graven, L. J. (2018). Problems experienced by informal caregivers of individuals with heart failure: An integrative review. International Journal of Nursing Studies, 80, 41–66. https://doi.org/10.1016/j.ijnurstu.2017.12.016

Green, J., & Thorogood, N. (2018). Qualitative methods for health research (4th edition). SAGE.

Greenwood, N., & Smith, R. (2015). Barriers and facilitators for male carers in accessing formal and informal support: A systematic review. Maturitas, 82(2), 162–169. https://doi.org/10.1016/j.maturitas.2015.07.013

Groot, B., Haveman, A., & Abma, T. (2022). Relational, ethically sound co-production in mental health care research: Epistemic injustice and the need for an ethics of care. Critical Public Health, 32(2), 230–240. https://doi.org/10.1080/09581596.2020.1770694

Gustafsson, P. E., Fonseca-Rodríguez, O., Castel Feced, S., San Sebastián, M., Bastos, J. L., & Mosquera, P. A. (2024). A novel application of interrupted time series analysis to identify the impact of a primary health care reform on intersectional inequities in avoidable hospitalizations in the adult Swedish population. Social Science & Medicine, 343, 116589. https://doi.org/10.1016/j.socscimed.2024.116589

Hamed, S., Bradby, H., Ahlberg, B. M., & Thapar-Björkert, S. (2022). Racism in healthcare: A scoping review. BMC Public Health, 22(1), 988. https://doi.org/10.1186/s12889-022-13122-y

Hancock, A.-M. (2019). Empirical Intersectionality: A Tale of Two Approaches. In O. Hankivsky & J. S. Jordan-Zachery (Eds.), The Palgrave Handbook of Intersectionality in Public Policy (pp. 95–132). Springer International Publishing. https://doi.org/10.1007/978-3-319-98473-5_5

Hankivsky, O. (2014). Intersectionality 101. The Institute for Intersectionality Research & Policy, SFU. https://www.researchgate.net/profile/Olena-Hankivsky/publication/279293665_Intersectionality_101/links/56c35bda08ae602342508c7f/Intersectionality-101.pdf

Hankivsky, O. (2020). Beyond gender to intersectionality in NCD policy. European Journal of Public Health, 30(Supplement_5), ckaa165.1250. https://doi.org/10.1093/eurpub/ckaa165.1250

Hankivsky, O., Grace, D., Hunting, G., Giesbrecht, M., Fridkin, A., Rudrum, S., Ferlatte, O., & Clark, N. (2014). An intersectionality-based policy analysis framework: Critical reflections on a methodology for advancing equity. International Journal for Equity in Health, 13(1). https://doi.org/10.1186/s12939-014-0119-x

Hart, T., Driver, S., Sander, A., Pappadis, M., Dams-O'Connor, K., Bocage, C., Hinkens, E., Dahdah, M. N., & Cai, X. (2018). Traumatic brain injury education for adult patients and families: A scoping review. Brain Injury, 32(11), 1295–1306. https://doi.org/10.1080/02699052.2018.1493226

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 & Social Care in the Community, 26(4), 474–485. https://doi.org/10.1111/hsc.12503

Hengelaar, A.H., Wittenberg, Y., Kwekkeboom, R., Van Hartingsveldt, M., & Verdonk, P. (2021). Intersectionality in informal care research: A scoping review. Scandinavian Journal of Public Health, 140349482110278. https://doi.org/10.1177/14034948211027816

Hocking, C. (2021). Occupation in context: A reflection on environmental influences on human doing. Journal of Occupational Science, 28(2), 221–234. https://doi.org/10.1080/14427591.2019.1708434

Hynek, K., Gotehus, A., Methi, F., Nes, R. B., Skirbekk, V., & Hansen, T. (2023). Caregiving + Migrant Background = Double Jeopardy? Associations between Caregiving and Physical and Psychological Health According to Migrant Backgrounds in Norway. International Journal of Environmental Research and Public Health, 20(10), 5800. https://doi.org/10.3390/ijerph20105800

Isham, L., Bradbury-Jones, C., & Hewison, A. (2020). Female family carers' experiences of violent, abusive or harmful behaviour by the older person for whom they care: A case of epistemic injustice? Sociology of Health & Illness, 42(1), 80–94. https://doi.org/10.1111/1467-9566.12986

