Disability and Rehabilitation

ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/idre20

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To cite this article: Bodil J. Landstad , Marianne Hedlund & Elizabeth Kendall (2020): Practicing in a person-centred environment – self-help groups in psycho-social rehabilitation, Disability and Rehabilitation, DOI: 10.1080/09638288.2020.1789897

To link to this article: https://doi.org/10.1080/09638288.2020.1789897

Published online: 16 Jul 2020.

DISABILITY AND REHABILITATION
https://doi.org/10.1080/09638288.2020.1789897

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ORIGINAL ARTICLE

Practicing in a person-centred environment – self-help groups in psycho-social rehabilitation

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ABSTRACT

Aim: The increasing prevalence of chronic conditions and impairments in the population is putting new demands on health and rehabilitation services. Research on self-help groups suggest that participation in these groups might have a positive impact on people who are struggling with chronic illnesses or disabilities. In this study, we explore person-centred support in which participants in self-help groups are undergoing rehabilitation to develop their knowledge, skills and confidence necessary to handle life's challenges.

Method: The design is exploratory, analysing data from informant interviews and focus groups (a total of 32 participants) using a Grounded Theory inspired approach to analyse. The participants were rehabilitation clients aged between 20 and 60 years; eight were men and twenty-six were women.

Results: Three main categories emerged as being important self-help processes that were likely to promote positive rehabilitation outcomes: (1) Learning and practicing safely, (2) A refuge from expectations, (3) Internal processes that accentuate the positives.

Conclusion: Peer support delivered through the structured self-help environment can facilitate the development of new self-awareness, promote acceptance and adjustment, facilitate the establishment of new skills and enable transfer of learning to new environments, including the workplace.

➤ IMPLICATIONS FOR REHABILITATION

- Self-help groups may support the process of rehabilitation.
- Participating in self-help groups provides an enabling context for individuals to address challenges and limitations.
- Peer support delivered through the structured self-help environment can facilitate the development of new self-awareness, promote adjustment, and facilitate the establishment of new skills.
- Participating in peer led self-help groups can assist with the transfer of learning to new environments, including development of potential work capacity.

ARTICLE HISTORY
Received 26 November 2019
Revised 26 June 2020
Accepted 27 June 2020

KEYWORDS
Self-care; rehabilitation; disability; chronic disease; therapeutic group activities; qualitative research

Introduction

The increasing prevalence of chronic conditions and impairments in the population is putting extreme demands on health and rehabilitation services and challenging the sustainability of most health care systems around the globe [1,2]. A partial solution to this challenge that has not been widely applied in rehabilitation is the use of self-help groups to mobilise additional supports, strengthen the process of return-to-work and improve the sustainability of vocational outcomes. People living with long term conditions and disabilities might need person-centred support when undergoing rehabilitation. By person-centred we mean a process that supports people in their quest to develop the knowledge, skills and confidence needed to handle life's challenges. Research suggests that participation in self-help groups can lead to improved health outcomes [3–7], but it is less common to focus on the personal processes of change that occur through self-help groups. Some research suggests that these process variables have an impact on well-being and improved health [8–13]. However, little is known about the self-help experience of people with disabilities or chronic conditions who are participating in a rehabilitation program following an injury, mental health condition or other chronic diagnosis. Thus, the aim of this study was to explore the processes and outcomes for participants in rehabilitation self-help groups.

A self-help group consists of members who share a similar condition or life situation and provide mutual support for each other [14]. The term self-help is complex, and the meaning of the term can vary considerably [15,16]. Not surprisingly, self-help groups can take many forms, but are usually self-organising and voluntary, run for and by their members as they deem necessary. Health professionals are not involved with these groups, neither in the initiation of the group or attendance of meetings unless by

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invitation from the group for a specific purpose [3,17]. Self-help groups are usually informative, egalitarian and supportive of all participants who attend [18,19].

Participants in self-help groups are usually concentrated arround a peer-led ethos. Indeed, this defines self-help groups and is often used to distinguish self-help groups from professionally run support groups. In professional-led support groups, the organisation occupies the position of power and control through the professional, who is usually linked to a statutory agency [20]. In contrast, self-help groups are often described as self-regulating and self-governing, with control of the group ultimately resting with its members [21,22].

Self-help groups are thought to benefit individuals struggling with health problems or disabilities as they provide knowledge by peers through the sharing of experiences [23–25]. Self-help or mutual aid groups generally face criticisms about their tendency to look inward, rather than outward [26]. Apart from those conducted in the area of substance and alcohol abuse, self-help groups are rarely discussed in the rehabilitation research literature. When self-help is explored in rehabilitation, it is often concentrated around psychoeducational interventions led by professionals or professionals and peers together [27–30]. Few studies have investigated the role of peer-led self-help groups managed by people with persistent illnesses, injuries or impairments who are engaged in rehabilitation.

