Unveiling inequity: diversity and power in collaborative care networks

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Chapter 7

General Discussion

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

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

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

Main findings

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

Central to this PhD thesis were the experiences of care recipients and carers with a background of migration, as well as healthcare professionals. While having a migration background is often assumed to be a primary axis of diversity by professionals, care recipients and carers rarely framed it as the most decisive factor influencing their experiences. When having a migration background was referenced by care recipients and carers, this was always in intersection with other aspects of diversity. Nonetheless, across all layers, having a migration background was consistently experienced, by care recipients, carers and professionals alike, as complicating the collaboration. It affected not only how professionals approached treatment and formed assumptions, but also the way in which collaboration took place within care networks (Chapters 2 and 4–6).

Disconnection in collaborative care

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

While Dutch policy recognizes carers as essential partners in care networks, this study has shown that there is a gap between this anticipated situation and the actual collaboration taking place. When professionals struggle to adopt a true partnership, they fall back on the role of being an expert and attribute less value to the knowledge of care recipients and carers. This results in an insufficient and unstructured way of collaborating, in which care is provided in fragmented unity. Collaboration in practice often takes a complementary form in which carers are turned into quasi-professionals. Informal care provision in care networks is essential, but guidelines on how to put this into practice are lacking. At the intersection of informal care and a migration background, it becomes clear that, for some professionals, cultural differences within care networks contributed to stressful experiences and were identified as complicating the collaboration (Chapter 2). At this intersection, it also became clear that when collaboration is experienced as difficult by professionals, accountability takes over. Accountability then emphasizes a focus on measurable outcomes, efficiency and compliance with protocols and guidelines to enhance transparency and quality of care. As an unintended result of this reflex, carers and care recipients with a migration background may become invisible, because they do not fit in standard categories or procedures, so their needs may be overlooked, misinterpreted or excluded (Chapter 6).

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

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

Othering in care networks

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

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

The process of Othering can be seen as a power dynamic within care networks because it involves drawing boundaries between a perceived dominant group (self) and those labelled as different (other). This distinction is not neutral and emphasizes a power dynamic which contributes to health inequity. A self–other binary unfolds in which professionals' sense of self, rooted in their own personal frame of reference and professional identity, is taken as the starting point for collaboration. Professionals tended to position their own worldview, with accompanying personal values, as the norm – that is, as the default perspective on collaboration. As a result, the views, experiences and contexts of carers with a migration background were perceived as different, unfamiliar and even problematic (Chapters 5–6). This finding highlights the importance of paying attention to providing insights to professionals about (un)conscious Othering and the consequences for health and wellbeing of carers who are at the receiving end of this process.

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

Epistemic injustice in care networks

Epistemic injustice is form of injustice in which someone is wronged based on their capacity as a knower (Fricker, 2007, 2018). In this study, epistemic injustice became visible when the knowledge of the care recipient and carer was not acknowledged but rather downplayed and silenced by professionals. It also appeared when assumptions of prejudice by professionals were challenged by care recipients and carers, they did not feel heard or taken seriously by professionals and professional attitudes often remained unchanged (Chapters 4–5). When carers brought discriminatory practices to the attention of professionals or to a higher management level within healthcare organizations, their experiences were often dismissed, which created very painful situations. Epistemic injustice is a harmful power dynamic in the collaboration, because professionals can decide whose experiences or knowledge is true and should be considered and whose can be dismissed. This power dynamic results in health inequity and puts quality care under pressure (Chapter 5). Epistemic injustice contributed to a sense of distrust in professionals and the Dutch healthcare system as a whole, ultimately leaving carers feeling powerless when sharing care with professionals. Carers felt a great dependency on professionals, which created a sense of insecurity (Chapter 5). Care recipients' accounts of epistemic injustice were evident, when the assumptions of professionals were challenged by care recipients, but professionals' assumptions did not change. This is alarming because care recipients argued that choices about their care were often made based on the assumptions of professionals (Chapter 4). Being silenced greatly affects the health and wellbeing of both care recipient and carer because it is a contributor to stress and experienced burden. Although it is the individual responsibility of care recipients and carers to speak up and let their voice be heard, there is also a responsibility on the receiving end to listen. (Un) conscious bias can contribute to significant gaps in healthcare provision, and there is a clear professional responsibility to recognize and address these situations (Chapters 4 and 5).

