

Research Article

Exploring the Sharing and Legitimacy of Experience-Based Knowledge of Living with Acquired Brain Injury in Two Practice Communities

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Background. Involving people with acquired brain injury in service development has the potential to improve service and give experience-based knowledge legitimacy. The objective of this study was to explore experiences of sharing experience-based knowledge of living with acquired brain injury with others, with a particular focus on the conditions for sharing and learning, and the legitimacy of experience-based knowledge. **Materials and Methods.** Using a single case study design, the processes in two groups that were part of a Swedish supportive network for people with acquired brain injury were explored. One group consisted mainly of people with acquired brain injury who authored a blog and the other group consisted of healthcare staff who produced educational material with the involvement of a person with own experience of acquired brain injury. The data consisted of forty-one collective blogs, fifteen semistructured individual interviews, and ten observations from meetings. The data were analysed by utilizing the community of practice framework and the concepts of legitimate peripheral participation and epistemic injustice. **Results.** The findings showed that both groups developed learning processes with a focus on everyday rehabilitation as a joint enterprise. Mutual engagement developed from doing activities together and legitimacy in the groups came from engagement in these activities. In the education group, the ambition to involve people with own experience of acquired brain injury was never realized in practice. Hence, experience-based knowledge of living with acquired brain injury never got legitimacy in the group. **Conclusions.** We conclude that integrating experience-based knowledge from people with own experience of acquired brain injury demands careful and deliberate planning with specific consideration to existing power asymmetries between healthcare professionals and people with own experience. Mitigating epistemic injustice and gaining legitimacy for such knowledge require that people with experience of living with acquired brain injury are recognized as knowledge producers.

1. Background

“Nothing about us without us” is the striking slogan that has emerged from the disability movement [1]. The slogan has been used to communicate the idea that no policy should be developed without the direct participation of members of the groups affected by that policy. This case study explores

sharing experience-based knowledge of living with acquired brain injury with the aim of contributing to the continued development of supportive networks.

Swedish policy is like that of many other countries, characterized by new forms of governance, with an emphasis on civil society as producers of welfare services [2]. Partnerships between the public sector and civil society

organizations are increasing [3, 4]. Thus, the formation of alliances with local communities has become central to health science research, especially with communities involving more vulnerable and excluded groups [5]. Regardless of whether alliances are located within formal partnerships or inside more informal networks, they will result in the coproduction of research and services, which are expected to increase in relevance [6–8].

Stroke and traumatic brain injury are the major causes of acquired brain injury. Potential sequelae of an acquired brain injury include impairments in memory, energy, and drive; muscle power and endurance; and limitations in activities and restrictions in societal participation [9]. Services that support social and community integration are important, but unmet needs even while using such services have been reported several years after an acquired brain injury [10–13]. Furthermore, several barriers in accessing such services are related to individual factors like lack of insight and cognitive difficulties, in addition to barriers related to the environment, including lack of transportation and accessible spaces and lack of knowledge and awareness among employees [13]. Thus, there is a well-documented gap between the needs experienced by people with acquired brain injury and the services offered in the community. While the knowledge about the value of coproduction with recipients of support has increased, there are still few studies that have focused on exploring the value and legitimacy of experience-based knowledge of people with acquired brain injury. Involving people with personal experience in acquired brain injury in the development of community services may contribute to services that better meet their needs [14, 15].

Cocreation processes involving people with stroke aiming to develop community rehabilitation or care after stroke using focus groups, codesign events, and workshops in which people with acquired brain injury share their knowledge and experiences have been described in the literature [16, 17]. Other means of including experience-based knowledge of people with acquired brain injury in services are peer-support groups [18, 19] and developing informational material and workforce training [20]. In addition to reducing the gap between needs experienced and services offered, sharing and utilizing information provided by people with acquired brain injuries has the potential to increase the legitimacy of experience-based knowledge and to increase collective processes of learning.

1.1. Theoretical Framework. Communities of practice (CoP) is a useful perspective for understanding collective processes of learning in local practice. CoP is defined by Lave and Wenger [21], p.98 as “. . .an emergent activity system within which participants develop and share understandings concerning what they are doing and what that means.” In this study, CoP is used as a theoretical framework to describe and explore different processes of sharing experience-based knowledge. The concept of legitimate peripheral participation is applied to shed light on the dynamics between the agencies exerted by members belonging to CoPs. Fricker’s elaboration on the idea of epistemic injustice [22] is utilized

to scrutinize the legitimacy of different types of knowledge and knowledge claims.

1.1.1. Communities of Practice. CoPs are formed by people who engage in a process of collective learning in a shared domain of interest [23]. To associate practice with community, there is interaction between the three dimensions that constitute the properties of a community: mutual engagement, joint enterprise, and shared repertoire. In addition, these dimensions are mutually reinforcing.

One distinguishing feature of a CoP is the mutual engagement of the members belonging to the CoP. However, it takes time to establish a CoP. Simply being in the same place or having a formal group affiliation is not enough for mutual engagement to emerge. Rather, a prerequisite for mutual engagement is to be able to meet and interact on a regular basis, to get “to know each other” [23] while doing activities that create shared meaning, negotiating the meaning of these activities, and being included in a “what matters” discussion [24]. Moreover, engagement in these processes becomes a mode of belonging [24]. Meaning and commitment are created when people develop a common interest, i.e., a joint enterprise that requires them to meet and do things together and to gradually create a repertoire of shared resources that reflects the group’s history of mutual engagement [24]. However, sustained engagement is only enabled when people invest time and commitment into building meaningful relationships and engaging in common areas of interest.

The common area of interest, the joint enterprise, occurs when members become engaged in a shared practice in which they make and negotiate decisions about things that matter in this CoP. Hence, it is the result of a collective negotiation process, where different members add different perspectives and skills. The common area of interest is created over time and is strengthened by the artefacts that the group members create, as well as the common history that is upheld between the group members by sharing experiences and memories of doing things together [24].

The group’s shared repertoire of resources can, for example, consist of metaphors, artefacts, established group rules, inside jokes and jargon, and experience-based knowledge of acquired brain injury. This shared repertoire both reflects the group’s history and is part of what is constantly negotiated and open for change. Furthermore, it reinforces a sense of belonging, as it enables group members to both sustain and introduce new members to their joint enterprise [24].

1.1.2. Legitimate Peripheral Participation. The term legitimate peripheral participation (LPP) has been used to describe and characterize the process and to capture conditions under which newcomers become members of a CoP [21]. In LPP, learning is identified as a contextual social phenomenon, achieved through participation in a CoP, which implies learning as a process that enables different types of individual learning trajectories. These learning processes also involve the development of members’ identities, which are conceived of as durable, ongoing relationships between persons and their place and participation within a CoP. “In

that sense, identity, knowing, and social membership entail one another” (21, p.53). Thus, LPP has the dual function of either evolving into an empowering position that signifies movement towards full participation, or a disempowering position if it keeps an individual from participating fully. Consequently, LPP by newcomers can both enable and hinder a person from full participation in a CoP. The inherent ambiguity in LPP is connected to issues of legitimacy, since connectedness, i.e., direct involvement in activities, can entail a powerful position if an individual’s knowledge is considered to be a valuable contribution.