The relative benefit of peer-led versus professionally-led groups remains unclear. For example, at least one study focused on the experiences of veterans with mental illness and found that both types of groups were beneficial to recovery [31]. However, some evidence suggests that the benefits of self-help groups may be found in more subtle processes that support recovery. For instance, one study conducted in the United States [32] investigated the history of women with disabilites and their use of peer groups to help them overcome social barriers to participation in the community. Other research has focused on the use of peer support group for adults with learning disabilities where they can learn and talk about sexuality and relationships. This study showed that peer-led self-help groups can offer people with learning disabilities a beneficial and positive environment in which to explore complex sexuality and relationship issues [33]. Another study showed that self-help groups designed for people with serious mental illness can allow them to build hope and a sense of inclusion [34]. There are also studies showing that self-help groups do not necessarily improve the mental health status of people with multiple sclerosis, but do have a positive impact on their social identity [35]. Similarly, another study showed that self-help groups can promote recognition processes, internal security and acceptance of illness among people with early stage dementia [36].

These findings suggest that self-help groups could be combined with professional rehabilitation services to promote better and more sustainable outcomes. Indeed, Article 26 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) [37] calls for: "… appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain their maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life." The process of developing physical, mental, social and vocational ability and capability to participate in community were addressed as a rehabilitation outcome in this study. This involved both structural factors, such as how the groups were organised and grounded with certain rules, shared leadership and the structure of the conversation, and process-related factors such as internal processes within the group referring to shared reflections, attitudes and motivation to try new skills.

The purpose was to explore the self-help experiences of people with disabilities or chronic conditions who are participating in a rehabilitation program. Specifically, this study aimed to explore processes and outcomes for rehabilitation participants in self-help groups.

Method

Research context

This research was conducted in three Norwegian settings, namely

1. A disability organisation within an open local municipal centre with its own activities and arrangements aimed at helping people with disabilities to participate in and be a part of the local communities. The self-help group organised their settings, activities and formulated their own rules for interaction.
2. A vocational rehabilitation centre. The rehabilitation centre applied self-help groups as an attempt to assist people to recover during a rehabilitation process. After attending a hospitalised rehabilitation program, with group therapy as an important element, all participants at the rehabilitation centre could attend a self-help group if wanted. The rehabilitation centre facilitated and hosted self-help groups that wanted to start, but the self-help groups were not included as part of the rehabilitation program at the centre. A starter from the centre assisted in the creation of the self-help group including establishing the common ground rules. They attended two of the group meetings.
3. The National Nodal Point for Self-Help (NPSH). NPSH was established as the expert centre to coordinate and implement self-help nationally in 2009 [38]. Some activities and events took place in permanent groups, and all activities and group discussion were self-governed and led by peers. Three different regional resource centres were contacted to recruit participants to the study. Participants were recruited through advertising in the local newspapers and public places by the resource centres as well as incoming requests from individuals searching for such groups. The guiding principles of these regional resource centres are to assist and facilitate localities and guidebooks for self-organised self-help groups within local municipalities, outside of primary or specialised health care and local organisations. A starter from NPSH formed the group and assisted in setting the common ground rules, as well as attended three of the group meetings. A confidentiality agreement was signed by this starter.

Participants and recruitment strategies

Potential participants were recruited to the research from all three organisations. They were invited to open meetings, where they received both written and verbal information about the purpose of the research, an opportunity for a question-answer session and the contact details for the researchers. The meetings were held in familiar places for the participants (i.e. where the self-help groups were held). Those who chose to participate in the study signed a written consent at the meeting or posted it to the researchers after the meeting. All participants were legally and physically competent to give consent and consent was fully informed, voluntary, expressed and documented. Thereafter, all contact

Table 1. Strategic sample, data collection methods, and total numbers of participants (in brackets).

	Strategic sample					
Data method	NPSH[a]	Rehabilitation center[b]	Disability movement[c]	Men	Women	Total No of people
Key informants		2			2	2
Informant interviews	4	2			6	6
Focus group interviews	1 (3)	2 (8)	1 (13)	9	15	24
Total No of people	7	12	13	9	23	32

[a]Nodal Point for self-help (NPSH). Health issues: anxiety, game dependency (mental), sleeping problems and depressions.
[b]Rehabilitation center. Health issues: worn-out, depressions, anxiety, lenient mental conditions but on long-term sick leave for more than 3 months, personal troublesome life such as divorce, loneliness, social isolation, sudden death in family etc.
[c]Disability movement. Health issues: (self-defined impairments) medical diagnosis such as Cerebral Pares, neurological conditions (Multiple Sclerosis and Parkinson), Minimal Brain Disorders, and blindness combined with reduced mobility or a combination of the listed conditions.

throughout the study was exclusively between the participants and the researchers.

The sample consisted of thirty-two participants, eight men and twenty-four women, between the ages of 20 and 60 years. Originally there were thirty-three participants, but one person withdrew from the study after having participated in the interview. The data from this participant is excluded from the analysis. The reason for withdrawal is unknown.