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

Prejudice within communication works in two ways – by assigning either more or less credibility to the testimony of the speaker based on characteristics such as their social positioning (Garry et al., 2017). Fricker (2007) argues that it is the responsibility of the hearer to gain access to "the just story" of the speaker by a correct interpretation of words and body language. Creating such sensitivity is an ongoing process shaped by aspects of diversity and motivational attitudes that are inherited and change over time through lived experiences (Auerback, 2021). There is a responsibility on the level of healthcare organizations, as well as among individual professionals, to address situations of epistemic injustice (Nielsen et al., 2025). Michaels (2021) argues that it is also necessary to reflect critically on how evidence-based guidelines might be based on bias and thus create situations of epistemic injustice. To achieve this in practice, healthcare organizations and professionals need to have insight into (un)conscious bias, epistemic privilege (Carel & Kidd, 2014) and Tronto's (2010) notion of privileged irresponsibility (Bozalek & Zembylas, 2023; Zembylas et al., 2014). The concept of privileged irresponsibility suggests that people who benefit from a privileged position can remain unaware of inequities experienced by others, and accountability may be deflected by relying on claims of professional neutrality or institutional protocols (Bozalek & Zembylas, 2023).

An intersectional perspective in care networks

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

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

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

In line with this study, Carbado et al. (2013) argue for expanding the scope of intersectionality to better capture the full range of intersecting power structures in society. In line with this, this study adopted an intersectional lens enabling an analysis of care networks as relational spaces shaped by the social positions of stakeholders (Crenshaw, 1991; Hankivsky, 2020; Stuij et al., 2020). Research has increasingly focussed on the experiences and needs of care recipients and carers with a migration background. This PhD thesis contributes to this emerging field by offering insights into collaborative care networks to support the development of diversity-responsive practices, which have begun to be addressed by other scholars and practitioners. For instance, the Pharos project *Taking Care of Caregivers* highlights the experiences of migrant carers for people with dementia (Ahmad et al., 2020). Pijpers and Carlsson (2018) explore outreach to older migrants, while Pijpers et al. (2022) advocate for intersectional policy at the municipal level. Organizations like the Knowledge Platform Inclusive Society (KIS.nl) and the National Network for Inclusive Care (NNIZ.nl) promote inclusion as a key value for healthcare. Samra and Hankivsky (2021) and Sharma (2019) emphasize the importance of using intersectionality to challenge power dynamics in medical institutions. Despite these valuable and necessary developments, healthcare policy often remains narrowly focussed on cultural diversity, with limited attention to broader intersecting aspects of diversity (Badou et al., 2023; Peñuela-O'Brien et al., 2023; van Loenen et al., 2022).

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

Critical reflexivity and ongoing dialogue

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

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

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

Methodological considerations

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

There has been an ongoing national and international debate about the terminology for describing diverse populations with a migration background respectfully. In the Netherlands, the term *person with a migration background* was introduced in 2016 to replace the words *allochtoon* and *autochtoon* (de Ree, 2016), and in 2022, the terminology transitioned to a division between born in the Netherlands and naming a country of origin (CBS, 2021). This is, however, still distinction that is not informative and may lead to stereotyping and evoke negative associations (Bovens et al. 2021). The question also arises: until which generation is it significant to identify a migration background? The narratives of people with a migration background in particular contribute to reinforcing social hierarchies within Dutch society, highlighting an *us-versus-them* mentality, even when social policies seek to address social problems that are experienced by particular groups (Akbulut & Razum, 2022; Helberg-Proctor et al., 2017). This occurs without assuming that care recipients and carers with a migration background are vulnerable by definition (Kremer, 2023). At the start of my PhD research, the research population was defined as *having a non-Western migration background*. In hindsight, this definition implies a rather essentialized view of the research participants. Over the course of the project, the terminology was changed to *carers with a migration background*, with an explicit focus on within-group differences in the group of carers with a migration background. Therefore, in the empirical studies the concept of migration background was used, but within the data collection and analysis emphasis was placed on relevant intersecting aspects of diversity that emerged in the stories of the participants. Still, the terms care recipients and carers with a migration background are not neutral, and it remains to be seen if there can even be a term that is relatively neutral, if exclusion, discrimination and racism continue to exist. However, it is essential to study experiences that are understudied in public health research to aim for a more inclusive approach to care provision.