1.1.3. Epistemic Injustice. Epistemic injustice is a form of social injustice that occurs when a group’s authority “as knowers” is dismissed or marginalized. Two distinct forms of epistemic injustice, *testimonial injustice* and *hermeneutical injustice*, either combined or separate, can contribute to undermining a person’s credibility as a subject of knowledge. Testimonial injustice can be understood to be a credibility deficit, which occurs when preconceptions (prejudice, stereotypes, and biases) cause a listener to attach a lowered level of credibility to a speaker’s words. Hermeneutical injustice appears when there is a gap in collective interpretive resources, namely, hermeneutical resources such as common language, educational background, or theoretical understanding, which puts the speaker at an unfair disadvantage when it comes to making sense of his/her social experiences [22].

1.2. Rationale and Aim. Our starting point in this study was not only that being recognized as a knowledgeable individual has value in and of itself but also that societal services that are developed in partnership between professionals and people with lived experience have the potential to be more relevant for their users. The involvement of people with conditions like acquired brain injury might involve challenges due to disabilities related to communication, memory, energy, and drive functions, and there is a lack of knowledge about how conditions that support the sharing of experience-based knowledge are created. The knowledge about the value of coproduction with recipients of support has increased and codesign events and workshops have been described as tools for capturing experience-based knowledge of people with acquired brain injury. However, there are still few studies that have focused on exploring the value and legitimacy of experience-based knowledge of people with acquired brain injury in the context of service development. CoPs are described as “social containers of competence” and being a member of a CoP, thus defines what is considered competence in a specific context. Consequently, using the CoP as a theoretical frame when exploring sharing experience-based knowledge has the potential to move beyond symbolic involvement and explore collective learning processes in real-life contexts.

The objective of this study was to explore experiences of sharing experience-based knowledge of living with acquired brain injury with others, with a particular focus on the conditions for sharing and learning, and the legitimacy of experience-based knowledge.

2. Method

2.1. Case Study Design. We used a case study with embedded units as this design provides an opportunity to obtain a holistic view and explore complex social phenomena integrated within their contexts in depth [25, 26]. The phenomenon of interest in this study (the case) was the sharing of knowledge of living with acquired brain injury and this phenomenon was studied in two units of analyses: a blog group and an education group (see Figure 1).

2.2. Setting. The context for the present study was a supportive network for people with acquired brain injury based in an urban region of Sweden. The network was established in 2015 and consisted of patient organizations and rehabilitation and welfare services providers, henceforth denoted “actors.” The network was led by a project leader supported by project employees. The network’s common goal was to enable collaboration between different actors and to contribute to improved quality of life, promote rehabilitation, and as far as possible, encourage a return to an active life for people with acquired brain injury. It was furthermore stated that the network, in accordance with the UN Convention for people with disabilities, should operate in collaboration with the target group for “full and effective participation and inclusion in society.” In practice, this meant promoting collaboration and mutual learning processes in which the experience-based knowledge of living with acquired brain injury could become an integrated part of the activities provided by the network, in terms of planning, designing, and implementing activities.

The network arranged various activities for people with acquired brain injury and related parties. To spread information about their activities, the network had a website that provided facts and information about acquired brain injury from both professionals and people with own experience of living with an acquired brain injury. Most activities were arranged by working groups consisting of representatives from the network’s actors. Two of these groups, the blog group and the education group, constituted the units of analysis in which the process of sharing knowledge was explored. Those groups were selected since they represented two different types of groups, one was driven by professionals and one by users. We also classified each of these groups as a CoP.

2.3. The Blog Group. The blog group was initiated in 2017 and the group had not been active during the COVID-19 outbreak due to pandemic restrictions since mid-March 2020. In total, the group had engaged eight participants during this period. Of this group, six of the members had personal experience of living with acquired brain injury. Three of them were middle-aged men who attended the group on a regular basis. The others, two men and one woman, joined the group occasionally. Two of the regular participants were asked to join the blog group since they were involved in patient organizations that were part of the

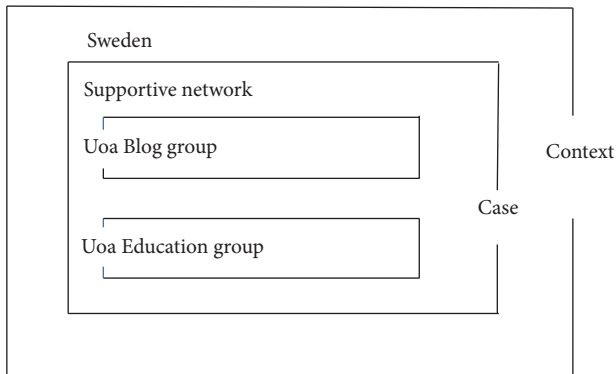


FIGURE 1: Single case study with embedded units of analysis (Uoa).

network, whereas the third participant was invited to join the group by one of the group members. In addition, there were project employees who had different functions within the supportive network and worked with the blog group at different periods of time. Their role was to coordinate group activities and take responsibility for summarizing the participants' experiences and transforming them into collective blog posts published on the network's webpage. In the collective blog posts, members described and reflected on their individual and collective experiences.

2.4. The Education Group. The education group was assigned (by the network's steering group) the task of developing web-based education on the theme of "rehabilitative approaches." The aim of this education was to raise awareness in society and teach and support relatives of people with acquired brain injury and staff about how to support people with acquired brain injury in managing the activities of daily life. Their intention was to develop educational materials that included experience-based knowledge from people living with acquired brain injury.

At the time of the present study, the education group had worked on a web-based education for about two years and some of the group members had been replaced during those years. The group consisted of four health professionals representing the supportive network's actors and a project employee. In addition, the project leader for the supportive network participated in some of the group's meetings.

2.5. Study Participants and Data Collection. The data from the blog group consisted of blog posts and interviews. The forty-one collective blog posts posted on the network's website publicly available were copied in their entirety. Seven individual interviews were conducted with people who had participated in the blog group at various time periods. The first set of interviews ($n=2$) focused on participants' involvement in the supportive network on a more general level, including its implementation and development, and was performed in 2018 by M.T. These interviews lasted 26–33 minutes. The second set of interviews ($n=5$) was conducted in 2021 and lasted 45–76 minutes. These interviews dealt specifically with their involvement in the

blog group and their experiences of learning and sharing experience-based knowledge. On both occasions, interview guides were utilized. All the people who had been involved in the blog group were invited to participate in the study and all but one accepted to be interviewed. However, all members are represented in blog posts.

Data from the education group consisted of interviews, participatory observations, and field notes. All members of the education group were interviewed. Eight individual semistructured interviews were conducted on two different occasions. Like the initial set of interviews with the blog group participants, the first set of interviews ($n=3$) focused on the supportive network on a general level and was performed in 2018 by M.T. These interviews lasted 45–75 minutes. In spring 2021, a second set of interviews ($n=5$) was conducted by L.H. These interviews had a specific focus on the participants' experience of being involved in the blog group and lasted 30–75 minutes. All interviews were recorded and transcribed verbatim.

Ten participatory observations were conducted during the group's digital working meetings and when the last part of the web-based education was produced, between March and September 2021. The observation covered content and group processes, e.g., what the group worked on, how they discussed the design and content of the web-based education, and the group's working methods. Time frames were documented in field notes.

