The group rehabilitation helped me adjust to a new life: Experiences shared by persons with an acquired brain injury.

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THE GROUP REHABILITATION HELPED ME ADJUST TO A NEW LIFE – EXPERIENCES SHARED BY PERSONS WITH AN ACQUIRED BRAIN INJURY

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ABSTRACT

Primary objective: The aim of this study was to describe how persons with acquired brain injury experience an out-patient group rehabilitation programme, and how the programme had contributed to their everyday lives. *Design and Method:* Qualitative interviews with 11 men and women with an acquired brain injury who had participated in an out-patient group rehabilitation programme were performed. Data was analysed with qualitative content analysis.

Findings: The findings formed the theme "The group rehabilitation helped me adjust to a new life" that revealed experiences related to the content and outcome of the programme, as well as the process they went through during the programme. The participants described how the rehabilitation gave them the tools they needed to change their everyday lives, especially in relation to improved knowledge, and learning new routines and habits. They perceived their rehabilitation as a long-term, individual, but also collaborative process, where professionals as well as family and friends had crucial roles.

Conclusion: Learning how persons with acquired brain injury experience participation in a group rehabilitation program can help to unravel parts of the 'black box of rehabilitation', and can support professionals to better understand the effective components of such programmes.

INTRODUCTION

Acquired brain injury (ABI) includes traumatic brain injuries as well as non-traumatic injuries, e.g., tumours, stroke, and infections [1]. In Sweden, the yearly incidence of ABI is around 45 000 to 50 000, including those who suffer a stroke and with traumatic brain injuries [2, 3]. An ABI may lead to different physical, cognitive and psychological impairments [4], but it is often the cognitive impairments that impact on a person's ability to participate in everyday activities in the community [5, 6].

A Cochrane report [7] stated that comprehensive rehabilitation is beneficial for people with ABI (pwABI), and that acute in-patient rehabilitation should always be followed by out-patient or community rehabilitation. That is, rehabilitation in ABI can be a process over several years, and each person's rehabilitation needs to be adapted to his/her current situation, offering the proper type of intervention at the right stage in the process. Moreover, goals should be co-ordinated together with the person [4, 8].

Geurtsen and colleagues [9] stated that comprehensive rehabilitation in the chronic phase of severe brain injury was effective, and that day-treatment programmes had the highest level of evidence. Many of these were performed as group programmes and lasted several weeks, sometimes months, and often targeted behavioural problems. For those with mild ABI, interventions that focus on information and advice have been shown to be more beneficial than intensive rehabilitation [7]. However, few studies have explored the effects of such programmes [7]. Furthermore, even though there is a demand for more rigorous studies that evaluate the effects of such rehabilitation for ABI [9], not all questions regarding rehabilitation can be addressed by randomised controlled trials or a rigorous design [10]. It is also crucial to elucidate how pwABI experience different interventions, and how they themselves perceive their process

of rehabilitation. To understand the benefits of rehabilitation programmes for persons with chronic conditions, both qualitative and quantitative methods can be used. With qualitative methods, the outcome of a rehabilitation programme and the process by which the outcome has emerged can be explored from a patient perspective.

One previous study used a mixed methods approach and evaluated the effects of a group rehabilitation programme [11]. The authors reported that the group programme had positive effects on coping strategies and improved self-awareness in pwABI. Another, qualitative study presented results where participants shared their experiences in relation to taking part in a rehabilitation programme, and how this programme affected their rehabilitation process [12]. Even though the participants revealed experiences in relation to the different components of the programme, as well as how the programme had contributed to their everyday lives, the results primarily focused on how the participants experienced the rehabilitation programme as having facilitated their process of change and how the different steps in this process were unravelled. Thus, there is a lack of knowledge regarding how people with an ABI experience their rehabilitation, and how such a programme can contribute to their everyday lives. Therefore, the aim of this study was to describe how pwABI experience a group rehabilitation programme, and how they experience that the programme had contributed to their everyday lives.

