

ORIGINAL REPORT

THE COMPLEXITY OF PARTICIPATION IN DAILY LIFE:
A QUALITATIVE STUDY OF THE EXPERIENCES OF PERSONS WITH
ACQUIRED BRAIN INJURY

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Objective: To describe and enhance the understanding of how adults with acquired brain injury experience participation in daily life.

Patients and methods: Qualitative interviews with 11 persons of working age with acquired brain injuries were analysed using qualitative content analysis.

Results: The informants' experiences formed 5 categories: "Performing tasks"; "Making decisions and exerting influence"; "Being engaged in meaningful activities"; "Doing things for others"; and "Belonging". The categories that needed to be present for the informants to experience a feeling of participation varied according to their individual daily life situations. In addition, their experiences showed that a variety of conditions, related to each of the 5 categories, influenced their participation. Individuals adopted a variety of strategies to enhance their experience of participation.

Conclusion: The meaning of participation and the conditions and strategies influencing participation are complex. Many of the categories identified for participation can be understood only through subjective experience and cannot be captured by professionals' observation of the performance of activities. These results emphasize the importance of considering clients' unique experiences of participation when designing individually tailored rehabilitation programmes intended to enhance participation.

Key words: patient participation, activities of daily living, disability evaluation, brain injuries, cerebrovascular accident, disabled persons, rehabilitation, qualitative research.

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INTRODUCTION

The concept of "participation" in the International Classification of Functioning, Disability and Health (ICF) (1) has rapidly become a multidisciplinary interest in rehabilitation (2–5). Conceptually, participation is defined as "involvement in a life situation" or as "the lived experiences' of people in the actual context in which they live" (1, p. 14–15). The use of the word

"involvement" in the definition of participation is explained further by some definitions that incorporate taking part, being engaged or included in a life area, being accepted or having access to the resources required. The concept of participation in the ICF (1) is described, together with the concept of activity, which is defined as the execution of a task or an action by an individual. A person's activity and participation are the result of dynamic interactions between health conditions and contextual factors, including both personal and environmental factors.

In the ICF (1), participation and activity are coded with 2 qualifiers: "capacity" and "performance". Although the definition of participation emphasizes people's subjective experiences, the use of these qualifiers reveals that the only way of coding participation is through external observations of performance. Consequently, the ICF gives no information on how to take into account and code the insiders' experiences of participation in their daily lives. As a consequence, rehabilitation practitioners lack good operational definitions and it is difficult to know if clients have a satisfactory level of participation in their daily lives, or what they would need to bring about such a level of participation. With respect to the fact that participation has been described as a central goal of rehabilitation (3, 6), this lack of operational definitions reveals a need to enhance our understanding of participation in daily life by qualitatively exploring experiences from the perspective of the individuals concerned.

Acquired brain injury (ABI) is a significant cause of long-term disability (7) and research has shown that people with ABI perceive that they are restricted in all domains of participation (6). However, participation in daily life by people with ABI has not yet received much attention from researchers. Previous research has tended to concentrate on aspects closely related to participation, such as activities (8), community integration (9, 10), reintegration (11) and handicap (12, 13). This body of knowledge, emanating from research conducted over different time intervals, indicates that persons with ABI can face a variety of challenges relating to their participation over both short- and long-term perspectives. It was, therefore, considered to be particularly important that experiences of participation in daily life were explored in this population.

To our knowledge, the subjective experiences of people with ABI regarding their participation in daily life and the factors influencing that participation have not yet been explored,

even if related aspects have been touched upon briefly and indirectly in qualitative studies of the experience of living with a brain injury (cf. 14, 15) and of community integration (16). The subjective experiences of participation among other groups of persons with disabilities are also almost unknown. A recent study of individuals with chronic pain showed that they experienced participation as taking the initiative and making choices, doing something physical, social and for others (17). Haak et al. (18) recently also found that the elderly experienced that participation had what they referred to as a performance-orientated dimension and a togetherness-orientated dimension. However, studies of other groups of people with disabilities, including those with ABI, are needed to enhance our understanding of how participation in daily life is experienced and to determine whether the meaning of participation is similar between different groups. Such knowledge is important in identifying operational definitions that take into account subjective dimensions of participation in daily life, which can be used in clinical practice.