2.6. Researcher Characteristics and Reflexivity. Together, the authors represent an interdisciplinary breadth of experiences of working together with people with acquired brain injury both in healthcare and in society: medical social workers (L.H., U-K.S.), physiotherapists (M.T. and L.vK.), and physician (E.Å.). Having experiences in providing health care could imply that it is easier to identify with the participants in the education group since they have the same or similar background as the researchers. Nevertheless, being aware of this risk has contributed to a dialogue regarding preconceptions. Reflections about our own experiences and discussions with community researchers with their own experience of acquired brain injury, that collaborate with the researchers, have sensitized us to become aware of our unspoken or "taken for granted" knowledge.

2.7. Ethical Considerations. The study was approved (Dnr 2018/407-31 and 2021-03548) by the Swedish Ethical Review Authority. The ethical dilemma of not putting personal integrity at risk while still presenting relevant and necessary information concerning the study population and context has been raised and discussed in the research group and among participants. In an effort to protect the personal integrity of the study population and not reveal personal information, conditions, or locations that could result in the identification of an individual, the following measures have been taken: (i) names and locations mentioned in the present report have been excluded or changed, (ii) only information of relevance for the study context has been described only in a generic manner in accordance with the

ethical permit and general data protection regulation, and finally, (iii) the study population has been categorized into two groups: people with own experience living with acquired brain injury (PwOE) or people without own experience living with acquired brain injury (Pwo/OE).

The participants received written and oral information about the study, and they gave either verbal or written consent. When verbal consent was obtained, it was recorded. Before the recording started, the participants anew were given information about the purpose of the study and a chance to ask clarifying questions. Since none of the participants were minors, consent from caregivers was not required.

The blog posts were extracted from the network's webpage and all information that could result in the identification of individuals was excluded when referred to in this manuscript.

2.8. Analysis. Initially, all the interview transcripts were read through, and three of them were line-by-line coded inductively by the first author to get a sense of the material (see Figure 2 for overview of the analytic process). After the initial coding, a first presentation of codes and categories was made to the coresearchers. Based on the emerging codes and categories, it was decided that Wenger's learning theory of CoP [24], Fricker's concept of epistemic injustice [22], and Lave and Wenger's concept of LPP [21] should be utilized. Hence, the first author initiated a deductive coding scheme, in which the properties of community building (mutual engagement, joint enterprise, and shared resources), LPP, and epistemic injustice were used as categories (see Tables 1 and 2). A similar process occurred with the blog posts, which at first were read through in the chronological order that they occurred on the network's webpage, with theoretical notes written in relation to the categories derived from CoP, LPP, and epistemic injustice (see Table 1). Notes from the observations during the work meetings in the education group were analysed by utilizing Fricker's (2007) concept of epistemic injustice to discover how different types of experience-based knowledge were given legitimacy within the group (see Table 2). The analysis focused on group processes and group dynamics, i.e., taking and keeping the initiative, having the ability to control the conversation space and gaining support for ideas. Questions guiding this specific part of the analysis focused on the interactions between group members by adhering to the following aspects: how often group members presented their ideas, and, if necessary, argued for support; how often an idea generated support from other members; and whether it made any difference who came up with the ideas.

In the blog group, aspects concerning legitimacy were detected by noticing which topics were discussed, how they were discussed, and the frequency with which topics occurred in the blog posts. In addition, we explored to what extent members were given space to share and develop their specific lines of thought concerning an issue. Although most blog posts were written in a collective voice (representing the group), some blog posts described individual experiences or reflections about a common topic or activity.

After the deductive coding, the findings were sorted thematically according to the principles of thematic analysis [27], and in each group, different themes related to the aim were generated. To increase trustworthiness, the authors met and together reflected on the findings of the analysis. The credibility of the generated themes was supported by data from several sources.

3. Findings

Findings from the blog group are described, followed by findings from the education group.

3.1. The Blog Group

3.1.1. Building the Community: Experiences in Learning, Mutual Engagement, and Joint Enterprise. When the members of the blog group initially met, they were a group of individuals with an interest in writing blogs but without a previously negotiated common interest. Thus, a prerequisite for building the blog group as a learning community was the members' ability to create processes of mutual engagement centered around a common area of interest. The Pwo/OE involved emphasized that they did not influence the group's search for a common area of interest. They described the importance of mutual learning processes but pointed out that they did not possess any expert knowledge and that their role was to support all group members in making their voices heard. "From the beginning, it was probably mostly that we...I wanted to meet everyone and see what we wanted to do together. So that I would not say that I had a clear picture from the beginning." (Pwo/OE, interview)

In their first blog post, the group members made a collective statement in which they presented a declaration of the blog group's intentions, which can be considered an initial and official joint enterprise.

We want to write about the difficulties that arise and how we choose to deal with them. We also want to inspire and motivate others who are going through similar difficulties as we ourselves are going through. Finally, we hope to be able to participate in developing the system we have today. We would like to remind you of the fantastic resource that exists among people with brain injury (blog post).

The view of people with acquired brain injury as resources and as holders of knowledge about living with acquired brain injury that differed from those of health professionals was also reflected in the interviews. Their experience-based knowledge could provide an insider's perspective that supplemented the professionals' theoretical knowledge, expressed in the following excerpt:

Physicians and physiotherapists are very good at responding to what happens physiologically in the body when you get an injury, a disability, or an acquired brain injury and you can find out what the consequences will be,

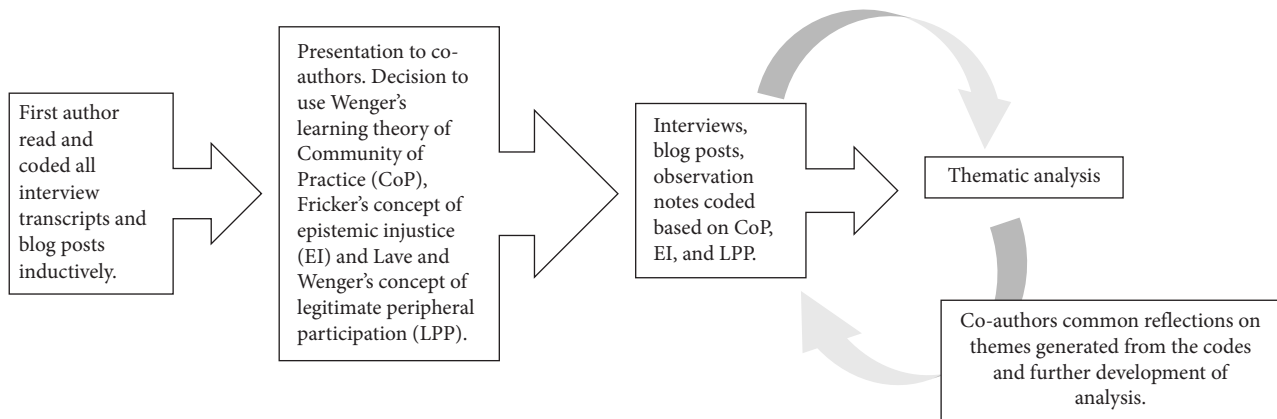


FIGURE 2: The analytic process.

in theory. But then it is another thing to live with it, in everyday life. (PwOE, interview)

The blog group's work process was flexible regarding when, for how long, and where they met and was mainly governed by the members' own abilities and wishes. During group meetings, mutual engagement was gradually established through the members' participation in what they considered meaningful activities. They tried different activities together, which served the dual purpose of sharing personal experiences of performing activities adapted to the limitations that had arisen due to living with acquired brain injury, and establishing a common starting point for constructing collective blog posts. Additionally, interactions between members contributed to the creation of a common history, which further reinforced their mutual engagement and joint enterprise.