METHOD

Study design and participants

This study had a qualitative design where semi-structured research interviews were conducted, which aimed to describe experiences from a participant perspective [13]. Participants were recruited among 23 individuals with an ABI who participated in a group rehabilitation

programme during 2004-2006. As part of the regular follow-up, the 23 participants received a questionnaire with questions concerning how they perceived their rehabilitation and if they had returned to work. Together with the questionnaire, the individuals also received written information of, and were asked to participate in, the present interview study. Sixteen former patients answered the questionnaire, of which 11 gave their informed consent to participate in the interviews. From the eleven participants, five were diagnosed with a traumatic brain injury (TBI), three had a subarachnoid haemorrhage, one had a brain tumour, one had a stroke and one had an anoxic injury. All of the participants lived in an ordinary housing, and in table 1, the demographic backgrounds of the participants are presented.

Insert Table 1 about here

Ethics

Before inclusion in the study, each person was given written and verbal information about it. Those who gave their written informed consent to participate were assured of confidentiality. The principles of the Helsinki Declaration were followed throughout the study.

Group rehabilitation programme

The group rehabilitation is offered to persons who have completed their acute in-patient, as well as post-acute rehabilitation, and who have experiences of the transition from the hospital to the community. Participants should also be independent in personal care but may still have difficulties managing household and leisure activities in their daily life, and/or want to be able to return to work.

The aim of the group rehabilitation is to give the participants an opportunity to reflect on their limitations and resources, and to give them insight and knowledge in relation to their life situation in order that they can engage in a process of adaptation. The programme includes information and practice how to manage and handle difficult situations in daily life that occur due to an ABI. Each participant has their own rehabilitation plan, based on the International Classification of Functioning, Disability and Health [14].The rehabilitation plan includes the participant's problems, resources, goals and interventions, and is used as a guide during the individual, as well as the group sessions. The individual sessions are planned according to the individual rehabilitation plans, and following the guidelines by Malia and Duckett [15]. The group sessions give the opportunity for the participants to meet with others in the same situation, to share similar experiences, and to help one another to learn new strategies in their daily lives. Family and relatives are also invited to participate in specific sessions where information regarding the ABI, its consequences for daily life, and information of the content of the group programme is presented.

The group rehabilitation is led by a team consisting of a physician, an occupational therapist, a physical therapist, a social worker and a neuropsychologist. The group rehabilitation is offered to five participants simultaneously, three days per week, with sessions lasting from 9 am to 4 pm, including regular breaks. The group programme continues over two periods, each of six weeks, with a two month intermission between the periods. After completion of the group rehabilitation programme, the participants meet for a group follow-up three months after discharge, and, if necessary, monitored for a longer period.

Data collection

All interviews were performed according to the participants preferences; ten in the participants' homes and one at the rehabilitation facility, and were performed by the second author (A-K A). Interviews lasted between 45 and 85 minutes, and ten of the interviews were tape-recorded. One of the participants did not want the interview to be recorded; instead, careful notes were made throughout the interview. All interviews followed an interview guide with open-ended questions. It included questions of how the participants experienced their everyday lives after discharge from the rehabilitation programme, how they experienced the group rehabilitation programme, if there was something in the programme that was particular useful, and how the group rehabilitation had influenced their current life situation. They were also asked if and how they thought the programme could be improved.

Data analysis

Data were analysed according to the principles of qualitative content analysis [16] and was mainly performed by two of the authors (A-KA and KO). The two authors started with a careful reading of the transcripts in order to get an understanding of the whole content. The text was then divided into meaning units that reflected similar experiences, as described by the participants. The meaning units were given a code, and codes were then compared and clustered until they could be gathered in preliminary categories. The analysis then moved on to compare the preliminary categories for all interviews. This continued until a set of categories, each containing underlying sub-categories, was defined. The two authors each analysed half of the interviews by themselves, and then compared and discussed their analysis with each other until agreement on preliminary codes and sub-categories were obtained. They stayed close to the text throughout the analysis, until the theme was formed. To increase the trustworthiness in the analysis, the

preliminary set of codes, sub-categories and theme were validated by the first author (EML) who read all the interviews and further scrutinised the results of the analysis. Finally, the findings were discussed by all three authors until consensus was obtained.

FINDINGS

The analysis of how the participants experienced the group rehabilitation programme formed one theme "The group rehabilitation helped me adjust to a new life" that revealed experiences related to the content and outcome of the programme, as well as the processes they went through during the programme. The theme consisted of two categories; a) the group rehabilitation gave me knowledge and tools to change my everyday life; and b) rehabilitation is a long-term, individual and collaborative process. In table 2, the theme, the categories and the sub-categories are presented. They are also described in greater detail in the following text, including quotations from the participants.

