Unveiling inequity: diversity and power in collaborative care networks

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Chapter 4

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

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Abstract

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

Introduction

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

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

Johnson and Diaz (2023) reveal that health inequities exist across the continuum of care for ABI and that race and ethnicity were most impactful on care received after ABI and overall perceived health outcomes. Research from the United States shows, for instance, that with stroke treatment ethnic minorities are underserved and have less confidence in healthcare facilities than people with a majority background (Cruz-Flores et al., 2011). Williams and Ovbiagele (2020) report that post-stroke disparities are widespread and may be attributed to experiences of racism within healthcare systems, which in turn disproportionately affects the health of minorities. It is therefore necessary to recognise that disparities in brain injury care and the fundamental causes of these disparities are social and structural as well as medical and biological in nature (Reeves et al., 2015). Mikolic et al. (2021) show that gender also matters as men and women differ in ABI epidemiology. Women show worse functional, health-related quality of life and mental health outcomes following mild ABI. However, men have a higher likelihood of sustaining a traumatic brain injury, for example. For this study we zoom in on people with ABI who also have a migration background. In the Netherlands, care recipients with a migration background belong to a minority group. However, it must be recognised that there are also differences within the group and that their experiences are based on their social position, which finds its basis in the contextualised intersections (Hankivsky, 2014).

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

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

Methodology

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

This study is part of a larger research study from which the experiences of professionals (Hengelaar et al., 2025) and carers (Hengelaar et al., 2024) have been published. During the interviews, both professionals and carers discussed the role of care recipients in care networks. Segments from the professional interviews and carer interviews and dialogue sessions were used to substantiate the results, shown in Figure 1.

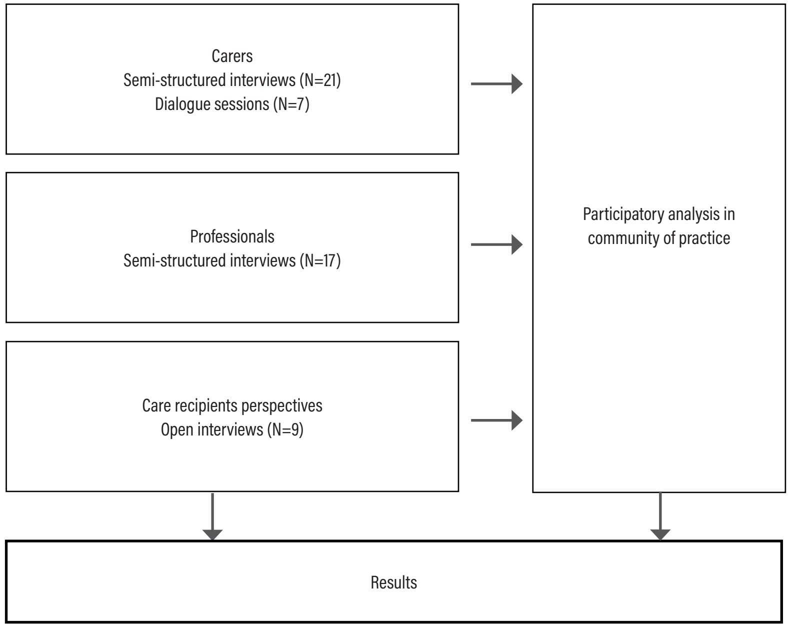

Figure 1. Visualisation data collection and analysis

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

Phase 1: Qualitative study

Participants

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

Table 1. Care recipient characteristics

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

Data collection

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

Intersectional analysis

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

Phase 2: Participatory analysis by the CoP

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

CoP Participants

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

Participatory analysis using intersectionality

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

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

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

Ethical considerations

Ethical approval was granted by the Medical Ethics Review Committee of VU University Medical Centre, project number 2017.395. Informed consent was provided by all participants prior to all forms of data collection. In the participatory analysis specific attention was given to fairness and authenticity of stakeholder accounts, and measures were taken to ensure the inclusion of stakeholders in every step of the research process (Abma et al., 2017). In order to do so we did the following: (1) invited carers, care-recipients and professionals to provide input in the phase of writing the research proposal guiding aim, research questions and demarcation of the larger research project; (2) organized a multi-stakeholder CoP that ran parallel to the research process and provided input from data collection to data analysis; (3) held informal conversations to reach as many care-recipients with a migration background; (4) besides written consent the use of verbal consent was taken into account during ethical approval, allowing for the participation of care recipients who were hesitant to provide written consent. These foci and steps stem from the epistemological belief that knowledge is embedded in social relationships and is deepened when produced collaboratively (Fine, 2010). Additionally, an individual reflexive journal was kept by the first author, critical friend as well as all members of the CoP, because it is important to not only state who you are, but also to reflect critically and self-scrutinize on yourself as a researcher and to explicitly describe how your own social position may have impacted this study (Darwin Holmes, 2020; Gani & Khan, 2024). The reflexive accounts were used as input for the dialogues amongst the first author, the critical friend and the members of the CoP. This influenced the findings because these dialogues deepened the interpretation of the data by bringing in various perspectives. For instance, as someone experienced the same as a research participant or the opposite, both helped to gain a better understanding of the influence of DEI on care recipients experiences.

