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Chapter 9

Participation of people with Acquired Brain Injury: Insiders Perspectives

‘Je kunt meer dan je dacht te durven’

(quote of a patient, participating in the study as described in this chapter)

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Abstract

Introduction: Participation is important in rehabilitation of people with Acquired Brain Injury (ABI). Studies have shown that their participation is problematic. It is, however, unknown how they experience their participation and what influences their participation. This study aims to answer the question how people with ABI experience participation and which environmental and personal factors may influence participation, as perceived by people with ABI.

Methods: A qualitative methodology was conducted by a team consisting of researchers, people with ABI and a mother of a daughter with ABI. Interviews and focus groups were held and followed by a working group in order to develop actions for improvement.

Results and conclusion: People with ABI contend that it is not the degree of participation that matters, but the quality of participation. They describe meaningful participation in terms of taking part, giving something and being someone. A model was constructed based on the experiences, which includes personal and environmental factors that, in interaction, may influence participation: participation is influenced by the process of recovery, support and treatment, the environment and society and communication and interaction. The study resulted in an overview of actions like continual care that may improve the participation of people with ABI.

Introduction

The concept of participation in society has become increasingly important and represents a key goal for many stakeholders, including constituents with disabilities, disability advocacy organizations, rehabilitation providers, community organizations, policy makers and governments.^(1,2) The move from ‘handicap’ to ‘participation’ within the International Classification of Functioning, Disability and Health (ICF) has inspired a body of research on participation.⁽²⁾ As a consequence the concept of participation has become more important in the rehabilitation of people with Acquired Brain Injury (ABI). Participation is nowadays used as an outcome variable, therapeutic goal and research focus.^(3,4)

The ICF-model describes participation as ‘involvement in a life situation’ and participation restrictions are, according the ICF, ‘problems an individual may experience in involvement in life situations’.⁽⁵⁾ In the ICF Model, participation after the onset of a health problem may not only be influenced by disturbances in body functions and structures and resulting activity limitations, but also by contextual/environmental factors, like practical barriers in our community and the attitude of the environment regarding people with a disability, that hinder or foster participation. Participation is, according the ICF Model, also influenced by personal factors like gender, age, education, profession, coping, adaptation styles, character and resilience.^(5,6) Research on personal and environmental factors is just beginning to focus on participation⁽⁷⁾ and insight in these factors can be important for successfully re-integration or participation.

Research on participation of people with ABI is growing and earlier research has shown that people with ABI have disadvantages in all kind of areas such as employment, income, education, cultural participation and leisure activities compared to people without disabilities.^(1,8-10) Regarding participation in work can be stated that people with ABI may have problems with returning to work. As an example can be mentioned that 26 percent of the employed patients, stopped working after an aneurysmal subarachnoid haemorrhage (SAH). Almost a quarter of the employed patients, worked shorter hours or had a position with less responsibility after the haemorrhage.⁽⁸⁾ Activity levels may also be diminished as

result of ABI. Activity levels of stroke survivors, dwelling in the community, were, for example, 50 percent lower than they used to be before the stroke occurred.⁽⁹⁾

Based on above mentioned studies can be concluded that people with ABI may, objectively, have participation problems in all kinds of areas. From an outsider's perspective, objective behaviours such as return to work or activity levels are of utmost importance. From an insider's perspective, however, the subjective experience of participation matters most.⁽²⁾ People with ABI or disabled persons may have another idea of the meaning of their situation, what meaningful participation is and what hinders or fosters their participation.⁽¹¹⁾ Insights in the participation and participation problems, as experienced by people with ABI are still missing.

Our qualitative study presented here was therefore aimed at the exploration and description of the subjective experiences of people with ABI concerning their social and societal participation. This study offers an answer on the question what meaningful participation is and which environmental and personal factors may hinder or foster participation, as perceived by people with ABI. These findings may contribute to the improvement of participation of people with ABI and help professionals to enhance their support to people with ABI and their relatives.