Insert Table 2 about here

The group rehabilitation gave me knowledge and tools to change my everyday life

This category has four sub-categories that describe how the group program provided the participants with the tools they needed to find solutions to problems in their everyday lives, and how this new knowledge helped them to change significant areas in their lives.

Learning to plan activities and to have a new routine in life

The participants described how, although they had previously had received rehabilitation, they still experienced a decreased possibility to perform activities in daily life due to their ABI. Even if this situation had not changed when the group rehabilitation program was completed, most of them were more satisfied with daily life than before. The group rehabilitation had taught them to re-organize their lives and to change everyday habits. They said they had learned the importance of having routines and to plan their everyday situations more effectively, and they had also had the opportunity to practise this during the program. They described how planning their daily activities had become necessary since they could no longer manage several activities at the same time. Thus, planning different activities in advance was necessary in order to get a better balance in their lives. The scheduling of activities also included finding time for rest, while some otherwise could not cope at all. Some even said that if they failed to follow their planned schedule, they often felt more confused and a few even said this caused chaos in their lives. The planning facilitated their life both at work and in the home. As described by one participant:

'…one has to plan a lot more in advance, I learned that during the rehabilitation. If I am doing something else besides the normal everyday life, I need to plan it in advance and have a lot of time to do it'.

During the program, they had also been taught to alter their way of performing activities, e.g., by doing one thing at a time, by decreasing the number of different activities or by ending engagement in certain activities in favour of others. A common experience encountered by the participants was how the new routines and the changes they made in their everyday activities meant that they now lived a less stressful life than before. For some, this made them feel more satisfied with life as a whole, but there were also participants who felt a sadness that they could not engage in activities in the same way as before.

Learning to use and accept support in daily life

The participants described how they, during the rehabilitation, had learned to use assistive devices, as well as to accept social support. This encompassed assistive devices as well as mobile phones and other everyday technology that could help them to compensate for their limitations. Mobile phones were used to compensate for memory difficulties, but they also used a calender and note-taking on a regular basis. Some said they took notes in order to know which activities they had already completed, and which they had not yet performed. Others used note-taking to get an overview of their activitites, so that they could balance them over a day. Note-taking could also be used to decrease stress, chaos and confusion. This was narrated by one participant:

'My manager [a calender] tells me what to do, it is a colourful, rather thick book. The text on the front reads manager. It's easy to find, it's difficult to mislay, and I have a special place for it as well. I write in it as a diary… and note things I need to do, like clipping my toenails, change sand for our budgerigar or when I need to do the annual vehicle test control or whatever I need to do…I write the date and then I cross over when I'm finished… it's a great help. I notice that if I don't use it [the calendar], I get more tired and things get more confused and I don't get as many things done as when I use it'.

Knowledge facilitates adaptation in everyday life

The participants said that the group program had provided them with knowledge of their injury, and also strategies to overcome perceived problems. The knowledge of their injury was an important factor for gaining insight, and to understand what had happened to them. The group intervention made it possible to mirror their own problems against the other group members

problems, which gave the participants a new understanding of their injury and its consequences. Some said that reading their medical records was a positive experience whereas one individual expressed that this had not given him any new information. However, participants agreed that the fact that family members could be involved, and take part in the rehabiliation program, as well as learn about the consequences of the ABI, was positive.

Understanding the importance of adapting the social network to one's ability

The participants described how, due to their ABI, relations with family and friends had changed, and they also shared a common experience of having difficulties when it came to socialising with friends. They experienced that the group program had provided them with knowledge that made it possible for them to adapt to their changed social network, e.g., by learning how to prioritise those social relations that were positive for them. They also said that they had learned to view their changed family relations from a positive perspective. That is, many were able to spend more time with their children, and they felt they participated more in family actitivies than before the injury. Some expressed how they, due to their ABI, had changed roles within the family which, in turn, had helped them to develop a closer relationship within the family. As described by one participant:

'…among friends I have always been considered as the person who can fix and arrange things, I still do that but not as much…at home my wife takes a greater part but we also divide things more between us. We learned that during the rehabilitation programme.'