Johnson, J. L., Bottorff, J. L., Browne, A. J., Grewal, S., Hilton, B. A., & Clarke, H. (2004). Othering and Being Othered in the Context of Health Care Services. Health Communication, 16(2), 255–271. https://doi.org/10.1207/S15327027HC1602_7

Kapilashrami, A., & Hankivsky, O. (2018). Intersectionality and why it matters to global health. The Lancet, 391(10140), 2589–2591. https://doi.org/10.1016/S0140-6736(18)31431-4

Kapinga, L., Huizinga, R., & Shaker, R. (2022). Reflexivity through positionality meetings: Religion, muslims and 'non-religious' researchers. International Journal of Social Research Methodology, 25(1), 103–117. https://doi.org/10.1080/13645579.2020.1853876

Karlsen, L., Mjølstad, B. P., Løfaldli, B. B., & Helvik, A.-S. (2023). Family caregiver involvement and role in hospital at home for adults: The patients' and family caregivers' perspective - a Norwegian qualitative study. BMC Health Services Research, 23(1), 499. https://doi.org/10.1186/s12913-023-09531-3

Kavga, A., Kalemikerakis, I., Faros, A., Milaka, M., Tsekoura, D., Skoulatou, M., Tsatsou, I., & Govina, O. (2021). The Effects of Patients' and Caregivers' Characteristics on the Burden of Families Caring for Stroke Survivors. International Journal of Environmental Research and Public Health, 18(14), 7298. https://doi.org/10.3390/ijerph18147298

Khrebtan-Hörhager, J. (2019). Intersectional Othering and New Border Cultures: Lessons From Italy. Women's Studies in Communication, 42(2), 125–129. https://doi.org/10.1080/07491409.2019.1605193

Kokorelias, K. M., Lu, F. K. T., Santos, J. R., Xu, Y., Leung, R., & Cameron, J. I. (2020). "Caregiving is a full-time job" impacting stroke caregivers' health and well-being: A qualitative meta-synthesis. Health & Social Care in the Community, 28(2), 325–340. https://doi.org/10.1111/hsc.12895

Lagewaard, T. J. (2021). Epistemic injustice and deepened disagreement. Philosophical Studies, 178(5), 1571–1592. https://doi.org/10.1007/s11098-020-01496-x

Laliberte-Rudman, D. (2002). Linking Occupation and Identity: Lessons Learned Through Qualitative Exploration. Journal of Occupational Science, 9(1), 12–19. https://doi.org/10.1080/14427591.2002.9686489

Lam, W. W. Y., Nielsen, K., Sprigg, C. A., & Kelly, C. M. (2022). The demands and resources of working informal caregivers of older people: A systematic review. Work & Stress, 36(1), 105–127. https://doi.org/10.1080/02678373.2022.2028317

Lazard, L., & McAvoy, J. (2020). Doing reflexivity in psychological research: What's the point? What's the practice? Qualitative Research in Psychology, 17(2), 159–177. https://doi.org/10.1080/14780887.2017.1400144

Lebano, A., Hamed, S., Bradby, H., Gil-Salmerón, A., Durá-Ferrandis, E., Garcés-Ferrer, J., Azzedine, F., Riza, E., Karnaki, P., Zota, D., & Linos, A. (2020). Migrants' and refugees' health status and healthcare in Europe: A scoping literature review. BMC Public Health, 20(1), 1039. https://doi.org/10.1186/s12889-020-08749-8

Lei, L., Leggett, A. N., & Maust, D. T. (2023). A national profile of sandwich generation caregivers providing care to both older adults and children. Journal of the American Geriatrics Society, 71(3), 799–809. https://doi.org/10.1111/jgs.18138

Levy, B. S., & Sidel, V. W. (Eds.). (2006). Social injustice and public health. Oxford University Press.