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

The empirical studies in this PhD thesis were completely rooted in qualitative research, which provides an in-depth understanding of relevant social positions of diverse stakeholders and their experiences in care networks. The research methods used find their origin within the Western world, and to be receptive to decolonial tendencies within research, it would be beneficial to learn from indigenous forms of evaluation to produce research whose voice is heard and whose voice represents world views that are not Western (Smith, 2022). Over the course of my PhD research, critical reflexive practices were put into practice and positionality statements were written by myself, the members of the CoP and the students involved, as well as critical friends. Providing reflexive positionality statements could, however, be open to criticism. Gani and Khan (2024) argue that it must be remembered that positionality statements were founded for the White researcher to better conduct research on the non-White other, albeit in a more ethical way, as the origins of reflexivity as a methodology in anthropology emerged from the practice of studying the "native other". It is thus necessary to recognize that a declaration of privilege can reproduce power hierarchies and reinforce colonial practices. Acknowledging privilege does not prevent someone from taking up space, seeking validation or performing allyship in ways that leave power structures intact and continue to sideline marginalized voices. Humility is therefore necessary when rethinking knowledge and reflecting how my own views and approaches may be influenced by stereotypes and pre-held assumptions. Humility is necessary to recognize that the personal crosses boundaries with the academic within research, and this requires ethical work on behalf of the researcher, especially when doing research which is participatory in nature (Groot & Abma, 2024). Ethical work may be invisible; however it is needed to avoid epistemic injustice within participatory research and ensure meaningful participation, especially of voices that are underrepresented within research (Groot et al., 2022).

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

Implications for policy

An important finding from this study is that current policies in healthcare do not provide professionals with the tools and guidance to collaborate adequately with carers with a migration background. Informal care policy should be developed that emphasizes a partnership approach, in which professionals and carers collaborate with and complement each other. It is important to note that an integral part of informal care policy should additionally focus on supporting carers. Healthcare organizations frequently do not have the resources to dedicate time for professionals to support carers, which results in carer support being offered only if there is time left after attending to care recipients. Lack of support by professionals greatly affects the health and wellbeing of carers, and the impact of providing care by carers should always be considered alongside other interests. Carer support should be formally embedded within care schedules by allocating time specifically for carer support. For example, multidisciplinary care meetings should include dedicated segments to address carer needs, as well as coordination of the collaboration between professionals and carers. In addition, care pathways should integrate check-ins with carers as part of routine assessments to ensure that their well-being and capacity to continue providing care are monitored and supported proactively. Additionally, informal care policy should have an interprofessional character and should be developed for healthcare professionals as well as social workers, as too often a lack of coordination between professionals negatively affects the collaboration in a care network.

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

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

Finally, it became apparent in this study that there should be specific policy on how to deal with situations of discrimination, as these appeared in all stakeholder perspectives in the three empirical studies. Recent studies conducted in the Netherlands (Badou et al., 2023; van Loenen et al., 2022) have also shown that discrimination exists within our healthcare system, although they did not specifically include informal care practices. When developing anti-discrimination policy, it is essential to include minority voices in policy development. Adequately dealing with situations of discrimination and having care recipients and carers feel heard is essential for quality care. Within these policies, specific attention should be given to the prevention of discrimination and providing an environment in which building trust is central. Noteworthy here is the useful framework developed by Van Marlen et al. (2023) for using intersectionality as a basis for assessing current policies and developing anti-discrimination policies in the future.