To summarize, the ICF concept of participation emphasizes the experience of involvement in daily life. However, the classification gives no information about how to take into account person-experienced participation, which indicates a need for further exploration of the participation of people with disabilities in daily life and of the factors influencing participation. Research into participation in daily life for people with ABI is sparse, but indicates that they can face a diversity of challenges relating to their participation. An examination of this population was therefore considered to be particularly relevant to increase our knowledge of people with ABI and to give an overview of subjective experiences of participation. Such knowledge is important for rehabilitation professionals, to increase their understanding of participation in daily life and in developing instruments that measure participation. The knowledge can also be important for professionals when designing and implementing interventions that tailor clients' needs related to participation in daily life. The aim of this explorative study was, therefore, to describe and enhance the understanding of how adults with an ABI experienced their participation in daily life.

METHODS

Subjects

Subjects were selected from a database at a rehabilitation clinic in northern Sweden. The selection was guided by a "purposive sampling" technique (19) with the following inclusion criteria: (i) at least 3 years having elapsed since the ABI and (ii) age between 18 and 65 years. The first criterion was chosen to allow the informants enough time to experience a variety of situations, with the intention of covering participation in a broad range of experiences. A medical secretary at the rehabilitation clinic selected potential new subjects consecutively until the richness of the data was considered sufficient to ensure the quality of the study. At the end of the sampling, the first 30 clients who fulfilled the inclusion criteria had been sent a letter providing information about the study and a reply form on which they could consent to participate. Eleven persons gave their informed consent to participate in the study. The informants were aged between 38 and 62 years (mean 55 years), and the time since they have received their

injury varied between 3 and 6 years. Two informants were interviewed 3 years after the onset of their injury, 3 informants 4 years after, 3 informants 5 years after and 3 informants 6 years after. More information on the informants is given in Table I. One of the informants had had 2 strokes. The study was approved by the ethics committee at Luleå University of Technology.

Data collection

Qualitative research interviews, based on an interview guide containing open-ended questions (20), were conducted to enable the informants to express freely their own experiences of participation in daily life. All informants were asked to describe their experiences of participation in different situations in their life and to describe situations where they felt that they either were or were not participating. They were also asked if they felt that they participated in the things they wanted to participate in and whether they participated in the way in which they desired. Finally, they were asked to describe what influenced whether or not they could participate in different situations.

During the interviews, it was common for the informants to not know what to say, and for them to ask the interviewer what she meant by participation. In these cases, the interviewer gave examples of the domains of participation as described in the ICF to enable the informants to describe the concept from an insider perspective (1) (e.g. participation in domestic life, community, social and civic life). The first author (AH) conducted the interviews in the informants' homes, except for 3 persons, where the interviews took place at the clinic in accordance with the informants' desires. The interviews were tape-recorded and transcribed verbatim and lasted between 25 and 75 min (mean 50 min).

Data analysis

A qualitative content analysis, inspired by Graneheim & Lundman (21), was chosen to analyse the content of the informants' experiences. The analysis started with the authors reading the transcripts of each interview several times to obtain a sense of the whole. Thereafter, meaning units that reflected the informants experiences of participa-

Table I. Characteristics of the informants with acquired brain injury

Characteristics	n
<i>Gender</i>	
Women	6
Men	5
<i>Diagnosis</i>	
Stroke, right	4
Stroke, left	2
Stroke, cerebellum	2
Stroke, brainstem	2
Traumatic brain injury, moderate	1
<i>Marital status</i>	
Cohabiting or married	7
Single	4
<i>Vocational status</i>	
Working part-time	2
Studying full-time	1
Studying part-time and work trial	2
Long-term sick leave or disability pension	6
<i>Mobility</i>	
No mobility aid	9
Wheelchair	2
<i>Social service assistance</i>	
No social service help	8
Personal assistant	2
Home help	1

tion in daily life were marked in the text and labelled with a code. The codes in each interview were then compared in order to identify their differences and similarities, whereupon they were grouped into preliminary categories. The comparisons continued, this time between the preliminary categories in all interviews, and further abstraction was reached when the preliminary categories from different interviews that resembled each other were brought together to form categories. Thereafter, the categories obtained were scrutinized by comparing their content, to enable sub-categories, at a lower level of abstraction, to be identified. To ensure that the results were grounded in the data and to ensure completeness, the emerging codes and categories were continuously compared against all data. In addition, every step in the analysis made by one of the authors was subject to examination by the other author. Peer review (22) of the evolving results was carried out on several occasions, throughout the process, by colleagues experienced in content analysis.