3.1.2. Sharing Personal Experiences Contributes to Creating a Sense of Belonging. The awareness that life can be difficult at times made the blog group members inclined to share their personal journey; both within the group and with others. In one of the blog posts, PwOE utilized one of the men's experiences to describe the importance of being able to recognize oneself in other people's experiences, i.e., to belong to a social community where people shared their personal experiences of living with acquired brain injury

How tough the journey was—how scared he was after his stroke and that he wished that the companionship that exists in the network, existed then. Not only for the social [aspects], but also to enable him to meet people who have been through similar journeys and experiences. He said that he had to search the internet to find stories and inspiration, which was not so easy. (blog post)

Another common intention was to convey a sense of hope in the blog posts when sharing their first-hand experience. This was sometimes done in a humorous manner with anecdotes about forgetting ingredients when cooking and reminders that others had experienced similar frustrations.

In one blog post, PwOE described emotions and thoughts related to the challenge of living with aphasia. Before the injury, aphasia was an unfamiliar phenomenon, and now, the PwOE wanted to inform others about the subject, so that they would understand that “it takes longer to get the words out.” Living with aphasia was compared to learning to speak a new language where the difficulty lies in finding the right speech rhythm and pace

Even if you learn all the words, it can be difficult to have a conversation as language is all about timing. For example, if you want to tell a funny story and you have the wrong timing, the joke will not be funny. If the people around you do not know why you have bad timing, you can feel quite stupid. We want to inform the people who read our blog about why we sometimes have bad timing! (blog post)

Mutual identification strengthened the process of their common struggle with self-perception and self-image, and by meeting regularly, a sense of trust was developed between the members. Thus, the initial joint enterprise of sharing their experience-based knowledge beyond the group expanded to include more focus on their individual learning trajectories with the support from other group members who could relate to their fears, hopes, and challenges. With support from the other group members, the PwOE became willing to participate in activities that they had felt reluctant to do on their own. The PwOE explained, “I do not want to go to a restaurant because I only have one hand. But then we were a few people. . .like we were there and then (we) did it” (PwOE, interview).

The group provided a safe space where the members confirmed each other's importance and participation in different activities. Some of these activities were ones they used to do before they had their injury, like riding a bike and playing table tennis, and some they had never tried before, like yoga. For the PwOE, this meant both an individual and collective exploration of new meanings and experiences, which were shared both in the moment and in blog posts. By sharing experiences and having fun while acquiring new skills, their mutual engagement transcended their initial

TABLE 1: The themes resulting from utilizing a deductive coding scheme in the analysis of interviews with members of the blog group and blog posts.

Themes	Categories	Properties of community of practice (CoP) and legitimate peripheral participation (LPP)	Representative quotes from blog posts and interviews
Building the community: experiences in learning, mutual engagement, and joint enterprise	Mutual engagement and joint enterprise (CoP)		We agree that it feels fun and exciting to try some new activities and hopefully be able to challenge ourselves to try things that we might not have tried if we were by ourselves. After all, it is a big reason why we created this blog. (blog post)
		Mutual engagement, joint enterprise, and shared repertoire (CoP)	This group started out as a blog group, but it evolved quite quickly. There were so many ideas in this group. So, it began to take shape as an inspiration group. It was a lot about exercise, and everyday life training. We wanted to give tips about everyday life training. Then we tried different activities and came up with different activities. We had one group member who was very resourceful and had a lot of experience in everyday life training. Almost every time we met, he came up with a new exercise that we tried. (interview Pwo/OE)
Sharing personal experiences contributes to creating a sense of belonging	Shared repertoire (CoP)		After the coffee break, we all went into the main hall again and we felt a bit nervous, as it was time for us to go up to the podium to introduce ourselves and our blog. The day before, we prepared a PowerPoint presentation with keywords and some pictures from the activities we did together. (blog post)
		Mutual engagement and joint enterprise (CoP)	We went and played ping pong, and we've been up here playing miniature golf and stuff. . . And tried to do things which we didn't really think we could. . . Because when you have a stroke-you can't play ping pong. My hand is dead. . . But then we tried things like that, and we had a lot of fun. (PwOE, interview)
The dual processes of learning and belonging	Mutual engagement and shared repertoire (CoP)		When the members of the blog group met last time, one of the members told us how happy he was that he could now carry two coffee cups at the same time, one in his left hand and one in his right, which he also proved when coffee was to be fetched from the machine to the table where we were sitting. Of course, the rest of us were impressed and congratulated on this progress. This led to a discussion where he shared that before the stroke, he had not seen this as progress, then it would have been something you just do. (blog post)

TABLE 1: Continued.

Themes	Categories Properties of community of practice (CoP) and legitimate peripheral participation (LPP)	Representative quotes from blog posts and interviews
Becoming a valued member or not	Social membership and learning (LPP)	It feels welcoming to be here. I'm new to the group. Popular [name of Pwo/OE] has handed over the assignment to me. It will be my pleasure to write on the blog. This Friday we talked about all sorts of things. There was a lot of laughter and some anecdotes about things I may not have thought of before. (blog post)
	Lack of social membership (LPP)	I have not been very involved in this. They have been more involved in this blog group and made blog posts. I do not really see what I could add. The only thing I can say I've done is this training video. (interview Pwo/OE).

TABLE 2: The themes resulting from utilizing a deductive coding scheme in the analysis of interviews with members of the education group and field notes from meetings.

Themes	Categories	Representative quotes from interviews and field notes
Establishing a joint enterprise and mutual engagement	Properties of community of practice (CoP), legitimate peripheral participation (LPP), and epistemic injustice (EI)	<p>Maybe it was not super clear from the beginning, but we had an idea that we wanted to address different situations, that based on our clinical experience, can be difficult to deal with. It is obvious now that we did not have a clear idea of how we wanted to do it, but eventually, it became a learning platform. (interview Pwo/OE).</p> <p>The process of the [development] of education itself, it has changed a little in that we have figured out what the web-based education should look like. At first, we only made manuscripts and scenes in PowerPoint. But it turned out to be a lot that we had to rework, maybe not in terms of content, but there were demands on graphic layout and headlines and descriptions of film clips, and so on. So, it has been quite a long process. (interview Pwo/OE)</p>
	Joint enterprise (CoP)	
Ambiguous value of the lived experience of PwOE	Mutual engagement and Shared repertoire (CoP)	<p>They (PwOE) have seen some of the artefacts that has been edited and just like us they can get an idea of how it turned out. Before we release it [as part of the web-based education] they will get a chance to see it. They are not involved in the process in that way of “twisting and turning” words and what is said. . . But they are still involved because both I and my colleague have been involved in producing the artefact with them. (interview Pwo/OE)</p> <p>Discussion about module 1 in the web-based education: Pwo/OE expresses that the feeling in the artefact is good. She believes that it must be clear from the artefact that the encounters between health professionals and people with acquired brain injuries are the most important thing. Another Pwo/OE continues by saying, “we want someone [a PwOE as an actor] to describe that rehabilitation takes time but there is progress”. (field notes)</p>
	Testimonial and hermeneutical injustice (EI)	
	Mutual engagement (CoP) and testimonial injustice (EI)	
The difficulty of valuing experience-based knowledge of living with acquired brain injury	Testimonial injustice (EI)	<p>It is also perhaps based on the experience that patients we have met have said, “they (staff) don’t have time to help me or they don’t have time to wait for me”. They just put on clothes. That was probably the starting point, it does not have to take more time, and especially not after a while, if you have a rehabilitative approach. (interview Pwo/OE)</p>

commitment to writing collective blogs, and the group became a familiar place where members were allowed to be themselves.