Two of the participants acted as key informants and were recruited from the vocational rehabilitation centre. They are the previously mentioned starters of self-help groups at the centre and were not ordinary participants in a group as they had experiences beyond the personal experiences. In the other organisations there were no starters that were not participants themselves. All participants had lived with a significant disabling chronic condition (or multiple conditions) for several years and had voluntarily joined a self-help group. Seven participants originated from the national resource centre for self-help, twelve from the rehabilitation centre, and thirteen from the disability organisation (see Table 1). Some participants belonged to the same self-help groups, but the majority were the only representative from their particular group. Table 1 provides an overview of the informants in the study.

Data collection

Data was collected between October 2010 and June 2013 through both individual interviews (eight former self-help group participants) and focus groups (24 current self-help group participants). Eight interviews were conducted with two founders of self-help groups and six former participants of self-help groups from across the three organisations. The individual interviews lasted from 90 to 150 min and were conducted at times and places preferred by the participants [39, p. 341].

The topic guide for the individual interviews focused on personal experiences from joining self-help groups. The interview covered reasons for participating in self-help groups, motivation for participation, experience of personal change, benefits to daily life from attending, feelings of empowerment, and resources gained from participating.

Four focus groups were conducted with 24 active self-help participants. The size of the focus groups ranged from 4 to 12 participants as recommended for focus group interviews [40]. However, as one individual withdrew from the study, one focus group contained only three individuals. The focus group interviews lasted from 90 to 180 min. A moderator and an assistant participated in each focus group [39]. One focus group interview took place in the national resource centre for self-help, one in a public meeting room, and two in the rehabilitation centre. The focus group interviews were conducted at different times to the existing self-help group meeting times.

The topic-guide for the focus-groups centred on the interactions within the groups and the resulting experiences from these interactions. The interview questions focused on experiences of mutual help and support within the groups, the discussed topics at meetings, the experienced impact of participation including both positive and negative interactions, group organization and social support. All the interviews were audio-recorded and transcribed immediately following the interviews.

The analysis

A two-step analysis was carried out where we first analysed the individual interviews before analysing the focus groups. The interview data were analysed for the purpose of exploring the participants' experiences with self-help groups. The focus group data were analysed for the purpose of exploring the interactions in the group that had an impact on the participants' rehabilitation process.

When analysing the individual interview data as well as the focus group data we used a stepwise method of constant comparison [41,42] to develop a flexible and heuristic strategy [41, p. 510], that adequately described the patterns in the data. We applied a less rigorous analytical approach than what is described by Grounded Theory (GT) [42], more allied with Crabtree and Miller [43] and along the same lines as more recent descriptions of GT [44–46]. In our flexible and heuristic strategy we did not define the categories and sub-categories in advance. The first analytical step involved a naive reading of the data to determine distinct patterns or commonalities. When these were found, we proceeded to search for properties or characteristics in each category, labelling them as sub-categories. In the second analytical step we continued to search for any found patterns and commonalities between each sub-category and main category. The authors discussed and agreed on the labelling of categories [41]. Saturation was considered achieved when all authors agreed on the description of the categories and that no additional data added value to the analysis [39,42].

In three of the self-help groups, participants had experience with mental health issues and in one group, they had experience with disability. These were not diagnosis-specific self-help groups and the participants had various challenges (lack of income, relational challenges, loneliness etc.) related to their health problems. Diagnostic-specific or co-morbidity experiences were not the focus of the self-help groups therefore it is difficult to select quotes referring to a range of different medical/mental problems.

Ethics

The study was approved prior to data collection by the Regional Committees for Medical and Health Research Ethics in Norway (REK file numbers: 2009/4.2009.776 and 2010/3323-3). All

Table 2. Patterns of rehabilitation processes and outcomes.

Sub-category	Category	Main category
A sounding board for emotions	Learning and practicing safely	
Learning how to manage one's own circumstances		
Being open to feedback		
Normalising experiences	A refuge from expectations	Practicing in a person-centred environment
Personalised help		
Connections that focus on positives	Internal processes that accentuate the positives	
Participation that makes me feel valued		
Leadership from within–learning to rely on self		

informants received information about their opportunity to withdraw from the study without giving any reason and with no implication for their participation in the groups; one participant did so. The participants provided oral informed consent, which is considered sufficient according to the Act on Medical and Health Research in the country where the data was collected [47]. The data was stored in accordance with the national legislation.

Results

The analysis revealed that self-help groups were an important adjunct to rehabilitation for people with disabilities, injuries and mental illnesses. Three main categories reflected participants' experiences within self-help groups that contributed to the rehabilitation process (see Table 2). They were: *Learning and practicing in safety*, *Refuge from expectations* and *Accentuating positives*.

Learning and practicing in safety

Participants were rehabilitated through a feeling of individual worth and capability that developed as a result of the safe environment created by self-help groups. Within the context of self-help groups, participants built and tested their own abilities. The participants described processes through which they practiced, tested and learned new skills in safety. The self-help groups provided a safe environment where they could learn how to manage their lives beyond the group.