RESULTS

The analysis of the content of how the informants experienced participation in their daily life formed 5 categories: “Performing tasks”; “Making decisions and exerting influence”; “Being engaged in meaningful activities”; “Doing things for others”; and “Belonging”. The informants’ experiences showed that if they were to experience a feeling of participation, then a diverse range of the 5 categories identified needed to be satisfied, and these were of different importance in different situations for each individual. Each category comprised 2 sub-categories, reflecting the main conditions and the main strategies that influenced the informants’ participation. An overview of the results is presented in Table II and a thorough description of the categories and sub-categories, including quotations from the interviews are given below.

Performing tasks

The informants described their experience of participation when they performed tasks or, sometimes, just actions, by themselves, without the support of others, which can be illustrated by this quote: “If I think about myself, then what I think of [in terms of what I count as participation] is what I can do by myself”. The informants also described how it was important that they perceived that they could perform their tasks with personal satisfaction, in accordance with their preferences, if they were to experience a feeling of participation.

Previous performance preferences. The informants’ accounts showed that the conditions that influenced participation were the limitations they had on their own ability to perform tasks and their limited ability to perform them “satisfactorily”, i.e. in accordance with deep-rooted preferences and habits. The informants described how it was difficult to have to accept that they would have to relinquish their previous deep-rooted preferences and habits and to introduce change in their performance. This is illustrated in this quote: “I sat there in... the farmyard and solved crosswords the whole damn summer... and that was not an exciting experience... when you are used to walking around”. The informants also described how inaccessible buildings and surroundings, as well as difficulties with noise and crowds, influenced their potential to perform activities satisfactorily.

Adapting performance and preferences. The informants’ experiences reflected how their sense of participation had been influenced positively by adapting the way that they performed those tasks that could no longer be done “in the usual way”, by

Table II. Overview of how the persons with acquired brain injury experience participation in daily life

Categories:	Sub-categories:	
Characteristics of participation	Conditions influencing participation	Strategies adopted to enhance participation
Performing tasks	Previous performance preferences	Adapting performance and preferences
Performing tasks without support	Limitations in own ability	Performing and planning tasks in new ways
Performing tasks with satisfaction	Deep-rooted preferences	Developing new preferences
	Inaccessible buildings and surroundings	Avoiding environments with hindrances
Making decisions and exerting influence	Need for support	Expressing and looking after one’s interests
Making decisions irrespective of their need for support	Restrictions in the social system	Expressing wishes and asking questions
Having different options	Limited access to social support	Rejecting unsatisfactory decisions
Exerting influence in society	Problems in collaboration	Hindering others from deciding in one’s place
	Limited access to information	Seeking information
Being engaged in meaningful activities	Changed meaning of and engagement in activities	Revaluing activities to enhance engagement
Meaningful activities is intrinsic to senses of engagement	Meaningful activities are lost	Revaluing which activities are meaningful
Engagement through doing	Meaning of activities diminishes	Replacing and adapting meaningful activities
Engagement through what is happening		Prioritizing the most meaningful activities
Doing things for others	Relationships with fewer persons	Doing the things one can do more frequently
Giving advice and doing things for others	Fewer social contexts	Doing the things one can do
Receiving others’ recognition	Fewer people to do things for	Revaluing what one does
Reciprocating the support and love of others	Limitations imposed by own ability	Establishing new relations
Belonging	Negative attitudes	Prioritizing activities that create a sense of belonging
Being bound to others	Prejudicial attitudes and treatments	Prioritizing activities
Being accepted and valued	Other people withdrawing	Avoiding activities
Meaning something to others	Tempo of society too high	Explaining one’s capability to others

learning alternative ways to perform them and by developing new preferences concerning how to perform activities satisfactorily. One informant said, "I can keep on spinninga (exercise bike), but I do not need to cycle like everybody else... but I can still participate". Their experiences of participation were also enhanced by adapting their planning of tasks over time and by avoiding tasks that needed to be conducted in environments with hindrances of some kind that would necessitate that help be given if the activity were to be performed.