Implications for practice

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

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

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

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

Implications for education

There are several implications to put forward for educational programmes. First, what it means to become a carer and provide informal care should be part of educational curricula for healthcare and social work professionals. There should be specific focus on possible positive and negative aspects of caring and the impact on everyday life and the caring relationship with the care recipient and larger social network, with an emphasis on sameness and differences within carer experiences. Sameness and difference should be integral with the use of diverse examples, cases, literature (e.g. Claeys et al., 2025; Franzen et al., 2021; Giesbrecht et al., 2021) and (guest) lecturers in the educational programmes of allied health professions and social work. From my own practice experience, I recognize the added value of using diverse cases of lived experiences and inviting diverse carers, like Kofi and Ama, into the educational programme to tell their story to upcoming professionals. There should also be specific attention to the impact of the larger healthcare system, including guidelines and policy with a focus on understanding who benefits and who is excluded. Additionally, educational curricula should specifically focus on teaching upcoming professionals what it takes to work in partnership with carers. Highlighting first and foremost the need to recognize carers in their role and carers' own support needs, as well as truly inviting them to participate in shared care (McPherson et al., 2014; Westerling et al., 2024; Wittenberg et al., 2024). This would be beneficial for all stakeholders involved, as research has shown that coordinating care between professionals, amongst each other and with carers diminishes conflicting ways of working and is thus a responsibility of all professionals involved (McPherson et al., 2014; Westerling et al., 2024). This includes building trust and communication, which are essential components of the care process, and having insight in one's own assumptions and biases towards carers in general

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

Implications for further research

Further research informed by intersectionality would be beneficial within care networks. This PhD thesis researched perspectives of diverse stakeholders; however, the included stakeholders did not belong to the same care networks. Following care networks as a whole and taking a care network journey as a research approach (Davies, et al., 2023) may fill in some of the remaining blanks. Central within a care network journey should be an observational approach, as aspects of power and inequity are often left unsaid and difficult to uncover within conversations. Observations within the different settings encountered by care recipients and carers should be followed by individual interviews and dialogue sessions including diverse stakeholders, as exploding process of power and inequity together would yield even richer results (Abma et al., 2018).

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

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

Conclusions

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

References

Abma, T., Banks, S., Cook, T., Dias, S., Madsen, W., Springett, J., & Wright, M. T. (2018). Participatory research for health and social well-being. Springer Berlin Heidelberg.

Ahmad, M., Van Den Broeke, J., Saharso, S., & Tonkens, E. (2020). Persons With a Migration Background Caring for a Family Member With Dementia: Challenges to Shared Care. The Gerontologist, 60(2), 340–349. https://doi.org/10.1093/geront/gnz161

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

Alpers, L.-M. (2018). Distrust and patients in intercultural healthcare: A qualitative interview study. Nursing Ethics, 25(3), 313–323. https://doi.org/10.1177/0969733016652449

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

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.

Bakkum, M. J., Verdonk, P., Thomas, E. G., Van Rosse, F., Okorie, M., Papaioannidou, P., Likic, R., Sanz, E. J., Christiaens, T., Costa, J. N., Dima, L., De Ponti, F., Van Smeden, J., Van Agtmael, M. A., Richir, M. C., Tichelaar, J., & for the EurOPE consortium. (2023). A Clinical Pharmacology and Therapeutics Teacher's Guide to Race-Based Medicine, Inclusivity, and Diversity. Clinical Pharmacology & Therapeutics, 113(3), 600–606. https://doi.org/10.1002/cpt.2786

Bovens, M., Bokhorst, M., Jennissen, R., & Engbersen, G. (2017). Migration and Classification: Towards a Multiple Migration Idiom. WRR.

Bozalek, V., & Zembylas, M. (2023). Responsibility, privileged irresponsibility and response-ability: Higher Education, Coloniality and Ecological Damage. Springer International Publishing. https://doi.org/10.1007/978-3-031-34996-6

Calvo, R., Jablonska-Bayro, J. M., & Waters, M. C. (2017). Obamacare in action: How access to the health care system contributes to immigrants' sense of belonging. Journal of Ethnic and Migration Studies, 43(12), 2020–2036. https://doi.org/10.1080/1369183X.2017.1323449

Carbado, D. W., Crenshaw, K. W., Mays, V. M., & Tomlinson, B. (2013). INTERSECTIONALITY: Mapping the Movements of a Theory. Du Bois Review: Social Science Research on Race, 10(2), 303–312. https://doi.org/10.1017/S1742058X13000349

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

Carel, H., & Kidd, I. J. (2014). Epistemic injustice in healthcare: A philosophial analysis. Medicine, Health Care and Philosophy, 17(4), 529–540. https://doi.org/10.1007/s11019-014-9560-2

CBS. (2022). CBS introducing new population classification by origin. https://www.cbs.nl/en-gb/news/2022/07/cbs-introducing-new-population-classification-by-origin

Centre for Social Justice and Community Action, & National Coordinating Centre for Public Engagement. (2022). Community-based participatory research: A guide to ethical principles and practice (2nd edition). CSJCA & NCCPE.