Rehabilitation is a long-term, individual and collaborative process

This category has four sub-categories describing how the participants experienced the collaborative process between group members and professionals, and how they perceived taking part in the group rehabilitation programme as the start of a process that occurred within themselves as well as the necessity of adapting to another, different life than they lived before.

Every group member has to be responsible for their own rehabilitation

It was emphasised how important it was that all participants understood the aim and the purpose of the the group rehabilitation programme, not only to benefit themselves but to involve themselves in the programme so that the other group members would also benefit. Several participants expressed that it was important to understand one's own responsibility for a successful rehabilitation period before entering the programme, regardless of whether the programme is an individual or a group intervention. As one participant described it:

'…participants [in the group rehabilitation] need to understand the aim [with the programme] and what it is all about…it takes time to understand, it's not something that is evident. [If you] are not motivated, then it takes time to understand every session's purpose…every single [participant] has to have a plan and take some responsibility…even if I don't understand [the purpose of] every meeting I have to give it a go and show some responsibility.'

Support from other people facilitated my rehabilitation

The participants expressed how the fact that they were attending a group programme where they shared experiences with other group members with similar problems, was, in itself, helpful during their rehabilitation. In fact, some of the participants experienced that this was one of the reasons behind their successful rehabilitation. They said that it felt good to know that they were

not alone, that other people shared the same problems, and how they could help each other to find solutions, a viewpoint reflected in the following quotation:

'..it felt good to talk to the others in the group because we shared a similar experience…you could tell them about your problems, if you didn't remember, how you felt and then you ask what they think and how they feel. It's good because you know you are not weird in any way… we got to know each other really well…about everything in life, and then you saw things that others didn't see and maybe gave and took help in different ways and learned things yourself…we helped each other, not as with a family member…you felt safe with the [other members of the] group'.

There were also a few of the participants who expressed that they did not share the same problems as the other participants in their group. Therefore, they did not experience that the group programme was directed towards the limitations they experienced. These participants suggested that this is important to consider for the staff, when they group the participants together, so that they can share problems, limitations and also possible solutions. The participants also described how they were able to discuss issues related to the programme during the evenings, since they were staying at the patient hotel and had the opportunity to socialise with the other group members during their spare time.

Another experience related to support from others was the fact that the staff had the knowlegde and skills to deal with an ABI, which some participants experienced as comforting and something which made them feel calm. Because the staff understood their problems, they said they felt confident that the team members as well as the other participants would support them through the process. This feeling of confidence continued after the group programme had

finished, when they narrated all the interventions that were made after the programme during e.g., individual vocational rehabilitation.

Rehabilitation is a long-term, necessary process

The participants argued that rehabilitation is not something that can be done by others or something to engage in only during week-days, but a process that continues during the rehabilitation sessions as well as during one's spare time. They described their rehabilitation as a process they had to go through, in order to accept their current situation. This process continued after the group programme had finished, and many described how they had struggled with adapting to their new life circumstances, and for some, this struggle was still ongoing.

In conjunction with their perceptions of the process, all of the participants talked about the length of the programme. In general, they percieved the length of the twelve week programme as sufficient since it helped them with their adjustment process. However, many expressed that their rehabilitation process had not finished when the group programme ended, and they needed more help afterwards. Therefore, they would have liked to have more follow-ups, both individually and together with the group.

They shared a common experience that the group rehabilitation programme had provided them with insight into their limitations, but also to solutions in how to live their lives again. By lowering their expectations in life, and by having a positive attitude to life, they were able to feel satisfied with the life they had. Several said they had managed to succeed with this adjustment, and thereby felt they lived a good life. Many even said that the group rehabilitation had been crucial for their adaptation, and that they had not been able to manage this on their own, as this man said:

‘I have benefited a lot from this [group rehabilitation], it has been absolutley crucial [to come here]. If you don’t get the help you need, it can get really difficult…without the group rehabilitation I doubt that I had managed it by myself…’.

However, there were also a few participants who did not feel that they had adjusted to the new circumstances in life. These participants expressed how they found life duller than before, and that they found it difficult not being able to live as spontaneously as they had before, since everything in life now has to be planned beforehand. A few also mentioned that needing help from others was something they found difficult to adjust to.