Making decisions and exerting influence

The informants' experiences clarified how they experienced participation when they made choices and decisions about their activities in different situations. Independently of whether the informants were able to perform activities without support, their experiences showed that it was essential that they could choose if, where, when and in what way they wanted carry out their activities, as illustrated in this quote: "I think that it is very important for me... to be involved in decision-making... even if I can't manage to do the activity by myself". To feel that they could make a decision themselves, the informants' experiences reflected how it was important for them to have some options to choose from. By making personal choices and decisions about their activities, the informants felt that they had control over their activities – and over their lives. The informants' also said that they experienced participation when they could exert their influence in the society and community where they lived, through, for example, being involved in political organizations, non-profit making associations and unions.

Need for support. The informants' experiences reflected the fact that restrictions in the social service system and the related legislation influenced their access to home help services and to personal assistants. If the informants needed social support and had limited access to these formal sources of support and to support from persons close to them, their opportunities to choose activities and to make decisions concerning them was restricted and affected their feeling of participation. When they had access to personnel, regulations relating to working hours could restrict the informants' participation. Furthermore, the informants' participation could be influenced by problems in their relationship with those providing the support and the assistants' ability to collaborate with them. The informants perceived that they encountered prejudice and that negative attitudes towards them influenced their opportunities to make a difference by expressing their opinions and, thereby, feeling that they were participating in social and societal contexts. Limited access to information concerning possibilities, rights, and the provision of support for people with disabilities by society was another aspect of the social service system that the informants identified as hindering them from making the right decisions and from exerting influence.

Expressing and looking after one's interests. The informants' statements demonstrated how they tried to enhance their participation by expressing their wishes and asking questions,

thereby attempting to make others aware of their priorities, in order to ensure that the support provided would be adapted in accordance with their preferences. The informants stated that this provided them with a way of looking after their interests, rejecting unsatisfactory decisions, and, even, of hindering others from taking decisions for them. They also sought out information from different sources to inform them of their options and rights.

Being engaged in meaningful activities

The informants stated that their sense of engagement in activities that were meaningful to them was important if they were to experience a feeling of participation. The informants' experiences reflected how the meaningfulness of activities was intrinsic to their sense of engagement and to the strength of the feeling of being engaged. The relationship between participation, meaning and engagement is illustrated by an informant who participated in adult education when she said, "If you are not interested in something that you take part in,... then you can't feel any sense of engagement either... I could go to the classes and sit there and... just sit through the lessons... but those [classes] that I am not interested in,... I do not feel that I am participating in". The experiences recounted by the informants showed that their sense of engagement could not only be evoked through the meaningful activities that they performed, but also through the fact that they were mentally engaged in what happened concerning activities that were meaningful to them.

Changed meaning of and engagement in activities. The meaning of and, thereby, engagement in many of the informants' activities had been affected, sometimes it had diminished, sometimes it had been lost completely when the informants were not able to do the activities when, where and in the way that they wanted. Thus, not being able to perform activities in accordance with their previous preferences meant the preferences could become a condition that had a negative influence on their experience of meaning and engagement and on their participation. This situation could also occur when the informants were not able to take part in activities they had previously enjoyed or when they had limited possibilities to use their time to different types of activities in a satisfactory manner.

Revaluating activities to enhance engagement. The experiences of the informants reflected how they enhanced their participation through a re-evaluation of the activities they found meaningful and worthwhile after their injury. This re-evaluation was influenced by the informants developing new habits and preferences for the way which they would perform their activities. The informants also said that they struggled to replace activities they had lost and, also, with managing to achieve the adaptations required to enable them to engage in those activities that they found meaningful. As the informants no longer had the capacity to do all the things that they had done before receiving their injury, they said that the meaning an activity held for them determined the priority that they

would assign to it in relation to their other activities. In this respect, one informant said, "The things that I don't really like, I skip nowadays... I don't bother at all... with things I am not interested in".