A sounding board for emotions

The participants distinguished the processes within self-help groups from those that occurred in treatment groups. Self-help groups are autonomous in that members had to rely on one another for help in dealing with stressful emotions. Most participants had experienced a sense of being alone and left to themselves, which engendered a sense of insecurity, and prompted the search for a place where connections could be made with other people. In one self-help group (Focus Group 3), the environment was described as a place in which to deal with emotions and to build capacity to deal with challenges in everyday life.

Many participants reported that they had initially thought it was better to shut down their feelings and try to figure it out themselves. However, they found it valuable to share these inner feelings without fear of criticism:

> I still get anxious, but I manage it in a different way. I don't let myself become paralysed by it, I don't freeze up. I often get anxious when I need to bring up an uncomfortable issue at work, for example. It's uncomfortable, but it's not a discomfort that disables me anymore. I dare to bring it up [because I have practised in the self-help group]. (Informant 2: female, 37 years old, mental health issue)

By participating in a self-help group, they were exposed to other participants' challenges and responses. Although participants recognised that there were different approaches to problems, hearing from other participants gave them courage to explore their own feelings. The experiences and strategies of other participants influenced their own approaches:

> That's of course part of the work we're talking about … when somebody else is talking, you sit there and think about how that impacts you. (Focus Group 3, male, 42 years old, mental health issue)

To retain a reflexive environment, participants consciously prevented the group from developing into a social club, which is a common criticism of self-help. Participants shared their stories and responded openly to each other. The participants agreed to notify each other if they were going to miss a meeting. Another agreement was to spend a maximum of two hours in each meeting, which prevented exhaustion. They also shared the leadership of the group, so no member was permanently assigned to this role:

> About formalities, that we're open to the idea that here there are certain patterns that we follow … that prevents us descending into chaos. I think that was an important part of getting started. I think we were able more quickly to find a structure that focused on the work … instead of becoming a social group, it became a working group. I think that's got a lot to do with the focus on rules that existed from the beginning. (Focus Group 2, female, 44 years old, mental health issue)

The participants expressed the importance of forming rules before starting the self-help group. It was important the participants agreed on the content and importance of the rules. The set of rules gave the assurance of predictability to all members. It was important to follow the rules, especially at those times when group meetings began to follow a negative path or were not perceived to be meaningful. In one group, the rules also focused on listening without interruption to the person who was talking and reflecting on the personal impact of the story being told:

> Yes, yes, so simple, but so difficult sometimes, and you get so many different perspectives on things that you haven't seen yourself. It becomes so much clearer, in any case for me, if I talk about something, or one of them talks about something, and then we get to hear how that impacts the others … that it's actually … normal to react that way. It triggers a lot of the same kinds of things, but you also see things from another side, you see it with "new eyes." (Focus Group 3, male, 44 years old, mental health issue)

The feeling that somebody was actively listening and paying attention created a sounding board on which to test intense and sometimes frightening emotions. Participants felt connected, but also retained a sense of privacy. Participants did not feel pressured to comfort each other so each participant could maintain a sense of control and autonomy and all participants respected this position. They did not feel as though they had to talk all the time and felt that they had some control over how and when they engaged with others:

> We don't console … we don't go into each other's … space. We can ask, "Do you want a hug?" and then the person can decide whether they want one or not. (Focus Group 2, female, 52 years old, mental health issue)

The participants revealed that sharing emotions and reflecting on others' experiences gave them insight and created meaning for their own experiences. Gaining insight about and giving meaning to their emotions allowed participants to take control in situations that previously they might have experienced as chaotic or meaningless. This contributed to feelings of equality and respect among the participants within the self-help group.

Learning how to manage one's own circumstances

The self-help context provided the opportunity for interactions that involved learning from and sharing the knowledge they gained as participants in self-help groups:

> I gained perspective on my situation, into my thoughts and reactions and attitudes. I also understand how it became the way it was, that I got those feelings because of the way I was thinking. (Informant 1, female, 33 years old, mental health issue)

The participants stated that the self-help environment was important to learn how to understand their own response patterns to different challenges. The respect in the group enabled them to tackle personal challenges outside the group, knowing that the group was there to support them in their decisions and experiences irrespective of the outcome. The group thereby assisted to move the person beyond personal hindrances that were preventing positive action. Such insight promoted empowerment as it created self-awareness and allowed participants to change those patterns to a more productive or beneficial approach. This, in turn, made it possible to learn new behaviours and respond differently to a wider society:

> To learn from experience, right, that speaking out isn't scary anyway, that I don't need to feel that anxiety anymore, right? (Informant 1, female, 33 years old, mental health issue)

The learning environment of the self-help group gave participants the confidence to talk about uncomfortable issues. Practicing the process of working through emotional discomfort delivered experiential knowledge about what to do in other personal circumstances. Sharing challenges helped participants develop an appreciation for life. One participant expressed the benefit of sharing challenges and solutions:

> It sounds strange now, four years after he got rid of his problem. I said, "Thank you so much." "Huh?" he said. "Thank you for having had this problem. If you hadn't had it, I wouldn't have found my way." Right? I believe that nothing is so wrong that it isn't good for something. (Focus Group 1, female, 28 years old, mental health issue)

Sharing experiences built new insights and knowledge that participants then used in other situations. This learning was a source of courage and self-confidence; the individual's experience was transformed into something meaningful, and participants were empowered to face situations they had previously found uncomfortable:

> I think we need a certain distance in order to be neutral about life histories and solutions to problems. I sit and have conversations and hear things that I don't talk about with my best friend, because she's not a neutral person in my life. She knows me on the outside, but maybe not so deep … on the inside. She knows me well, but maybe not as intimately as the group here knows me. (Focus Group 3, female, 39 years old, mental health issue)

Through the group, participants became aware of their own freedom of choice and how their own patterns of behaviour brought obstacles into their lives. They reflected on how their own behaviour impacted on others and how this could be changed.

Being open to feedback

Participants reported that the self-help groups were a place that allowed them to receive feedback. Feedback is essential for the process of becoming empowered, but it is important that it is provided in a structured and respectful way. The groups had agreed rules about the way in which feedback was provided. Participants emphasised the need for feedback to be structured and respectful, which made it possible to share difficult or complicated stories and emotions.

The fact that they agreed upon rules and trusted others to contribute through meaningful feedback allowed participants to feel secure enough to show themselves "naked" and vulnerable. By being open to receiving feedback delivered in a respectful way, participants learned to rely on themselves and trust their own judgment.

A refuge from expectations

This category describes the processes of shaking off the expectations and judgments of, and dependency on the outside world. Positive experiences within the self-help groups helped participants to be proactive, but also to normalise their experience and suspend the judgments they made about their own circumstances. It also helped them to see when they required assistance and how to get that support.

Normalising experiences

Through the self-help process, participants gained access to feelings of being normal and valued. Sharing experiences helped participants to realise that they were facing common challenges and that they did not need to feel devalued by their experiences. One example involved unemployment where a participant discussed not having employment, which lead to discussions about the value of work and participation in society. This discussion normalised the unemployment experiences of those in the group:

> So, it [having a job] means a lot, you get out, you meet other participants, you have something to do, and that is really important. (Informant 2: female, 37 years old, mental health issue)

Participants shared experiences of being at the "edge" of the labour market. Talking about this alienation in a self-help group gave new expectations and hope. Being a part of a self-help group became a supplementary and motivating activity, leading individuals to reflect on changing their employment or applying for employment:

> Let me say it this way: If it hadn't been for this self-help group, I probably would have written fewer job applications than I have thus far. … this group has helped me to not fall back into old ruts … and if it weren't for that, I wouldn't have come as far as I have. (Focus Group 3, male, 27 years old, mental health issues)

Participation made it easier to share stories about acceptance and non-acceptance in working life. The story-sharing sessions that formed the substance of self-help group meetings appeared to assist participants to accept and tolerate unemployment, simply because it was a normal condition for most group participants:

> All three [group participants] still deal with anxiety, but on a different level. All three of us live complete lives. And I will never work again, that's a bitter pill to swallow. (Informant 3, female, 57 years old, mental health issue)

In this way, participation in self-help groups provided a counterweight to common negative societal expectations and built resources to deal with significant problems such as long-term

exclusion from the labour market. For many participants, the group normalised their isolated social status and enabled them to engage in normal social interactions. For participants, sharing their sense of a lack of social value allowed them to reorient their position, from being an "outsider" in society, to becoming an "insider" in the self-help group:

> Yes, it's good that you make [new friends]. If I hadn't gotten the illness, I wouldn't have made those friends either. (Focus group 4, female, 57 years old, physical impairment)

Participation in a self-help group offered the opportunity to build new friendships and share commonalities, both of which are important for encouraging feelings of social value and respect. To interact in close friendships within the context of the self-help group and to be selective about those interactions imparted an experience of value (Focus Group 3). To be valued within the context of a self-help group could make participants reflect on their existing social relations and thus become more assertive. One participant described it as follows:

> I had a discussion with [a family member]; he thinks I've changed. That's great, you're supposed to change, so it isn't anything negative, and it's clear that I've lost friends, but that is not such a big deal because I've become more selective, I don't need to be liked, and so I've become a lot more assertive. (Informant 3, female, 57 years old, mental health issue)

Participating in self-help groups provided support, insight, strength and the ability to take part in society in different ways. The participants shared experiences and attempts to overcome the barriers of social expectations, and this helped them build new abilities: a new sense of autonomy, self-esteem and courage and inner strength. These new abilities helped the participants to meet social challenges and deal with societal expectations. They became resources that were valuable in situations where participants felt discredited or lacking in social value. Participation in the self-help group allowed them to normalise challenges to their sense of value and address these challenges productively:

> And that helped me to dare to be more open with others about what I'm struggling with, and through that I see that it isn't so bad [to talk] about what I think is hard. (Informant 1, female, 33 years old, mental health issue)