3.1.3. The Dual Processes of Learning and Belonging. Another area that became increasingly prominent and which the group developed together, and shared knowledge about, was issues related to rehabilitation. A common goal among the PwOE was to take responsibility for their physical rehabilitation, as they explained “Society only accompanies people who have an acquired brain injury part of the way, and the rest you have to walk by yourself.” It was also stated in a blog post that rehabilitative exercises were important to make them feel good about themselves but also to “maintain the functions we have and to be able to regain functions we have lost” (blog post).

Since many PwOE experienced fatigue, going to a training facility was not a viable option since traveling to the gym, changing into training clothes, and taking a shower would take too much energy. Thus, integrating rehabilitative exercises into everyday chores emerged as a parallel joint enterprise. Some PwOE set the tone in coming up with suggestions for daily exercises that group members could do. By challenging themselves to use “the wrong hand” when putting keys in their pocket, holding a drumstick, or carrying a coffee cup, they tried to “awaken and activate” their weak hand, with the ambition of maintaining or regaining functional abilities.

By jointly developing their knowledge through processes of mutual engagement, members got a chance both to appreciate and value their own progress as well as to validate the progress of their peers. Receiving recognition for carrying a cup of coffee from others who know how much effort it takes gave them a boost of confidence and the encouragement to keep on training, while at the same time, the acceptance that things had changed, and that everyday life must be adapted to the new situation. This accepting and validating climate both encouraged them to develop mutual learning processes and in finding a place in which they were accepted for the persons that they are today.

Although the initial intention of the blog group was not to become a support group for the participating members, it seemed to have developed into a supportive environment. In the blog group, the dual process of learning (sharing knowledge) and reframing social identity had contributed to an increased sense of belonging.

3.1.4. Becoming a Valued Member or Not. Trustful relationships took time to develop, and they were maintained and configured through the process of the PwOEs becoming full members of the group. Through ongoing negotiations regarding their joint activities, members either moved from a peripheral position and became full members of the community or withdrew from the group.

Pwo/OE supported the strong focus on rehabilitation and activities that had emerged by encouraging PwOE to suggest activities to do together and afterward to write about them in their collective blog posts. Thus, being resourceful

and driven in proposing such activities gave the PwOE status in the group. For PwOE who were less involved in suggesting such activities, legitimacy in the group came from their involvement in these joint activities. In addition, the group members attended conferences and spread information about the blog group’s activities and the group’s significance for their well-being. Their roles as representatives for the blog group and for the larger supportive network confirmed their legitimacy and belongingness in the blog group. In addition, their roles as representatives strengthened their mutual engagement, since it added a common experience to the group members’ shared repertoire and developed their competence as advocates for the group.

Some PwOE believed that the blog group would have benefitted from a more diverse group composition and that the presence of women would have enabled discussions of other topics, such as grief and sorrow. Although PwOE discussed emotions and feelings related to difficulties living with acquired brain injury, this was not a prominent feature in the collective blogs. Some PwOE perceived that a more diverse group composition would not have changed the prevailing focus, since rehabilitation and training were too prominent in group discussions and activities to allow the inclusion of other topics.

For short periods of time, the group had PwOE as newcomers. However, neither of them felt like the blog group was the right place for them. Unlike the other members, they did not have any visible impairment, and one said “I do not really know what I could add there. It’s just this training video. But that’s good. The idea is great. . . I remember that one of the men showed cooking with one hand and another man, he is in a wheelchair. . . I did not know what to show. . . I do not really have those difficulties. Doubtful about my role in that context” (PwOE, interview).

For them it would have been important to reach out to people who recently suffered from an acquired brain injury, especially people with fatigue and other types of “hidden impairments.” However, hidden impairments were beyond the scope of the blog groups’ joint enterprise for the time being. In addition, the PwOE newcomers did not expect to join a blog group that was based on joint activities, which led to their withdrawal after a few meetings.

3.2. The Education Group

3.2.1. Establishing the CoP and Gaining Legitimacy for Different Knowledge Claims. The Pwo/OE in the education group had worked together for approximately two years. Although work meetings were online, the Pwo/OE valued informal conversations. Before they engaged with the task at hand, they gave each other quick updates about things that had occurred in their everyday lives. Sometimes they made internal jokes, which can be considered part of their shared repertoire, and talked about their overall engagement in the supportive network.

Being resources allocated by their employers enabled the Pwo/OE to gain legitimacy for their work and allowed them to make steady progress, which reinforced their mutual

engagement. However, the allocated time could not compensate for the hours they put into the project, which created a sense of time pressure. The Pwo/OE believed that their common work around designing and creating web-based educational content contributed to expanding their professional competence, as expressed in the following quote

My own learning is on many levels; it's about interacting with others, establishing contacts, being part of the reference group, getting access to external knowledge that there are caregivers, there are patient organizations and that the people who have worked with it [the platform] have contributed [with] a lot of knowledge to me. (Pwo/OE, interview)

During meetings, they discussed the content that was to be highlighted in separate modules. There had been continuous negotiations about both the value and content of education, which is exemplified by the following questions, "Early on, we started talking about rehabilitative approaches and twisted and turned, what is it for? What does it mean to us? And how can it be interpreted by others? And a lot of discussions (happened) there to find our core, what are we looking for?" (Pwo/OE, field note).

In the education group, legitimacy was also gained by being able to present a well-thought-out idea by utilizing common concepts and vocabulary. Legitimacy could also be gained by receiving support from other persons of high status or by holding onto an original idea and promoting this idea continuously until other people agreed that it was important.

A joint enterprise around "helping people to help themselves" emerged from these negotiations between the Pwo/OE. They wanted to provide staff and relatives with strategies that encouraged people with acquired brain injury to participate in and become actively involved and more independent in performing activities of daily living

"So that was the basis; how to treat people in a way that makes them more and more independent. The easiest way is perhaps to help, to dress the person and that is probably what happens many times because there is a lack of time or because you do not know better or because the person says no, I do not want [to do it myself]. It is also perhaps based on the experience that patients we have met have said; but they [the staff] do not have time to help me or do not have time to wait for me. They just dress me" (Pwo/OE, interview)

3.2.2. Ambiguous Value of Lived Experience of People with Acquired Brain Injury. In the group, only one of the Pwo/OE worked as frontline staff and met patients, while the other had previous experience in stroke rehabilitation. Thus, the experience-based knowledge in the group was mainly based on their previous experience of working with adults with acquired brain injury.