Lieshout, F. van, & Cardiff, S. (2011). Innovative Ways of Analysing Data With Practitioners as Co-Researchers. In J. Higgs, A. Titchen, D. Horsfall, & D. Bridges (Eds.), Creative Spaces for Qualitative Researching (pp. 223–234). SensePublishers. https://doi.org/10.1007/978-94-6091-761-5_22

Lo, R. S. (2018). Changing childhoods: Using queer theory and intersectional methods to reconsider the epistemic resources of children with gay and lesbian parents. Global Studies of Childhood, 8(1), 91–104. https://doi.org/10.1177/2043610618758404

Lobo, E. H., Abdelrazek, M., Grundy, J., Kensing, F., Livingston, P. M., Rasmussen, L. J., Islam, S. M. S., & Frølich, A. (2021). Caregiver Engagement in Stroke Care: Opportunities and Challenges in Australia and Denmark. Frontiers in Public Health, 9, 758808. https://doi.org/10.3389/fpubh.2021.758808

Lutz, H., Vivar, M. T. H., & Supik, L. (Eds.). (2016). Framing Intersectionality (0 ed.). Routledge. https://doi.org/10.4324/9781315582924

Mackenzie, A., & Greenwood, N. (2012). Positive experiences of caregiving in stroke: A systematic review. Disability and Rehabilitation, 34(17), 1413–1422. https://doi.org/10.3109/09638288.2011.650307

Manor, S. (2021). Being a Working Grandmother, Mother, and Daughter at the Same Time: A "Double Sandwich" in a Four-generation Family. Journal of Family Issues, 42(2), 324–344. https://doi.org/10.1177/0192513X20921520

Mapedzahama, V., Rudge, T., University of Sydney, West, S., University of Sydney, Kwansah-Aidoo, K., & Ghana Institute of Journalism. (2018). Making and maintaining racialised ignorance in Australian nursing workplaces: The case of black

African migrant nurses. Australasian Review of African Studies, 39(2), 48–73. https://doi.org/10.22160/22035184/ARAS-2018-39-2/48-73

Mathews, H. F., Burke, N. J., & Kampriani, E. (2015). Anthropologies of cancer in transnational worlds. Routledge.

McCall, L. (2005). The Complexity of Intersectionality. Signs: Journal of Women in Culture and Society, 30(3), 1771–1800. https://doi.org/10.1086/426800

McCartney, G., Popham, F., McMaster, R., & Cumbers, A. (2019). Defining health and health inequalities. Public Health, 172, 22–30. https://doi.org/10.1016/j.puhe.2019.03.023

McIntyre, M., Ehrlich, C., & Kendall, E. (2020). Informal care management after traumatic brain injury: Perspectives on informal carer workload and capacity. Disability and Rehabilitation, 42(6), 754–762. https://doi.org/10.1080/09638288.2018.1508511

McPherson, K. M., Kayes, N. K., Moloczij, N., & Cummins, C. (2014). Improving the interface between informal carers and formal health and social services: A qualitative study. International Journal of Nursing Studies, 51(3), 418–429. https://doi.org/10.1016/j.ijnurstu.2013.07.006

Meyer, S. B., Luong, T. C., Mamerow, L., & Ward, P. R. (2013). Inequities in access to healthcare: Analysis of national survey data across six Asia-Pacific countries. BMC Health Services Research, 13(1), 238. https://doi.org/10.1186/1472-6963-13-238

Mills, C. W. (2015). Global white ignorance. In M. Gross & L. McGoey (Eds.), Routledge International Handbook of Ignorance Studies (1st ed., pp. 217–227). Routledge. https://doi.org/10.4324/9781315867762-27

Montero-Sieburth, M. A. (2020). Who gives "Voice" or "Empowers Migrants" in Participatory Action Research? Challenges and Solutions. Migration Letters, 17(2), 211–218. https://doi.org/10.33182/ml.v17i2.806

Muntinga, M., Bendien, E., Abma, T., & Groot, B. (2024). Participatory action research and intersectionality: A critical dialogical reflection of a study with older adults. Quality in Ageing and Older Adults, 25(1), 9–20. https://doi.org/10.1108/QAOA-03-2023-0024

Muntinga, M. E., Krajenbrink, V. Q. E., Peerdeman, S. M., Croiset, G., & Verdonk, P. (2016). Toward diversity-responsive medical education: Taking an intersectionality-based approach to a curriculum evaluation. Advances in Health Sciences Education, 21(3), 541–559. https://doi.org/10.1007/s10459-015-9650-9

Nalder, E., Fleming, J., Cornwell, P., & Foster, M. (2012). Linked Lives: The Experiences of Family Caregivers During the Transition from Hospital to Home Following Traumatic Brain Injury. Brain Impairment, 13(1), 108–122. https://doi.org/10.1017/BrImp.2012.4