Personalised help

Self-help groups offered a friendly and supportive environment that responded as needed in a personalised way. This context made participants feel supported by open-minded and friendly peers who encouraged the development of autonomy and gave them help when it was needed. The timeliness of this help enabled participants to regulate their approaches to family conflicts and challenges:

> So, if [something serious happened in the family], it didn't hurt so much that it broke me, like it would have five, six, seven years ago. I don't think I would have dared to make some of the choices I do without it [participation in the group]. That is, I wouldn't have dared to say to [family members], "Don't worry about me when you make your choices, I am standing on my own two feet, I can handle whatever you choose." (Informant 3, female, 57 years old, mental health issue)

Participants described humanity and kindness were the most important features of the help they needed. They stated that they experienced much more compassion and tolerance in the group than they did in all other social or treatment contexts, such as at work or in family life (Focus Group 3). As a result of this personalised and person-centred environment, participants spoke with the other group participants about things that they did not normally share. They dared to share their innermost feelings, normalising the process of being vulnerable and translating it into an opportunity to mobilise support for personal growth:

> It's really amazing to be able to share those feelings, things that sometimes are the deepest of the deep. And you're met with respect, understanding, and kindness anyway, you know, and that's really great, and that's something that stays with you. That you believe that you're good enough even though you struggle with different things, that there are people that can like you anyway. (Focus Group 3, female, 53 years old, mental health issue)

Participants reported that they were not judged when sharing their problems and were able to communicate their feelings without the shame that would ordinarily encourage them to hide these inner and personal states. This sharing and reflection normalised even the most intense feelings and gave them energy to keep going. The self-help group was a context where one could share everything, even forbidden feelings, without being condemned:

> I can put it all on the table … everything, regardless, I never get cut off, and I get it all out. Nobody comforts me; nobody … even if I start to wail and sob … nobody comes over to hug me. Because that hug can kill the moment, it's like, "stop crying!" They take in the whole story, the whole spectrum in a totally different way, so it was like … it was like a secure place for my sorrows … . (Informant 5, female, 34 years old, mental health issue)

Although individuals typically set their own limits, other participants could challenge them to take on a little more than they initially thought they could manage. The interactions in the self-help group helped participants to focus on resources and possibilities rather than problems and limitations. This enabled them to make both personal changes and environmental changes.

Internal processes that accentuate the positives

Self-help groups provide a powerful environment that builds on positivity and participant's experience of empowerment.

Connections that focus on positives

The self-help groups focused on a process of identifying commonalities by sharing stories, feelings, challenges and solutions. Once commonalities were found, participants could identify with others in the group, creating a positive sense of belonging that was defined by solutions rather than problems alone:

> Having something in common … we have a lot in common. Even if you do not have [precisely that illness], you still have a lot in common. (Informant 4, female, 43 years old, mental health issue)

The demonstration of care for one another despite their own perceived "failures" was an important component of the construction of positive social identities. Participants demonstrated an openness to the stories told by other participants, and always responded with positivity regardless of the content. One participant expressed how this process resulted in a feeling of being better when they left the group than when they had arrived (Informant 1, female, 33 years old, mental health issue).

The groups maintained a normative agreement about confidentiality and keeping members' stories within the group. They also agreed that the self-help group was a place where one should use the experiences of peers in positive ways to deal with issues of self-control. If a participant persisted in unproductive complaining about their own situation, the other participants often perceived this as a breach of the rules. Such rule breaking could trigger feelings of insecurity and stress among the other participants. At the same time, they distanced themselves from

the complainer and actively decided not to indulge in self-pity themselves:

> Some of the members were so illness-focused that they ruined it … one just sat and talked about how nauseated she was and just wanted to throw up. Like, when you've heard this week after week, you get so sick and tired, because that's not actually working on yourself; she needs to work on what makes her that way. So, it's not the symptoms you should work on, but what's behind the symptoms. (Focus Group 4, female, 33 years old, neurological impairment)

This approach constructed a positive community that contributed further to a positive social identity which was important for participants.

Participation that makes me feel valued

An atmosphere of positive interaction promoted the feeling of social support, gentleness, understanding, and affirmation. This created a positive sense of belonging and value:

> You feel valuable, you feel like you are worth something to society, which you might not have felt before you came here. (Focus Group 4, male, 29 years old, neurological impairment)

The feeling of being valued was triggered both by giving and receiving support from each other. By sitting in a circle and sharing stories and problems, the groups formed what [18, p.40] called a "circle of sharing."