Struggle to find myself

A common experience shared by the participants was the struggle to find their new identity and roles in life. Some described how they were still struggling to find their inner self, since they did not recognize themselves anymore. Others thought the group rehabilitation had helped them to recognize themselves again, or at least accept who they had become. One participant shared this quotation:

‘I am who I am…I don’t keep up something, I try to be myself even though I pull back more than I did before. I am diminshed in my person…but I just try to be myself. It was a lot of help to learn that this is how things [the consequences of the ABI] can be. Before [the ABI] I was very good in my work role and structured, but now things have changed and I learned a lot [during the rehabilitation] when these issues were explained.’

DISCUSSION

This study describes how pwABI experience a group rehabilitation programme, and how the programme contributed to their everyday lives. In the findings, the participants experienced the group rehabilitation programme as a facilitator for their adjustment, by providing them with the tools they needed to change their everyday situation. They also experienced the rehabilitation as a long-term, individual, as well as a collaborative process. The fact that the participants experienced the group rehabilitation programme as a facilitator for their adjustment is in accordance with previous research [12]. The participants also emphasised that it was the tools that they were provided with during the group rehabilitation programme that facilitated this adjustment process. The tools were the knowledge they had received of their ABI and its consequences, but also how they had learned to have routines in their daily lives, to plan their daily activities, and how they had learned the importance of accepting different types of support.

Many of the participants had previously received both in-patient and out-patient rehabilitation, and yet, they identified the group rehabilitation programme as a means to get insight into and to gain self-awareness of their problems. This, in turn, facilitated their process of adjustment to the consequences of the ABI. A lack of self-awareness concerning disability is common among pwABI, and is also known to be an obstacle during the rehabilitation process [17]. Awareness of disability often increases when the ability to perform activities increases [18], and an increased self-awareness has therefore been judged to be an important first step towards reaching a successful rehabilitation outcome [17]. Rehabilitation after a brain injury is known to be a long process that has to be implemented in several phases [7]. During the acute stage of the rehabilitation, pwABI are probably pre-occupied with enhancing the specific functions and performance of activities, thus, learning strategies that improve generalized participation may not be their main focus. There is reason to believe that an increased self-awareness can influence the

ability to learn and benefit from compensatory strategies, something the participants may not have been ready for during previous rehabilitation periods. It is possible that the participants in our study also benefited from the time spent at home, between the acute rehabilitation and the group rehabilitation programme. During this time they obtained an experience of living with an ABI at home and in the community, thereby, facilitating their process of adjustment.

The participants also referred to the fact that they had learned how to have routines and to plan their daily activities. Changing roles or habits is known to be difficult [19], and the group programme – the content as well as the group format – seemed to facilitate this process. Another process that the participants shared was how they had learned to accept the use of assistive devices in daily life. Previous studies have shown that people with a disability adapt differently to using and accepting assistive devices and that the significance in using an assistive device is more than just a compensation for impairments [20, 21]. It is not only assistive devices that are difficult to learn to use. Using everyday technology is also perceived as difficult for pwABI [22, 23], as well as accepting help from others, even though it is well known that pwABI benefit from compensatory techniques [24].

The participants said that the strategies they had learned could not only be used in specific situations but could also be generalized to different situations that they faced in life. This is in agreement with the study by Lundqvist et al [11] and show that a group rehabilitation programme can help the participants to develop coping strategies that enhance daily living. Learning strategies that facilitate empowerment and offer a possibility to handle problems in everyday life is an important part in this later phase of rehabilitation. This type of intervention is often defined as 'self-management education' – it focuses on a person's own empowerment by enhancing his/her self-efficacy to facilitate problem-solving related to everyday life [25]. This

type of intervention has been common in the management of chronic diseases such as arthritis, and diabetes but has also been acknowledged as a possible intervention for people living with chronic stroke [26] as well as for improving perceived self-efficacy in people with traumatic brain injury and their caregivers [27]. For stroke, there is emerging evidence regarding self-management education [28], and a growing consensus that rehabilitation cannot only focus on objective cognitive problems but also needs to include subjective problem-solving [29].