Results

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

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

Navigating diversity

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

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

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

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

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

Gender-related loneliness

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

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

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

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

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

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

For the CoP members, the fact that care recipients did not speak about getting support from a carer was as much an eye opener as it was a painful observation. The assumption that care recipients with a disability and migration background have family to support them upon discharge is an assumption overly present in professional accounts, and this assumption does not coincide with the reality told by care recipients. Additionally, when professionals lose care recipients out of sight after discharge this has a tremendous impact on their daily lives as they do not seem to find their way back to care organisations which contributes to loneliness.

Hidden challenges

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

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

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

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

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

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

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

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

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

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

Challenging assumptions

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

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

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

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

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

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

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

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

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

‘*Every meeting we have had I learned something new, about myself and why I think the way I do, the work that I do, or my eyes are opened by the story of one of the other CoP members or participants. It would be amazing if every professional who works in complex collaborative networks would have the time to focus on what I call sensitive learning. In my workplace, as is common in others, we have clinical lessons where we discuss new evidence-based interventions for example, but learning about the role diversity has within our work is something we do not create space for. It is a process that you need to go through, it cannot be solved in one meeting or separate meetings, there needs to be a red thread of learning together, asking the difficult questions to realise that there is a layer underneath our work that needs exploring, and I found that the reflexive process we went through very insightful. There is no toolkit, you need to be willing to do the work.*’ (Occupational Therapist)

Discussion

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

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

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

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

Most care recipients disappear from the health care system 'radar' after discharge home, and the question arises about how to keep them in sight of healthcare organisations upon discharge or when it becomes necessary over time. This may signal a severe disadvantage and health inequity, as Johnson and Diaz (2023) show in their international scoping review, according to which persons belonging to the majority population, in comparison to persons with ABI and a migration background, are more often discharged to a rehabilitation center or nursing home rather than to the home context. These groups are thus somehow privileged over people with a disability and migrant background, yet this privilege might be invisible to the people involved. Additionally, being married is often a determining factor in the decision of whether or not a care recipient is able to be discharged home (Nguyen & Connelly, 2017). For several care recipients in our study, divorce occurred after discharge, again leading to severe disadvantages in life and they were met with cultural taboos on divorce within their existing social network. Participants encountered cultural taboos, as has been described in literature (Furtado et al., 2013; Landau & Hissett, 2008). As a result, the care recipients were left to themselves and could no longer find their way back to healthcare. Providing insights in the consequences of (un)conscious privilege within the context of care networks and into power structures that (re)produce privileged positions within healthcare is necessary to overcome health inequities (Schram et al., 2025). Brown & Jones (2024) specifically advocate for the use of a modified privilege walk within healthcare organizations to promote dialogue about privilege and disadvantage within a healthcare setting. A modified privilege walk can create a safe space to discuss 'privilege, race and racism and their impact on daily life' (p.2). Using privilege walks is not without risk and there should be ample attention to potential harm and emotional distress during an following the exercise (Patel & Kutac, 2024)

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

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

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

Methodological considerations

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

What worked well in the recruitment process included the following: informal conversations with civil society organisations and investing time to get to know and built trust among care recipients. Several care recipients subsequently agreed to participate in a formal interview. During this interview, they also provided information tailored to them so they could better explain the interview process. Snowball sampling was used amongst care recipients who did respond to the invitation to interview, and they actively supported the recruitment process.

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

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

Conclusion

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

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Intermezzo

Doing justice, is that possible?

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

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

After almost every interview, every dialogue session, and especially after informal conversations with these kinds of groups, I needed time. Time to realize what I had heard, time to feel what I felt. Time to admit to myself that I did not always know what to do with the sadness, the guilt, the admiration. It was hard to be the outsider. I did not belong to their world, but I felt a deep responsibility to do justice to their stories. Yet the question remained: Can I? Am I even in a position to do so? During the analysis phase, these questions did not go away. Indeed, they became louder. I constantly doubted myself. When the women spoke about discrimination in healthcare, their words sounded raw and powerful. But I wondered: Am I interpreting this correctly? Am I just amplifying what I want to hear to make my point? I was afraid of exaggerating the truth in the name of urgency. So I kept returning to the data, sharing doubts with critical friends and letting the community of practice challenge me. I continued questioning whether I was telling the honest story.

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