Doing things for others

Another experience of participation that emerged from the informants' descriptions came from doing things for others, primarily those with whom they had a close relationship, and the activities involved included carrying out tasks and giving advice. The informants said that doing things for others often implied that they received recognition for their contribution, which made them feel that they were of use in society, rather than being a burden on it. One informant said, "Sometimes I help people... they call me to ask [for help]... and then I feel that I am appreciated and... participating". By doing things for others, the informants' experiences reflected how they could have reciprocal supporting and loving relationships.

Relationships with fewer persons. According to the informants, one condition that influenced the informants' participation negatively was that they were involved in fewer social contexts than they had been prior to their injury. This could, for example, arise because they no longer worked, and the resultant reduced social circle in which they were active influenced the number of people for whom they could do things. Other conditions influencing participation were related to the limitations on the informants' ability to do things.

Doing the things one can do more frequently. The informants' descriptions reflected how they were trying to enhance their participation by taking on more voluntary work than they had done before to give them the opportunity to do something for others more frequently. This concerned those things that they were able to do well, both in their old and in new social contexts. The informants also revalued the "few" things they did for others because these things and the people concerned had become much more significant to them, making these activities more important for their sense of participation than they had been before. Yet another strategy was to get involved in new social contexts by establishing new relations.

Belonging

Another experience of participation that was reflected in the informants' descriptions was that of belonging. The informants' descriptions revealed that having a feeling of belonging meant that they felt that they had a bond with others. When the informants experienced that they belonged, they also felt that they were accepted as the person they really are, and that they were valued and loved. The informants said that they meant something to others, and were allowed to be themselves, as reflected in this comment: "I think it is so pleasant to have such friends as these, they are so close and... they are healthy, and... never make high demands on me... we just are". Another informant said, "Participating..., that is, if you... take part in something...; but participation, you feel in another way... that

you are accepted... in a group for example". On other occasions, belonging had to do with being allowed to be included in activities with others. Belonging could also embrace feelings of being seen, listened to and respected.

Negative attitudes. Prejudice and negative attitudes on the part of others formed a condition that had a negative influence on participation, as did being treated differently subsequent to receiving the injury than prior to receiving it, examples given being ignored or being pushed aside. The informants described how others withdrew from interacting with them, with the result that they had fewer persons with whom they could relate. The tempo of activities in society being too high for the informants to follow, was another condition that influenced their participation.

Prioritizing activities that create a sense of belonging. The informants' experiences reflected how their participation was enhanced by prioritization of activities conducted with those who made them feel good, such as people close to them, persons who had their own experiences of having a disability and pets. The informants also avoided contact or withdraw from activities with those with prejudices and other negative attitudes, who took energy from them as illustrated in this quotation, "It's just like, um,... that one is not OK in the head. [As though they are thinking:] We shouldn't bother with him. So, on many occasions, I have withdrawn... not bothered to participate [at all] when it comes to these activities".

Another way to enhance their sense of participation was to explain how they felt and what they could do and demonstrate their capability to others. This was a way to correct others' false perceptions, and also a way to reach out to others.

DISCUSSION

The 5 categories of participation, as found in the results of this study formed by the experiences of persons with ABI, support the belief that participation encompasses more than the actual performance of activities (2, 4, 17). The informants' experiences also reveal that many of the characteristics of the 5 categories of participation identified (namely, the experience of having autonomy, the meaning the activities hold, having a sense of engagement and belonging) can only be subjectively experienced and not by others observing the person concerned engaging in the performance of an activity. These results therefore support the discussion (4, 23, 24) criticizing the ICF (1) for neglecting important subjective aspects in the coding of participation.

All 5 categories of participation were related to doing a multitude of tasks in the natural context of the daily lives of the informants. In line with other qualitative studies of participation (17, 18), this result suggests that the experience of doing tasks and activities is of central importance in subjective experiences of participation. However, although the importance of performing tasks for individuals' sense of participation is undisputed, the importance of the other categories of participation, as described

in the results of this study, also seems to be acknowledged in published research concerning participation (2, 4, 5, 17, 18, 25). Participation in daily life, as experienced by those with ABI, can be considered to be characterized by complexity and individuality, at least where the 5 categories identified are concerned. Existing evidence confirms this complexity, in that people's experience of participation in daily life can spring from various "characteristics or qualities" (17) in addition to which, evidence indicates that a variety of conditions and the adoption of particular strategies can influence participation (26–28).