Feelings of value were most often experienced when participants shared stories and each participant then shared their reaction to that story. Participants explained that there should be openness and honesty in sharing one's reaction to another's story. Being open about personal reactions gave a sense of value to both parties (Focus Group 3). Sharing in groups gave participants feelings of strength, importance and self-confidence:

> I've received more, myself, a better self-image, I think; my assertiveness has been strengthened. The idea that a person is worth just as much as all the others … there's no one that steals the floor and makes you feel like they're just that much better than you. I'm used to that from before, so I've learned that I really am worth just as much as the others … I feel worth just as much, and that's a good feeling (laughs a little). (Focus Group 2, female, 31 years old, mental health issue)

Group meetings were conducted and organised in a way that created a symbolic "watering hole," or temporary relief from life's challenges through the sharing of personal stories. Participants' feelings of being valued by the group empowered them to make changes. They identified with one another and created supportive processes by sharing stories of solutions and receiving mutual affirmation. The cohesion of the group strengthened their own capacity for change beyond the group.

Leadership from within – learning to rely on self

Participants learned to direct their own lives in the way they wanted and to rely on themselves. Participants re-evaluated themselves based on knowledge they gained from listening to the experiences of others in the group:

> If we talk about change … how difficult it is to change patterns of behaviour … and then when you hear stories that you recognise, we feel like we recognise ourselves, and then we think that it's possible, it must be possible to do something about this. I, in any case, have learned a lot about changing patterns, and I'm very alert to that. To make sure that it doesn't- that it doesn't come back, whatever it was that made you sick. (Focus Group 2, female, 47 years old, mental health issue)

This recognition of self in the experiences of others made it possible to gain new and liberating insights about one's own situation. This realisation empowered participants to take responsibility to redefine previous experiences and become capable and confident in the management of their own life.

The autonomous organisation of the self-help groups allowed participants to gain experience in the art of taking responsibility and accepting leadership of one's life. This meant they were able to get on with their lives in a stronger and more conscious way. Through their interactions, they built their own inherent resources that supported them in taking a leadership role in their own lives–finding their inner voice and personal goals (*Informant 1, female, 33 years old, suffering from anxiety).*

Emotional recognition of oneself, based on reactions to stories from others, can elicit confidence in one's own resources and capacity for self-determination:

> When she told her story about what she had gone through and her experiences, she left me feeling like "yeah, that's how it is for me too." But it doesn't sound so strange actually – I had the opportunity to normalise my emotions, right? It wasn't so bad after all, because in the way she told it, I recognised myself. So, it wasn't so bad, something to regret. (Focus Group 4, female, 68 years old, neurological impairment)

Increased self-confidence meant participants could redefine their situation and reorient themselves, forming a more positive identity. Among peers, participants experienced being "normal," which meant that their problems were not "different" or "deviant." By describing their personal experiences, they reinterpreted their identity and changed their self-perception to one defined by capability and acceptance:

> For me, it's important because I experience it as very liberating because I don't have to wear any masks, I can be one hundred percent myself and be accepted for who I am with my limitation, and everyone has some problem or other. I think it is the same out in the world, everyone has some problem or other, but if you put your problem on the table, I feel like I don't need to say so much because I am – because many others struggle with the same things. (Focus Group 1, male, 55 years old, mental health issue)

Rehabilitation was enhanced when participants had the energy to lead themselves away from old response patterns or experiences of stigma.

Discussion

The aim of this study was to explore processes and outcomes for rehabilitation participants in self-help groups. We found that the interactions experienced within the self-help groups were important for the rehabilitation process. The analysis revealed three categories that defined the potential role of self-help in rehabilitation: *Learning and practicing in safety, A refuge from expectations,* and *Accentuating the positives.* These three qualities appeared to be unique to the self-help environment and may not be found in traditional rehabilitation or treatment environments or general social interactions.

In the self-help group the focus on health and disabilities was holistic, approaching the problem of each participant according to what Wade [48, p.1145] called: The holistic biopsychosocial model of illness. This orientation made the interactions in the group valuable for each person and meant that they experienced a rehabilitation process that was personalised and goal directed. As Wade [48] stated, this level of person-centredness and goal-directedness is important for the person undergoing rehabilitation for them to be encouraged and enabled to engage in rehabilitation activities. For chronically sick and disabled people, this approach allowed them to map out the possibilities and opportunities for functioning and well-being rather than merely focusing on the challenges and problems. In a self-help group, participants could access a supportive social community where they could

learn from interacting with other peers. The groups worked in an egalitarian manner, supporting all participants who attended. This quality has been described as an essential characteristic of self-help groups [18,19]. A self-help group enables sharing, support and recognition from other participants which assists individuals with illnesses or disabilities to mobilise their own internal and external resources, facilitating the opportunity for change [16,18]. In our study, participants placed value on sharing the goal of becoming "we," similar to what Seebohm et al.[14] originally called "constructing social identities." Through becoming "we," each participant could associate positively with the group rather than identifying solely as an individual with "problems."

Seebohm et al. [14] argued that social identity arises from identification with other participants in self-help groups. Identification with a social identity can create and reinforce positive emotional energy and a sense of solidarity within the group [49], enabling participants to feel capable and positive. The positive emotional energy is likely to improve the benefit gained from simultaneous rehabilitation processes whereas low energy is likely to lead to passivity and resignation [49]. There were few indications of negative feedback to participation in a self-help group. This might depend on the fact that it was voluntarily to join a group and that the participants were highly motivated and positive to the ongoing group processes. The findings did not demonstrate any internal group conflicts which might be due to the groups being peer-led and egalitarian in shape.