Choy, B., Arunachalam, K., S, G., Taylor, M., & Lee, A. (2021). Systematic review: Acculturation strategies and their impact on the mental health of migrant populations. Public Health in Practice, 2, 100069. https://doi.org/10.1016/j.puhip.2020.100069

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

Claeys, A., Berdai-Chaouni, S., Tricas-Sauras, S., & De Donder, L. (2025). Bridging the gaps: Narratives of informal carers of older migrants with dementia using professional care. Ageing and Society, 1–25. https://doi.org/10.1017/S0144686X25000017

Crenshaw, K. (1989). Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics. University of Chicago Legal Forum, 1989(8). https://chicagounbound.uchicago.edu/uclf/vol1989/iss1/8/?utm_source=chicagounbound.uchicago.edu%2Fuclf%2Fvol1989%2Fiss1%2F8&utm_medium=PDF&utm_campaign=PDFCoverPages

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

Davies, E. L., Bulto, L. N., Walsh, A., Pollock, D., Langton, V. M., Laing, R. E., Graham, A., Arnold-Chamney, M., & Kelly, J. (2023). Reporting and conducting patient journey mapping research in healthcare: A scoping review. Journal of Advanced Nursing, 79(1), 83–100. https://doi.org/10.1111/jan.15479

Dawson, J., Laccos-Barrett, K., Hammond, C., & Rumbold, A. (2022). Reflexive Practice as an Approach to Improve Healthcare Delivery for Indigenous Peoples: A Systematic Critical Synthesis and Exploration of the Cultural Safety Education Literature. International Journal of Environmental Research and Public Health, 19(11), 6691. https://doi.org/10.3390/ijerph19116691

de Bruijn, Y. (2025). Critical Reflection into Action: Facilitating Conditions of Antiracist Action among White Youth in the Netherlands. Journal of Youth and Adolescence. https://doi.org/doi.org/10.1007/s10964-025-02169-w

De Coninck, L., Declercq, A., Bouckaert, L., Döpp, C., Graff, M. J. L., & Aertgeerts, B. (2023). The willingness and barriers to collaborate in the care of frail older adults: Perspectives of primary care professionals. BMC Geriatrics, 23(1), 488. https://doi.org/10.1186/s12877-023-04163-y

de Ree, M. (2016). Termen allochtoon en autochtoon herzien. CBS.

DiAngelo, R. (2015). White fragility: Why it’s so hard to talk to White people about racism. The Good Men Project.

Dohmen, M. D. W., Visser, M., Huijg, J. M., Groot, B. C., & Abma, T. A. (2025). Morality in the Making: The Collaborative Relationship Between Formal Caregivers, Informal Caregivers, and Nursing Home Residents. The Gerontologist, 65(6), gnaf082. https://doi.org/10.1093/geront/gnaf082

Fiske, S. T., Cuddy, A. J. C., & Glick, P. (2007). Universal dimensions of social cognition: Warmth and competence. Trends in Cognitive Sciences, 11(2), 77–83. https://doi.org/10.1016/j.tics.2006.11.005

Franzen, S., Eikelboom, W. S., Van Den Berg, E., Jiskoot, L. C., Van Hemmen, J., & Papma, J. M. (2021). Caregiver Burden in a Culturally Diverse Memory Clinic Population: The Caregiver Strain Index-Expanded. Dementia and Geriatric Cognitive Disorders, 50(4), 333–340. https://doi.org/10.1159/000519617

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

Fricker, M. (2018). Epistemic Injustice and Recognition Theory: A New Conversation —Afterword. Feminist Philosophy Quarterly, 4(4). https://doi.org/10.5206/fpq/2018.4.6235

Gangarova, T., Yildiz, M., & Kabangu, L. (2025). Racism in German healthcare: Uncovering the construction and silencing of the “other.” Frontiers in Public Health, 12, 1485933. https://doi.org/10.3389/fpubh.2024.1485933

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

Garry, A., Khader, S. J., & Stone, A. (2017). The Routledge companion to feminist philosophy. Routledge.