This complexity of participation in daily life highlights several possible challenges when applying the concept in clinical practice. One challenge for rehabilitation professionals, in supporting their clients' participation in daily life, is to identify which categories are important for an individual's sense of participation in each one of the many different situations in his or her daily life. In addition, it is necessary to identify the conditions that influence participation negatively in these situations. On the positive side, the many categories of participation and the many conditions and strategies that can influence them reveal many opportunities for enabling and enhancing clients' sense of participation.

Other possible challenges in applying the concept in practice are indicated by the fact that many restrictions to participation can be attributed to the physical and societal environment. In addition, some of the categories of participation (making decisions and exerting influence, doing things for others and belonging) clearly show that an individual's possibility to experience participation is related to others in their environment. This is in accordance with previous research (17, 18, 29, 30). These results reveals that participation is not solely dependent upon the individual, but rather upon whether the situation the person finds themselves in enables them to experience participation. This implies that restrictions to participation cannot be solved by rehabilitation services alone. It also implies that current rehabilitation practice, in accordance with recent discussions in the field (26, 31, 32), needs to expand the treatment to concentrate more on supporting clients as they try to manage and overcome hindrance in the environment.

Yet, another challenge is to develop instruments that can assess all the categories of participation identified in this study, and their importance in different situations from clients' point of view. The recently developed person-perceived questionnaire, "Impact on Participation and Autonomy" (IPA) (33–34) encompasses the categories of participation found in the present study. Nevertheless, as found in the results of this study with respect to the complexity and personal nature of participation, it is argued that interviews will always add qualitative depth to the results obtained from questionnaires. Finally, another challenge reflected is that many informants did not know what to tell the interviewer about participation and, during the data collection, asked what was meant by participation, indicating that the concept was unfamiliar for many of them. This might introduce an additional challenge when using the concept in clinical practice.

The fact that similar experiences of participation in daily life to that found in the present study are reported in 2 other qualitative studies of participation: in Borell et al. (17), in a study of persons with chronic pain; and in the study by Haak et al. (18) of elderly persons, indicates that the experiences of participation in daily life can be similar even if the health condition influencing participation is different. The similarity of the results with other studies suggests a possibility to transfer (cf. 22) the results to groups of persons with disabilities other than ABI. In transferring the results, it is important to consider that the physical disabilities of just a few of the persons interviewed were severe, that only persons who were 3–6 years post-injury were included, and that the use of interviews excluded persons with complete aphasia. The fact that only one person with a traumatic brain injury took part in the study needs to be considered when transferring the results; this situation arose because the rehabilitation of this type of injury primarily takes place at other clinics than the one concerned in this study. It is also important to consider the possibility that the inclusion of new informants, until saturation, would have added additional experiences of participation. One also needs to consider, even if each interview continued until no further experiences were revealed, the possibility that repeated interviews with the informants might have added new information (20, 22). This is especially important considering the cognitive impairments related to ABI, such as memory deficits, difficulties related to concentration and to express experiences.

The connections between the results presented here and those obtained from other research in the area (2, 4, 5, 16, 26–28), including that of Borell et al. (17) and Haak et al. (18), strengthens the possibility of being able to generalize the results on an analytical (theoretical) plane (20), even if they cannot be generalized in a statistical sense. Consequently, the results from these different studies of participation could form a base for a new hypothesis about the meaning of the concept of participation. In the continued research it would be possible to use the results from these studies to develop a taxonomy of participation, and, thereby, to develop new instruments.

In conclusion, the informants' experiences show that participation in daily life is complex and encompasses more than the observed performance of activities, because many of the categories identified for participation can only be experienced subjectively. These results emphasize the importance of professionals considering each client's unique experience of participation and of not focusing only on the observation of performance in designing individually tailored rehabilitation programmes intended to enhance individuals' participation.

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