# Unveiling inequity: diversity and power in collaborative care networks

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## Citation

Dijk- Hengelaar, A. H. van. (2026, January 21). *Unveiling inequity: diversity and power in collaborative care networks*. Retrieved from https://hdl.handle.net/1887/4285866

## Summary

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

**Chapter 1** elaborates on the background and methodology of this PhD thesis. People who have suffered some form of acquired brain injury, must reconcile immense changes to their daily lives and often have to accept that they have become recipients of care provided by others. Care is provided in care networks where professionals collaborate with informal care. While the importance of adequate collaboration between professionals and carers is evident, current research insufficiently addresses the diverse realities of carers with a migration background. In addition, Dutch government policy emphasises the provision of informal care for people with health and welfare needs in their own living environment, however within current informal care policy there is little attention for carers and care recipients with a migration background. Carers providing informal care for someone with an acquired brain injury experience a higher care burden compared to those providing care to care recipients with other diseases, due to the long-term nature and high level of complex care required. Additionally, amongst carers with a migration background there is an urgent need for support from professionals, as they are more at risk of carer burden than informal carers without a migration background. However, carers with a migration background face significant barriers in accessing adequate care, due to insufficient communication and distrust in professionals. Moreover, professionals often do not feel sufficiently competent in supporting carers and care recipients with a migration background, and there is limited specific policy and few targeted interventions to support them. Participatory Health Research is the research design used in this PhD thesis. Participation of care recipients with acquired brain injury, carers with a migration background and professionals, was sought after through the involvement of the community of practice, critical friends and students from the occupational therapy program, as well as the participants of the different sub studies. An intersectional approach were used as theoretical underpinning, providing a framework for understanding how different dimensions of diversity interact to produce patterns of (dis)advantage in people's lives, social norms, cultural beliefs, institutional structures, and understand the outcomes of these interactions in terms of power, social inequities, and health disparities. This PhD thesis does not solely focus on cultural aspects or differences but goes a step further to explore the influence of the multiple intersecting aspects of diversity in the context of care networks. The intersectionality lens helps to embrace rather than obscure the heterogeneity of peoples lived experiences. In doing so, intersectionality is understood to challenge health inequities and structural disadvantages within care networks.

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

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

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

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

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

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

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