Oliphant, T. (2021). Emerging (information) realities and epistemic injustice. Journal of the Association for Information Science and Technology, 72(8), 951–962. https://doi.org/10.1002/asi.24461

Omran, W., & Yousafzai, S. (2024). Epistemic Injustice and Epistemic Resistance: An Intersectional Study of Women's Entrepreneurship Under Occupation and Patriarchy. Entrepreneurship Theory and Practice, 48(4), 981–1008. https://doi.org/10.1177/10422587231208621

Patin, B., Sebastian, M., Yeon, J., Bertolini, D., & Grimm, A. (2021). Interrupting epistemicide: A practical framework for naming, identifying, and ending epistemic injustice in the information professions. Journal of the Association for Information Science and Technology, 72(10), 1306–1318. https://doi.org/10.1002/asi.24479

Pattillo, M., Stieglitz, S., Angoumis, K., & Gottlieb, N. (2023). Racism against racialized migrants in healthcare in Europe: A scoping review. International Journal for Equity in Health, 22(1), 201. https://doi.org/10.1186/s12939-023-02014-1

Pohlhaus, G. (2014). Discerning the Primary Epistemic Harm in Cases of Testimonial Injustice. Social Epistemology, 28(2), 99–114. https://doi.org/10.1080/02691728.2013.782581

Pont, W., Groeneveld, I., Arwert, H., Meesters, J., Mishre, R. R., Vliet Vlieland, T., Goossens, P., & on behalf of the SCORE-study group. (2020). Caregiver burden after stroke: Changes over time? Disability and Rehabilitation, 42(3), 360–367. https://doi.org/10.1080/09638288.2018.1499047

Rekis, J. (2023). Religious Identity and Epistemic Injustice: An Intersectional Account. Hypatia, 38(4), 779–800. https://doi.org/10.1017/hyp.2023.86

Rønn-Smidt, H., Shim, J. K., Fitzsimmons, A., Larsen, K., & Pallesen, H. (2020). Different Caregiver, Different Collaboration. Journal of Social, Behavioral, and Health Sciences, 14(1). https://doi.org/10.5590/JSBHS.2020.14.1.06

Salad, J., Verdonk, P., De Boer, F., & Abma, T. A. (2015). "A Somali girl is Muslim and does not have premarital sex. Is vaccination really necessary?" A qualitative study into the perceptions of Somali women in the Netherlands about the prevention of cervical cancer. International Journal for Equity in Health, 14(1), 68. https://doi.org/10.1186/s12939-015-0198-3

Satink, T., Josephsson, S., Zajec, J., Cup, E. H. C., de Swart, B. J. M., & Nijhuis-van der Sanden, M. W. G. (2016). Negotiating role management through everyday activities: Narratives in action of two stroke survivors and their spouses. Disability and Rehabilitation, 38(24), 2354–2364. https://doi.org/10.3109/09638288.2015.1129442

Sebring, J. C. H. (2021). Towards a sociological understanding of medical gaslighting in western health care. Sociology of Health & Illness, 43(9), 1951–1964. https://doi.org/10.1111/1467-9566.13367

Shrestha, S., Arora, S., Hunter, A., & Debesay, J. (2023). Changing dynamics of caregiving: A meta-ethnography study of informal caregivers' experiences with older immigrant family members in Europe. BMC Health Services Research, 23(1), 43. https://doi.org/10.1186/s12913-023-09023-4

Steiner, A. M., & Fletcher, P. C. (2017). Sandwich Generation Caregiving: A Complex and Dynamic Role. Journal of Adult Development, 24(2), 133–143. https://doi.org/10.1007/s10804-016-9252-7

Stenberg, J., & Hjelm, K. (2023). Migrant informal caregiver perceptions and experiences of caring for a family member with dementia: A systematic review and thematic synthesis. Journal of Clinical Nursing, 32(9–10), 2178–2192. https://doi.org/10.1111/jocn.16390

Stuij, M., Muntinga, M., Bakker, M., Bendien, E., & Verdonk, P. (2020). Secundaire intersectionele analyse in kwalitatief onderzoek. Amsterdam Public Health onderzoeksinstituut.