Giesbrecht, M., Crooks, V. A., Williams, A., & Hankivsky, O. (2012). Critically examining diversity in end-of-life family caregiving: Implications for equitable caregiver support and Canada’s Compassionate Care Benefit. International Journal for Equity in Health, 11(1), 65. https://doi.org/10.1186/1475-9276-11-65

Groenvynck, L., De Boer, B., Hamers, J. P. H., Van Achterberg, T., Van Rossum, E., & Verbeek, H. (2021). Toward a Partnership in the Transition from Home to a Nursing Home: The TRANSCIT Model. Journal of the American Medical Directors Association, 22(2), 351–356. https://doi.org/10.1016/j.jamda.2020.09.041

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

Hammell, K. R. W. (2014). Belonging, occupation, and human well-being: An exploration: Appartenance, occupation et bien-être humain : Une étude exploratoire. Canadian Journal of Occupational Therapy, 81(1), 39–50. https://doi.org/10.1177/0008417413520489

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

Helberg-Proctor, A., Meershoek, A., Krumeich, A., & Horstman, K. (2017). ‘Foreigners’, ‘ethnic minorities’, and ‘non-Western allochtoons’: An analysis of the development of ‘ethnicity’ in health policy in the Netherlands from 1970 to 2015. BMC Public Health, 17(1), 132. https://doi.org/10.1186/s12889-017-4063-8

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

Ho, I. S.-S., McGill, K., Malden, S., Wilson, C., Pearce, C., Kaner, E., Vines, J., Aujla, N., Lewis, S., Restocchi, V., Marshall, A., & Guthrie, B. (2023). Examining the social networks of older adults receiving informal or formal care: A systematic review. BMC Geriatrics, 23(1), 531. https://doi.org/10.1186/s12877-023-04190-9

Hoek, L. J., Van Haastregt, J. C., De Vries, E., Backhaus, R., Hamers, J. P., & Verbeek, H. (2021). Partnerships in nursing homes: How do family caregivers of residents with dementia perceive collaboration with staff? Dementia, 20(5), 1631–1648. https://doi.org/10.1177/1471301220962235

Hovenga, N., Landeweer, E., Zuidema, S., & Leget, C. (2022). Family involvement in nursing homes: An interpretative synthesis of literature. Nursing Ethics, 29(6), 1530–1544. https://doi.org/10.1177/09697330221085774

ICPHR. (2021). Position Paper 6: Participatory Health Research with Migrants: Opportunities, Challenges, and Way Forwards. (Version: September 2021). International Collaboration for Participatory Health Research.

Jacob, J. D., Gagnon, M., Perron, A., & Canales, M. K. (2021). Revisiting the Concept of Othering: A Structural Analysis. Advances in Nursing Science, 44(4), 280–290. https://doi.org/10.1097/ANS.0000000000000353

Jacobson, D., & Mustafa, N. (2019). Social Identity Map: A Reflexivity Tool for Practicing Explicit Positionality in Critical Qualitative Research. International Journal of Qualitative Methods, 18, 160940691987007. https://doi.org/10.1177/1609406919870075

Kidd, I. J., Medina, J., & Pohlhaus, G. M. (2017). The Routledge handbook of epistemic injustice. Routledge, Taylor & Francis group.

Kremer, M. (2023). Bridging social distances in home care in super-diverse settings: A study of workers, clients and care organisations in the Netherlands. International Journal of Care and Caring, 7(3), 391–407. https://doi.org/10.1332/239788221X16686165114021

Kremer, M. (2025). Brandbrief aan de verzorgingsstaat. Uitgeverij vanGennep.

Leyerzapf, H. (2019). Doing diversity: Unsettling the Self-Other binary: Culturaldiversity in Dutch academic health care. Vrije Universiteit.