Due to the injury, pwABI need to adapt to the new consequences that the ABI imposes on him/her [30], and our participants described this as being both an individual process that they had to perform, as well as something that had to be performed in collaboration with others. In conjunction with this, they emphasized the importance of having a clear goal with their rehabilitation and taking personal responsibility for reaching the goals. This highlights the importance of using a rehabilitation plan that coordinates all assessments, goals and interventions together with each patient, even if the intervention is performed in a group format. The rehabilitation plan's positive influence on the adaptation process has been emphasized before in a study of how people with late effects of polio experience a rehabilitation programme [31], but its contribution for the adaptation process in pwABI has not previously been highlighted.

Many of the participants in this study described how they did not recognize themselves, i.e., their self was changed, and that they struggled to find their new self during the rehabilitation. This is well in accordance with previous literature, which states that it is common for persons with ABI to struggle in an urge to achieve normalcy, and to find their new selves [32]. This, in turn, often changes their identity, due to difficulties in relation to engaging in activities that they previously identified themselves with doing [33, 34]. This was also emphasised by the participants when they revealed that in the individual sessions, participants

and professionals worked towards reaching each participant's goals in his/her rehabilitation plan. That is, to be able to engage in previous activities or to find new activities that they found meaningful, and could engage in. The group format helped the participants to mirror their new identities with others, to share experiences with other people in a similar situation, and supported problem solving among the participants. This shows that the format in the present rehabilitation programme – group as well as individual sessions – was well suited to fit the goals of the programme and facilitated the participants' adaptation process. Yet, a few of the participants said they were still struggling with adapting to the ABI, showing that adaptation is an individual process that takes a different amount of time, and that participants that are admitted in a group programme need to be carefully selected so that they can benefit from participating.

Since this study used qualitative interviews, it was not designed to generalize the findings to all pwABI. Still, the findings may be transferable [16] to other pwABI in a similar situation. The selection of participants was made from those 23 patients who had previously participated in the group rehabilitation programme. Since only 11 gave their informed consent to participate in the qualitative interviews, no purposive sampling was possible. Still, the participants represented diverse backgrounds, and represented the different patients that previously had participated in the group rehabilitation programme. A possible bias during interviews is the fact that the author who performed the interviews previously had been involved in the group programme to some extent. This may have influenced the quality of the interviews since it is possible that those participants that she was familiar with did not share experiences as fluently as would have been the case if the interviewer was unknown to them. Our data were collected during only one occasion, and it is possible that if repeated interviews had been performed, participants would have shared more experiences in relation to their rehabilitation.

During the analysis, the two last authors cooperated, and tried to stay as close to the text as possible during the first steps in the analysis. The emerging findings were later scrutinized by the first author, which strengthened the credibility in the analysis.

In conclusion, this study has shown that pwABI experience a group rehabilitation programme as a contributor to their everyday lives, which helped them to adjust to a new life. They described how the rehabilitation programme had given them the tools they needed to change their everyday situation, especially in relation to gaining more knowledge, and learning new routines and habits. They also perceived their rehabilitation as a long-term, individual, but also a collaborative process, where professionals as well as family and friends had crucial roles. Learning how pwABI experience participation in a group rehabilitation programme can help to unravel parts of the 'black box of rehabilitation', and can support professionals to better understand the effective components of such programmes.

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DECLARATION OF INTEREST

The authors report no declaration of interest

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Table 1. Characteristics of the 11 participants with brain injury.

Characteristics	n
Sex (n)	
Women	6
Men	5
Age (years; mean, range)	45.2, 25-62
Diagnosis (n)	
Traumatic brain injury	5
Aquired brain injury	6
Time since injury (years; mean, range)	6.4, 4-13
Living arrangement (n)	
Living alone	5
Living with other person (partner, husband/wife)	6
Vocational situation (n)	
Working/studying full-time	1
Working/studying part-time	7
Full-time disability pension	3

Table 2. An overview of the core category and subcategories.

Theme	**THE GROUP REHABILITATION HELPED ME ADJUST TO A NEW LIFE**	
Categories	**The group rehabilitation gave me knowlegde and tools to change my everyday life**	**Rehabilitation is a long-term, individual and collaborative process**
Subcategories	Learning to plan activities and to have a new routine in life	Every group member has to be responsible for their own rehabilitation
	Learning to use and accept support in daily life	Support from other people facilitated my rehabilitation
	Knowlegde facilitates adaptation in everyday life	Rehabilitation is a long-term, necessary process
	Understanding the importance of adapting the social network to one's ability	Struggle to find myself