Although the Pwo/OE agreed upon the importance of gaining knowledge based on the experience of living with

acquired brain injury, they found it difficult to give any specific examples of how people with acquired brain injury had contributed with their expertise. They remembered that they met with a reference group of adults with acquired brain injury but could not describe any input that they had received as exemplified by the following quote

Since I do not meet the target group [people with acquired brain injury] in my everyday life, I have almost nothing . . . And when we were at the Aphasia Association and met a group there, I cannot say that I remember anything specific." (Pwo/OE, interview)

One of the Pwo/OE believed that previous encounters with patients and family members had sensitized her and enabled her to act as an interpreter of the experience-based knowledge of people living with acquired brain injury, which is exemplified in the following statement

I think of all the meetings I have had with patients and all the years that I have met patients and heard about their experience, [those] have also become my experiences. It's not the same thing when I reflect on an individual's experiences that have had a stroke, but I have stood beside quite a lot and tried to bring it with me. (Pwo/OE, interview)

Although the ambition of the education group was to involve PwOE, this was not realized in practice. The professionals expressed that the presence of restrictions due to the COVID-19 pandemic made it more difficult both to involve Pw/OE in meetings and the production of artefacts.

In addition to having sporadic contact with reference groups that included PwOE, there was a pronounced idea of involving PwOE in the production of artefacts that would be part of the educational material. The artefacts would exemplify typical everyday activities and situations where people with an acquired brain injury might need support. Nevertheless, when the group started to work on web-based education they did not involve any PwOE who could share their experiences of activities or situations in daily life in which they wanted support. Instead, the work continued in the professional CoP and the Pwo/OE deepened their mutual engagement in this issue and utilized their professional experiences to identify such situations.

When the Pwo/OE made preparations for producing artefacts for web-based education, they did not have any specific PwOE in mind. With help from the supportive network, they got in contact with PwOE who wanted to participate in the production. The engaged PwOE were users of homecare services and had experiences with impairments related to mobility and long-term memory. To increase involvement and make it more comfortable to participate in production, Pwo/OE decided to adapt the situations to these PwOE. One of the Pwo/OE explained, "We had a basic idea of different things that we wanted to include, and then, when we found PwOE, we redirected the script based on these PwOE" (Pwo/OE, interview).

Among the Pwo/OE, there were different opinions regarding the support needs of the Pwo/OE during the production of artefacts. One Pwo/OE felt responsible for the well-being of the Pwo/OE and wanted to make sure that it was understood why there were instructions to act in certain ways during the production process. Other Pwo/OE thought that Pwo/OE had control of the situation and could act and rely on lived experiences. Even though the Pwo/OE directed Pwo/OE on what to do, they still thought that the experience and knowledge of the Pwo/OE about how to perform activities contributed in a valuable way to the creation of the artefacts.

3.2.3. The Difficulty of Valuing Experience-Based Knowledge of Living with Acquired Brain Injury. Unlike the Pwo/OE, Pwo/OE did not participate in any workgroup meetings or were not asked to contribute with experiences that could add input to the production of the web-based education. Consequently, their first-hand experience of being recipients of rehabilitative and social support was not included in the negotiations around the education group's joint enterprise, helping people to help themselves, and Pwo/OE did not get a chance to engage in the CoP.

Even after completing the production of the artefacts, mutual engagement was not made possible for the Pwo/OE. Interviews with some of the Pwo/OE explained the limited participation of Pwo/OE by referring to structural barriers such as limitations in physical meetings due to COVID-19 and time pressure. The Pwo/OE had different opinions about the value and meaning of showing the artefacts to the Pwo/OE before they were finalized. In the end, Pwo/OE did not see the artefacts before they were fully edited and thus had no opportunity to influence how Pwo/OE were represented. The decision was motivated as not "spoiling the surprise" promised to the Pwo/OE. In comparison with the newcomers in the blog group who decided for themselves that they did not fit into the group, there were no invitations to Pwo/OE to become members of the education group. As peripheral participant positions remained, the position of Pwo/OE as outsiders within the education group never changed.

4. Discussion

The situated nature of learning described in the CoP framework challenges the traditional supremacy attributed to academic learning [28]. Both the blog group and the education group exemplified well-functioning CoPs, where the different dimensions, mutual engagement, shared repertoire, and common areas of interest, had become mutually reinforcing. The groups had different aims and conditions in their processes of sharing and using experience-based knowledge about living with acquired brain injury. Whereas the blog group had "sharing experienced-based knowledge and experience" as its main task the education group's main task was to produce educational material about rehabilitative approaches in care and social services. However, even though both CoPs had the ambition of including people with personal experience of living with acquired brain injury in their processes, only the blog group seems to

have achieved this aim. The two groups' processes are compared and discussed in the following paragraphs.

The education group's work process was, to a large extent, governed by the conditions at the members' regular work and what was intended as the final product, i.e., a web-based education. Previous studies have pointed out that organizational issues, such as competing organizational priorities, and time factors are barriers to involvement [14, 15, 29, 30]. For the education group, the time pressure most likely influenced the very limited participation of Pwo/OE. Even though they had allocated time for the project, their time was limited as they still had to attend to their main work tasks at their regular workplace. Hence, a negotiation process to identify a joint enterprise involving both experience-based knowledge from people with acquired brain injury and professional knowledge may have seemed overwhelming to organize and carry out within the prevailing timeframes. Furthermore, the involvement of managers and executives has been recognized as a key facilitator for successful engagement [15]. However, the members in the education group were employed by different healthcare providers, and none of their managers were responsible for the task of developing the web-based education. Consequently, no manager could secure organizational commitment to involve people with personal experience of living with acquired brain injury in the group.

Mutual engagement in the blog group gradually developed around what the group's Pwo/OE judged to be important, and the group's joint enterprise around rehabilitation and activity emerged. The fact that these interests coincided with the Pwo/OE's own interests and were suitable as a starting point for writing blogs probably influenced the group's joint enterprise. Consequently, conversations about the topic and suggestions for activities gained legitimacy in the group. Since the main purpose in the blogs was to explore and share experience-based knowledge, it lent Pwo/OE legitimacy as experts when sharing their perspectives with others. However, the focus and interest in rehabilitation and activity were not perceived as relevant by Pwo/OE who joined the group for a while but did not have any visible impairment that constituted any substantial barrier to activities and exercises. Consequently, they may have felt unable to add experience-based knowledge that contributed to the group's joint enterprise and get an opportunity to create a shared repertoire with the other members. Similar findings were reported in a study of peer support, in which a peer supporter with stroke and no visible disability was concerned that he lacked credibility among new stroke survivors, as they might believe that he had not experienced a stroke [31]. This highlights that experience-based knowledge of living with acquired brain injury has a breadth and variety and is largely dependent on peoples' various life situations.

In both CoPs, mutual engagement and joint enterprise revolved around knowledge about different aspects of rehabilitation, which was given legitimacy in both groups. A similarity between the groups is their interpretation of dependence and independence, in which "dependence" implies the need for assistance due to functional limitations,

whereas “independence” suggests that individuals do not need any assistance from other people [32]. Instead of demanding changes at the societal level (such as requirements for universal design) the members in both groups focused on the individuals’ responsibility to improve their own physical ability, where the goal is to perform activities and everyday life chores with as little support from others as possible.