Sullivan, A. B., & Miller, D. (2015). Who is Taking Care of the Caregiver? Journal of Patient Experience, 2(1), 7–12. https://doi.org/10.1177/237437431500200103

Tannenbaum, C., Greaves, L., & Graham, I. D. (2016). Why sex and gender matter in implementation research. BMC Medical Research Methodology, 16(1), 145, s12874-016-0247–7. https://doi.org/10.1186/s12874-016-0247-7

Tezcan-Güntekin, H., Özer-Erdogdu, I., Yilmaz-Aslan, Y., Aksakal, T., & Bird, R. (2022). Ethical and Methodological Challenges in Research With Hard-to-Reach Groups: Examples From Research on Family Caregivers for Migrant Older Adults Living With Dementia. The Gerontologist, 62(6), 823–831. https://doi.org/10.1093/geront/gnab179

Tonkens, E. (2018). Liever kwaliteit van leven dan zelfredzaamheid. Tijdschrift voor gezondheidswetenschappen, 96(8), 309–310. https://doi.org/10.1007/s12508-018-0195-1

Tronto, J. C. (2010). Creating Caring Institutions: Politics, Plurality, and Purpose. Ethics and Social Welfare, 4(2), 158–171. https://doi.org/10.1080/17496535.2010.484259

Van Nistelrooij, I., & Visse, M. (2019). Me? The invisible call of responsibility and its promise for care ethics: a phenomenological view. Medicine, Health Care and Philosophy, 22(2), 275–285. https://doi.org/10.1007/s11019-018-9873-7

Van Wees, M., Duijs, S. E., Mazurel, C., Abma, T. A., & Verdonk, P. (2023). Negotiating masculinities at the expense of health: A qualitative study on men working in long-term care in the Netherlands, from an intersectional perspective. Gender, Work & Organization, gwao.12952. https://doi.org/10.1111/gwao.12952

Vanidestine, T., & Aparicio, E. M. (2019). How Social Welfare and Health Professionals Understand "Race," Racism, and Whiteness: A Social Justice Approach to Grounded Theory. Social Work in Public Health, 34(5), 430–443. https://doi.org/10.1080/19371918.2019.1616645

Verdonk, P. (2015). When I say … reflexivity. Medical Education, 49(2), 147–148. https://doi.org/10.1111/medu.12534

Verdonk, P., Muntinga, M., Leyerzapf, H., & Abma, T. (2019). From Gender Sensitivity to an Intersectionality and Participatory Approach in Health Research and Public Policy in the Netherlands. In O. Hankivsky & J. S. Jordan-Zachery (Eds.), The Palgrave Handbook of Intersectionality in Public Policy (pp. 413–432). Springer International Publishing. https://doi.org/10.1007/978-3-319-98473-5_18

West, C. H., Dusome, D. L., Winsor, J., Winther Klippenstein, A., & Rallison, L. B. (2022). Dialoguing With Images: An Expressive Arts Method for Health Research. Qualitative Health Research, 32(7), 1055–1070. https://doi.org/10.1177/10497323221084924

Williams, A., Wang, L., Duggleby, W., Markle-Reid, M., & Ploeg, J. (2017). Gender and sex differences in carers' health, burden and work outcomes: Canadian carers of community-dwelling older people with multiple chronic conditions. International Journal of Care and Caring, 1(3), 331–349. https://doi.org/10.1332/239788217X15079062338928

Wittenberg, Y., Boer, A., Plaisier, I., Verhoeff, A., & Kwekkeboom, R. (2019). Informal caregivers' judgements on sharing care with home care professionals from an intersectional perspective: The influence of personal and situational characteristics. Scandinavian Journal of Caring Sciences, 33(4), 1006–1016. https://doi.org/10.1111/scs.12699

Zanoni, P., & Janssens, M. (2015). The Power of Diversity Discourses at Work: On the Interlocking Nature of Diversities and Occupations. Organization Studies, 36(11), 1463–1483. https://doi.org/10.1177/0170840615593584

Zembylas, M., Bozalek, V., & Shefer, T. (2014). Tronto's notion of privileged irresponsibility and the reconceptualisation of care: Implications for critical pedagogies of emotion in higher education. Gender and Education, 26(3), 200–214. https://doi.org/10.1080/09540253.2014.901718

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.