Leyerzapf, H., Rifi, H., Abma, T., & Verdonk, P. (2020). Veiled ambitions: Female Muslim medical students and their ‘different’ experiences in medical education. In M. Crul, L. Dick, H. Ghorashi, & A. Valenzuela Jr (Eds.), Scholarly Engagement and Decolonisation: Views from South Africa, The Netherlands and the United States (1st ed., pp. 187–213). African Sun Media. https://doi.org/10.18820/9781928314578/07

Lips, S. R., Boxem-Tiemessen, J. C. G., Ligthart, A. M., Schuitmaker-Warnaar, T. J., De Bruijne, M. C., Verhoeven, C. J. M., Verdonk, P., & De Jonge, A. (2024). Bridging Perspectives, Building Resilience: Safety-II Guided Reflexive Dialogues Between Care Professionals and Clients as Part of Developing Integrated Maternity Care. International Journal of Integrated Care, 24(4), 4. https://doi.org/10.5334/ijic.8588

Mantelzorg.nl. (n.d.). Stappenplan—Ondersteuning van mantelzorgers met een migratieachtergrond. https://www.mantelzorg.nl/pro/publicaties/stappenplan-ondersteuning-van-mantelzorgers-met-een-migratieachtergrond/

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

Michaels, J. A. (2021). Potential for epistemic injustice in evidence-based healthcare policy and guidance. Journal of Medical Ethics, 47(6), 417–422. https://doi.org/10.1136/medethics-2020-106171

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

Nielsen, K. M., Nordgaard, J., & Henriksen, M. G. (2025). Fundamental issues in epistemic injustice in healthcare. Medicine, Health Care and Philosophy, 28(2), 291–301. https://doi.org/10.1007/s11019-025-10259-6

Peled, Y. (2018). Language barriers and epistemic injustice in healthcare settings. Bioethics, 32(6), 360–367. https://doi.org/10.1111/bioe.12435

Peñuela-O'Brien, E., Wan, M. W., Edge, D., & Berry, K. (2023). Health professionals' experiences of and attitudes towards mental healthcare for migrants and refugees in Europe: A qualitative systematic review. Transcultural Psychiatry, 60(1), 176–198. https://doi.org/10.1177/13634615211067360

Peoples, H., Satink, T., & Steultjens, E. (2011). Stroke survivors' experiences of rehabilitation: A systematic review of qualitative studies. Scandinavian Journal of Occupational Therapy, 18(3), 163–171. https://doi.org/10.3109/11038128.2010.509887

Pharos. (2025). Infosheet/ Tolken in de zorg.

Pijpers, R., & Carlsson, H. (2018). De impact van het wijkgerichte werken voor de toeleiding naar zorg van oudere migranten: Oudere migranten en het wijkgerichte werken in zorg en welzijn. Tijdschrift voor Gerontologie en Geriatrie, 49(6), 244–252. https://doi.org/10.1007/s12439-018-0271-7

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

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

Pollard, C. (2015). What is the right thing to do: Use of a relational ethic framework to guide clinical-decision-making. International Journal of Caring Sciences, 8(2), 362–368.

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

Roberts, M. L. A., & Schiavenato, M. (2017). Othering in the nursing context: A concept analysis. Nursing Open, 4(3), 174–181. https://doi.org/10.1002/nop2.82

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

Samra, R., & Hankivsky, O. (2021). Adopting an intersectionality framework to address power and equity in medicine. The Lancet, 397(10277), 857–859. https://doi.org/10.1016/S0140-6736(20)32513-7

Schuitmaker-Warnaar, T. J., Gunn, C. J., Regeer, B. J., & Broerse, J. E. W. (2021). Institutionalizing Reflexivity for Sustainability: Two Cases in Health Care. Sustainability, 13(21), 11712. https://doi.org/10.3390/su132111712

Schwartzman, E., Alaei, R., & Rule, N. O. (2023). Accuracy and Consistency in Social Categorization Across Context, Motivation, and Time. Social Cognition, 41(2), 103–136. https://doi.org/10.1521/soco.2023.41.2.103

Sharma, M. (2019). Applying feminist theory to medical education. The Lancet, 393(10171), 570–578. https://doi.org/10.1016/S0140-6736(18)32595-9

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

Smith, L. T. (2022). Decolonizing methodologies: Research and indigenous peoples (Third edition). Bloomsbury Academic.