Difficulty in achieving epistemic justice for PwOE became a prominent theme in the education group, i.e., a CoP that only consisted of Pwo/OE where they had the dual role of individual epistemic agents and representatives of medical discourse. The lack of input from PwOE meant that the Pwo/OE had to replace the experience-based knowledge from PwOE with their own clinical knowledge or their pre-conceptions. In addition, it reduced the legitimacy of Pwo/OEs’ experience-based knowledge and limited Pwo/OEs’ opportunity to know whether or to what extent their clinical experiences were consistent with the experience-based knowledge of PwOE. In terms of hermeneutic resources, group members already shared a common language which facilitated the mutual understanding which also was guided and reinforced by their joint enterprise to create web-based education with an emphasis on the rehabilitation of individuals. According to Anderson [33], this joint enterprise and shared belief in rehabilitation can create and sustain structural group-biased credibility deficits: differential markers of credibility, ethnocentrism, and the shared reality bias. Thus, in this study, the shared reality bias becomes the medicalized models [34, 35] that make training and rehabilitation the path to achieve independence. In its application, a rehabilitative approach focusing on improving bodily function makes visible how disability is normatively imbued and always related to an implicit ideal of “able” functioning rather than questioning societal perceptions of normality [36]. It reinforces the construction of the “normal” body, or the “normate” as Garland Thomson [37] has called the idea of a human being who always functions fully. To create sustainable epistemic justice, epistemic institutions such as medical institutions need to be constructed or reconstructed to prevent “the unwarranted epistemic privilege frequently afforded to medical institutions and medicalized models of phenomena” (35, p. 341). Consequently, it is important to keep in mind that challenges related to epistemic injustice also are dependent on recognizing that social institutions such as educational and medical bodies function as epistemic institutions, i.e., individual agency is dependent on organizational structures.

Legitimacy for the experience-based knowledge provided by PwOE differed between the CoPs. Within the frame of their predefined assignment, the education-group developed their joint enterprise around educational support in “helping people to help themselves” from a purely professional perspective. They oversaw decisions as to when and how experience-based knowledge from people with acquired brain injury was relevant. The CoPs’ shared repertoire was built solely on the knowledge of Pwo/OE. The professionals’ reluctance to validate PwOE as “knowers” [22] resonates with Beresford’s [38] results which indicated that knowledge based on lived experience is often ignored or marginalized

by professionals. In contrast to the blog group, PwOE in the education group were never invited to participate fully as members or given the opportunity to engage in “what matters” discussions on the topics or to participate in creating the shared repertoire. Instead, the role and function of PwOE were defined by other trustworthy actors rather than experts with an inside perspective, and they were not given a chance to obtain legitimacy in the education group. Previous studies describe that working with service users in the development of health services has the potential to positively influence professionals’ attitudes and beliefs toward involving service users and valuing laypersons’ skills [14]. However, the transformation from being a patient with stroke’ to “a knower” seems to involve challenges for both persons with stroke and health professionals [20]. If service users (i.e., PwOE) are not adequately supported, which seemed to be the case in the education group, they are not given a fair chance to contribute. Neither are professionals without own experience of acquired brain injury given the opportunity to reimagine the patient as “a knower” whose experience-based knowledge contributes to develop support interventions. According to the theory of CoP, members add different perspectives and skills during negotiation processes in developing their common area of interest. Consequently, crucial in the creation of a CoP involving both PwOE and health professionals is the empowerment of people with acquired brain injury to share knowledge and assert that PwOE have much to contribute. Of equal importance is supporting health professionals in feeling confident in accepting and valuing people with acquired brain injury’s experience-based knowledge. Some techniques have been described to facilitate patient engagement, e.g., to involve more PwOE than Pwo/OE in the group, to enable PwOE to set the agenda, include PwOE in all parts of the process, and allow time to develop a trusting relationship [15].

A strength of the present study is the exploration of groups that were held in a real-world context without any influence of researchers, which makes the findings relevant to everyday practices with the ambition of supporting collective learning processes. Furthermore, the combination of data sources including blogs, interviews, and field notes from observations enabled the triangulation of data during analysis to find the most credible interpretations. Having the opportunity to read blog posts ahead of the interviews made it possible for the interviewer to ask more about some of the topics in the blog posts. This allowed the interviewees to further develop some of the thoughts expressed in the common blog posts and add their specific points of view to the collective blog post. In addition, posing questions related to the blogs could also assisted participants from the blog group to recall experiences and events, which might have been important as memory impairments are common in people with acquired brain injury. One limitation is that the education group developed into a purely professional group, which made it impossible to explore learning processes involving both people with acquired brain injury and professionals. On the other hand, this enabled the exploration of barriers to participate in learning processes and the exploration of the peripheral position as an outsider.

5. Conclusions

Gaining legitimacy often requires that people with experience of living with acquired brain injury are recognized as knowledge producers by people that belong to influential groups, such as practitioners, scientists, and policymakers. Furthermore, when creating conditions for involving people with acquired brain injury in collaborative projects, the three dimensions of a COP, mutual engagement, joint enterprise, and shared repertoire, could most likely be used as guidance.

Our findings have several implications for practice.

- (i) Integrating experience-based knowledge from people with own experience requires careful and deliberate planning which allows for time to consider how the mutual reinforcement of all three dimensions of CoP can be utilized to enable beneficial learning processes.
- (ii) It is important to create resources that enable people with own experience to share their unique perspectives and to be vigilant of epistemic injustice that can occur due to power asymmetries that causes people with own experience a credibility deficit.
- (iii) People with own experience need to be involved in all parts of the process and it is important to consider the group composition between people with own experience and people without own experience in CoPs dominated by professionals.

Future research could benefit from focusing on communities that only consist of people with acquired brain injury that are allowed to grow organically and have a bottom-up perspective, instead of a top-down perspective. Further research should also explore whether these types of organic communities utilize different hermeneutic resources in developing ways of achieving epistemic justice and whether different types of discourses resist dominant frameworks emerging when experience-based knowledge does not have to compete with other types of knowledge claims.

Data Availability

The dataset generated and analysed during the current study is not publicly available as that would compromise participants' consent but is available from the corresponding author on reasonable request.

Disclosure

The funders had no influence on data collection, interpretation of findings, or reporting.

Conflicts of Interest

One of the authors (E.Å.) was, besides being a researcher at KI, also involved in the steering group for the supportive network as a representative for one of the actors. However, E.Å. has not participated in either the educational or blog group and, during the study phase, minimized her

participation in the steering group. Furthermore, E.Å. had no active role in the performance of the research interviews, primary data collection, and initial analysis but rather as clinician with experience of ABI acquired brain injury added her perspective in the manuscript production phase.

Authors' Contributions

L.H., L.vK., U-K.S., M.T., and E.Å. were engaged in the design, interpretation of findings, and writing the manuscript. L.H. and M.T. were responsible for data collection. M.T. did the first set of interviews. L.H. did the second set of interviews, as well as collecting blog excerpts and doing observations and field notes in relation to digital meetings in the education group. L.H. analysed the data in close collaboration with M.T., L.vK., and U-K.S. L.H. led in drafting the manuscript and all the authors read and approved the final manuscript.