Importantly, self-help groups repudiate dominance and subordination in favour of human equality and importance. Borkman [18], one of the earliest researchers in the area of self-help groups, argued that insight and meaning are important for developing experiential knowledge in self-help groups. Positive experiences in the rehabilitation process were connected to the feeling of capability. This occurred when the participants got pride and confidence gained from the experiential knowledge in the group that helped them achieve what Borkman [18, p. 156] called "experiential authority." They learned to be assertive about their preferences, to stop blaming their environment, and instead to look inward for positive solutions and change.

Participation in self-help groups was important for the rehabilitation process in the sense that it enabled participants to better understand themselves and their abilities, but also to enact their learnings beyond the self-help and rehabilitation environments. Hence, participation in a self-help group assisted them to not only look inward, but also outward to gain new experiences that contributed to change. This finding is in contrast to previous research claiming that participation in self-help groups tends to have an inner, not outer focus [26]. The unique combination of positive support, encouragement, emotional safety and acceptance within the self-help context combined with clear and shared rules about interactions provides a safe environment that can promote improved rehabilitation outcomes.

The self-help group context encouraged participants to rely on themselves, and the response from peers had a strong influence on their understanding of how others viewed them and their behaviour. Accordingly, the self-help context constructed what Collins [49] called "self as a mirror" based on the dynamic interactions in the group. Self-help interactions enabled participants to focus on expressing and managing intense emotions but simultaneously focusing on positive solutions, feeling valued, and learning to relate productively within their own environments. Thus, self-help groups in combination with traditional rehabilitation provided a special context where the participants could safely practice their skills. The context of the self-help group allowed a new kind of social interaction, new experiences and the ability to positively yet constructively reflect on one's own performance. The self-help groups may allow participants to measure their own behaviour and attitude to each other differently, and thereby relate differently to their situation.

Our study suggests that professionals and rehabilitation providers need to understand how to harness self-help as a means of supporting rehabilitation processes. Change is facilitated by practicing new patterns in a safe, normalising environment with positive feedback from peers and protection from expectations. Together, these processes define the strength of the self-help environment and position it as an essential component of rehabilitation. Further research should examine the ways in which self-help groups can operate for people with different types of chronic conditions, diagnoses or disabilities and at different stages of the rehabilitation process. The current study suggests that the processes of self-help might be universal given the diverse range of conditions present in our sample. If self-help groups can be more formally integrated into the rehabilitation process without damaging their fundamental processes, they may become an important adjunct intervention for the future.

There are structural factors inherent to self-help groups that may be responsible for both distinguishing these groups from professionally-led groups and for influencing positive changes among group members. Certain structural factors of the group model might have positive effects on the participants, including the member-determined ground rules, a shared leadership model, scheduled times for meetings and the location of the meetings. They learned new skills of organizing groups, to manage a group and be in a position of structuring the conversations. These experiences gave positive outcomes in settings other than the self-help group. Additionally, the participants gained confidence and security within themselves. Other factors that had a positive effect on the participants are considered more process-related, that is outcome of the internal processes in the groups. These factors refer to feedback from other group participants, shared reflections and attitudes, and motivation to try new skills outside the group. These process-related experiences could also provide positive outcomes in settings other than in the self-help group.

Limitations and strength of the study

In the interpretation of our results, it is important to note that this study was conducted in the Norwegian context. The findings should, therefore, be interpreted with this limitation in mind. Another limitation is that we did not collect secondary data (diagnoses, contact with health professionals, hospitalisations, etc.) on other characteristics of participants in the self-help groups. The purpose of qualitative research is not to generalise findings derived from selected samples to the general population, but rather to develop an in-depth understanding of a complex issue and apply the findings to similar or related situations. Thus, the findings in this study are likely to be transferrable to similar contexts where traditional services could be augmented by self-help processes. The resulting data have a skewed gender difference as more women than men participated in the self-help groups and thereby the sample became gendered. However, this was random and not intentionally.

The strength of this study is that the sample includes both males and females and a range of ages and types of disabling conditions. Thus, it is possible that the findings have revealed some universal processes and opportunities offered by the self-help context.

Conclusion

This study has shown that peer support delivered through the structured self-help environment can facilitate the development of self-awareness, promote positive adjustment, facilitate the establishment of new skills and enable transfer of learning to new environments, including the workplace. Participants described positive outcomes in all domains of life, including independence, social engagements, family, work, emotional wellbeing and physical functioning. The self-help environment appeared to offer a sense of confidence and supportive social interactions that promoted the development of a positive identity. The benefit of this adjunct environment for the outcomes from more traditional rehabilitation needs to be further tested, but this study has indicated the potential opportunity to be gained by combination these two elements.

Disclosure statement

No potential conflict of interest was reported by the author(s).

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