Starosta, A. J., Mata-Greve, F., Humbert, A., Zheng, Z., Prado, M. G., Au, M. A., Mollis, B., Stephens, K. A., & Hoffman, J. M. (2023). Intersectionality of Systemic Disadvantage on Mortality and Care Following TBI. Journal of Head Trauma Rehabilitation, 38(2), 137–146. https://doi.org/10.1097/HTR.0000000000000830

Stewart, M. A. (2018). Stuck in the middle: The impact of collaborative interprofessional communication on patient expectations. Shoulder & Elbow, 10(1), 66–72. https://doi.org/10.1177/1758573217735325

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

Subramani, S. (2024). Othering and ethics of belonging in migrants' embodied healthcare experiences. Sociology of Health & Illness, 46(8), 1942–1961. https://doi.org/10.1111/1467-9566.13829

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

Unson, C., Njoku, A., Bernard, S., & Agbalenyo, M. (2023). Racial and Ethnic Disparities in Chronic Stress among Male Caregivers. International Journal of Environmental Research and Public Health, 20(12), 6188. https://doi.org/10.3390/ijerph20126188

Van Kemenade, E., De Kuiper, M., Booij, M., & Minkman, M. (2022). How Different Quality Paradigms Undermine a Shared Value Base for Integrated Care: The Need for Collective Reflexivity. International Journal of Integrated Care, 22(1), 5. https://doi.org/10.5334/ijic.5935

van Loenen, T., Hosper, K., & Venderbos, J. (2022). Discriminatie en gezondheid. Over de invloed van discriminatie (in de zorg) op gezondheidsverschillen en wat we hieraan kunnen doen. Pharos.

van Marlen, J., Tupan-Wenno, M., & Baboeram, P. (2023). Eindrapportage Pilot intersectionele blik in de discriminatieaanpak. Echo. https://www.rijksoverheid.nl/documenten/rapporten/2023/04/05/eindrapportage-pilot-intersectionele-blik-in-de-discriminatie-aanpak

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

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

Waling, A., Lyons, A., Alba, B., Minichiello, V., Barrett, C., Hughes, M., Fredriksen-Goldsen, K., Edmonds, S., & Bath, N. (2022). Experiences of informal caregiving among older lesbian and gay adults in Australia. Australasian Journal on Ageing, 41(3), 424–430. https://doi.org/10.1111/ajag.13076

Westerling, U., Hellgren, M., Hermansson, L., & Strid, E. N. (2024). Informal caregivers' experiences of support from a tailored primary healthcare unit for older adults – A focus group study. Scandinavian Journal of Caring Sciences, 38(3), 730–744. https://doi.org/10.1111/scs.13260

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

Wittenberg, Y., Kwekkeboom, R., & Verhoeff, A. P. (2024). "It Is about How Kind They Are": The Significance of Professionals' Attitudes towards Caregivers in the Dutch Care System. Health & Social Care in the Community, 2024(1), 4023865. https://doi.org/10.1155/2024/4023865

Wittenveen, E., Siteur-Scholten, A., & Brandts, M. (2021). Hartenkreten van mantelzorgers. Over de kunst van het samenwerken.

Woldring, J. M., Gans, R. O. B., Paans, W., & Luttik, M. L. (2023). Physicians and nurses view on their roles in communication and collaboration with families: A qualitative study. Scandinavian Journal of Caring Sciences, scs.13185. https://doi.org/10.1111/scs.13185

World Economic Forum. (2025). Blueprint to Closwe the Women's Health Gap: How to Improve Lives and Economies for All. World Economic Forum.

Zarzycki, M., Morrison, V., Bei, E., & Seddon, D. (2023). Cultural and societal motivations for being informal caregivers: A qualitative systematic review and meta-synthesis. Health Psychology Review, 17(2), 247–276. https://doi.org/10.1080/17437199.2022.2032259

Zarzycki, M., Seddon, D., Bei, E., Dekel, R., & Morrison, V. (2022). How Culture Shapes Informal Caregiver Motivations: A Meta-Ethnographic Review. Qualitative Health Research, 32(10), 1574–1589. https://doi.org/10.1177/10497323221110356

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

Zygouri, I., Cowdell, F., Ploumis, A., Gouva, M., & Mantzoukas, S. (2021). Gendered experiences of providing informal care for older people: A systematic review and thematic synthesis. BMC Health Services Research, 21(1), 730. https://doi.org/10.1186/s12913-021-06736-2