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References

- [1] J. I. Charlton and ProQuest, *Nothing about Us without Us: Disability Oppression and Empowerment*, University of California Press, Berkeley, CA, USA, 1st edition, 1998.
- [2] T. Harding, "Civil society of the future: background report 3 to the future commission," 2012, <https://www.regeringen.se/contentassets/b63e19afcada460da9c723fd5bf211b9/framtidens-civilsamhalle/>.
- [3] S. Municipalities and C. Councils, "Dialogues and agreements with civil society: concrete examples from eight municipalities," 2014, <https://skr.se/download/18.5627773817e39e979ef9b698/1643029618742/7585-113-6.pdf>.
- [4] Ministry of Culture, "Palette for a strengthened civil society," 2016, https://www.regeringen.se/contentassets/907a5e554a23428f9aef3c2d7221a2de/palett-for-ett-starkt-civilsamhalle-sou-2016_13.pdf.
- [5] M. Minkler and N. Wallerstein, *ProQuest. Community-Based Participatory Research for Health: From Process to Outcomes*, Jossey-Bass, San Francisco, CA, USA, 2nd edition, 2008.
- [6] M. Geddes, "Tackling social exclusion in the European union? The limits to the new orthodoxy of local partnership," *International Journal of Urban and Regional Research*, vol. 24, no. 4, pp. 782–800, 2000.
- [7] L. Green, M. Daniel, and L. Novick, "Partnerships and coalitions for community-based research," *Public Health Reports*, vol. 116, no. 1, pp. 20–31, 2001.
- [8] S. Staniszewska and S. Söderholm Werkö, "Mind the evidence gap: the use of patient-based evidence to create "complete HTA" in the twenty-first century," *International Journal of Technology Assessment in Health Care*, vol. 37, no. 1, pp. e46–e, 2021.
- [9] B. Alguren, A. Lundgren-Nilsson, and K. S. Sunnerhagen, "Functioning of stroke survivors--A validation of the ICF core

- set for stroke in Sweden,” *Disability and Rehabilitation*, vol. 32, no. 7, pp. 551–559, 2010.
- [10] C. McKevitt, N. Fudge, J. Redfern et al., “Self-reported long-term needs after stroke,” *Stroke*, vol. 42, no. 5, pp. 1398–1403, 2011.
- [11] M. T. Olaiya, D. A. Cadilhac, J. Kim et al., “Long-term unmet needs and associated factors in stroke or TIA survivors an observational study,” *Neurology*, vol. 89, no. 1, pp. 68–75, 2017.
- [12] K. Laurie, M. Foster, and L. Gustafsson, “Personal experiences of appropriate access to post-acute care services in acquired brain injury: a scoping review,” *Brain Impairment*, vol. 24, no. 1, pp. 1–26, 2022.
- [13] A. Norman, V. Curro, M. Holloway, N. Percuklievska, and H. Ferrario, “Experiences of individuals with acquired brain injury and their families interacting with community services: a systematic scoping review,” *Disability and Rehabilitation*, vol. 45, no. 4, pp. 739–751, 2023.
- [14] C. Mockford, S. Staniszewska, F. Griffiths, and S. Herron-Marx, “The impact of patient and public involvement on UK NHS health care: a systematic review,” *International Journal for Quality in Health Care*, vol. 24, no. 1, pp. 28–38, 2012.
- [15] Y. Bombard, G. R. Baker, E. Orlando et al., “Engaging patients to improve quality of care: a systematic review,” *Implementation Science*, vol. 13, no. 1, p. 98, 2018.
- [16] S. Lindblom, M. Flink, M. Elf, A. C. Laska, L. von Koch, and C. Ytterberg, “The manifestation of participation within a co-design process involving patients, significant others and health-care professionals,” *Health Expectations*, vol. 24, no. 3, pp. 905–916, 2021.
- [17] J. Dobe, L. Gustafsson, and K. Walder, “Co-creation and stroke rehabilitation: a scoping review,” *Disability and Rehabilitation*, vol. 45, no. 3, pp. 562–574, 2022.
- [18] R. Morris and P. Morris, “Participants’ experiences of hospital-based peer support groups for stroke patients and carers,” *Disability and Rehabilitation*, vol. 34, no. 4, pp. 347–354, 2012.
- [19] R. Wobma, R. H. Nijland, J. C. Ket, and G. Kwakkel, “Evidence for peer support in rehabilitation for individuals with acquired brain injury: a systematic review,” *Journal of Rehabilitation Medicine*, vol. 48, no. 10, pp. 837–840, 2016.
- [20] N. Fudge, C. D. Wolfe, and C. McKevitt, “Assessing the promise of user involvement in health service development: ethnographic study,” *BMJ*, vol. 336, no. 7639, pp. 313–317, 2008.
- [21] J. Lave and E. Wenger, *Situated Learning: Legitimate Peripheral Participation*, Cambridge University Press, Cambridge, UK, 1991.
- [22] M. Fricker, *Epistemic Injustice: Power and the Ethics of Knowing*, Oxford University Press, Oxford, UK, 2007.
- [23] E. Wenger, “Communities of practice and social learning systems,” *Organization*, vol. 7, no. 2, pp. 225–246, 2000.
- [24] E. Wenger, *Communities of Practice: Learning, Meaning, and Identity*, Cambridge University Press, Cambridge, UK, 1998.
- [25] R. Yin, *Case Study Research and Applications: Design and Methods*, SAGE, Los Angeles, CA, USA, 2018.
- [26] M. Denscombe, *The Good Research Guide: For Small-Scale Social Research Projects*, Open University Press, Berkshire, UK, 2014.
- [27] V. Braun and V. Clarke, “Using thematic analysis in psychology,” *Qualitative Research in Psychology*, vol. 3, no. 2, pp. 77–101, 2006.
- [28] M. Hammersley, “What can the literature on communities of practice tell us about educational research? Reflections on some recent proposals,” *International Journal of Research and Method in Education*, vol. 28, no. 1, pp. 5–21, 2005.
- [29] P. Sarrami-Foroushani, J. Travaglia, D. Debono, and J. Braithwaite, “Implementing strategies in consumer and community engagement in health care: results of a large-scale, scoping meta-review,” *BMC Health Services Research*, vol. 14, no. 1, p. 402, 2014.
- [30] J. Ocloo and R. Matthews, “From tokenism to empowerment: progressing patient and public involvement in healthcare improvement,” *BMJ Quality and Safety*, vol. 25, no. 8, pp. 626–632, 2016.
- [31] D. Kessler, M. Egan, and L. A. Kubina, “Peer support for stroke survivors: a case study,” *BMC Health Services Research*, vol. 14, no. 1, p. 256, 2014.
- [32] L. Barton, *Disability and Dependency*, Falmer P, London, UK, 1989.
- [33] E. Anderson, “Epistemic justice as a virtue of social institutions,” *Social Epistemology*, vol. 26, no. 2, pp. 163–173, 2012.
- [34] M. Oliver, *Understanding Disability: From Theory to Practice*, Macmillan, London, UK, 1996.
- [35] A. Wardrope, “Medicalization and epistemic injustice,” *Medicine, Healthcare and Philosophy*, vol. 18, no. 3, pp. 341–352, 2015.
- [36] R. McRuer and ProQuest, *Crip Theory: Cultural Signs of Queerness and Disability*, New York University Press, New York, NY, USA, 2006.
- [37] R. G. Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*, Columbia University Press, New York, NJ, USA, 1997.
- [38] P. Beresford, “From ‘other’ to involved: user involvement in research: an emerging paradigm,” *Nordic social work research*, vol. 3, no. 2, pp. 139–148, 2013.