Methods

This study was commissioned by the Dutch fund for brain research (*'Hersenstichting'*). It was carried out between February and November 2009. The team of researchers, with different disciplinary backgrounds, was completed with two research partners (two young women with ABI) and one mother of a daughter with ABI to redress the traditional hierarchic relations between researcher and researched⁽¹²⁾ and to explore as a team how we could create a welcoming working environment for people with ABI. The research team was controlled by a steering committee, consisting of experienced professionals in the field and representatives of relevant patient's organisations (*'Vereniging Cerebraal'* for people with ABI and their relatives, *'CVA-vereniging Samen Verder'* for people with a cerebrovascular accident and their relatives and *'Afasie Vereniging Nederland'* for people with aphasia and their relatives).

Study design

A qualitative study was conducted to explore the experiences of people with ABI regarding participation and to formulate actions to improve the participation of people with ABI. People with ABI were, with varying levels of control and influence, actively involved in the research process in order to use their experiential knowledge. People with ABI were involved as equal and regular members of the research team, as advisors in focus groups and as information-givers in interviews. The qualitative design of the study emerged gradually as relevant variables were not known in advance and to be as open as possible to the issues of people with ABI. The process of data collection and analysis was iterative so that emerging themes could be further explored and validated over the course of the research.⁽¹³⁾ In order to do so the study was divided into four stages (exploration; consultation; collaboration and integration) which were connected; every single stage formed the input for the next stage. The specific activities of the several stages are mentioned in table 1 and will be explained later on.

Table 1 Stages in research with persons with Acquired Brain Injury

Activities	Goal
Exploration stage	
Recruiting research partners for research team (2 people with ABI and 1 caregiver).	Incorporating experiential knowledge in whole research process which leads to the improvement of the design, better results and establishing trust.
Informing and contact with patient organisations and funds.	Creating social conditions and collaboration.
Reading literature and stories of patients.	Getting insight in what it is to live with ABI and getting input for the topic list.
Composing topic list for interviews based on issues derived from the research team's experiences, written stories of patients and scientific literature.	A topic list is used in order to check if all relevant topics are discussed during an interview.
Recruiting members for steering committee.	Improving and validating the research process and results.

Table 1 Stages in research with persons with Acquired Brain Injury (continued)

Activities	Goal
Recruiting participants by patient organizations, the Dutch fund for brain research and support and institutions for health care (with maximal variation).	Multiple ways of recruiting in order to get maximal variation to get as many perspectives as possible and to learn as much as possible.
Consultation stage	
Semi-structured interviews (N = 26).	Getting information about the experienced restrictions or bottlenecks regarding participation, the perceived possibilities of participation and the needs of participants regarding participation. The conversations were furthermore aimed at getting information on how participants perceived the concept of participation and how they evaluated their own participation in society.
Thematic content analyses of the interviews.	Getting a first insight into relevant themes.
Meeting of the steering group	Validating and deepen the analyses of the interviews and preparing the content and focus of the focus groups.
Collaboration stage	
6 focus-groups (N = 36)	Validating and deepening the information from the interviews and clustering the data from the interviews leading to an overview of personal and environmental factors that may influence participation.
Integration stage	
Two meetings of the working group (N = 8)	Formulation of methods and actions that may lead to the improvement of the participation of persons with ABI, based on the influencing factors that were found in earlier stages.

Table 1 Stages in research with persons with Acquired Brain Injury (continued)

Activities	Goal
Writing the research report	Describing project and results in order to make these generally known and in order to improve participation of people with ABI.
Meeting of the steering group	Getting feedback on research report and getting ideas for implementation of results and needed actions in order to improve participation.

Sample

Participants for the interviews, focus groups and working group were recruited by three Dutch patient organisations, the Dutch fund for brain research and support and institutions for health care. The selection of participants for the interviews and focus groups was based on maximal variation to get as many perspectives as possible¹⁴. The selection was guided by the desire to learn as much as possible from the different persons involved.⁽¹⁴⁾ Participants were selected, based on age (25-60 years), gender, the cause of the ABI and whether they were working or not. All of them were living on their own or with family and had brain injury for minimal one year. Participants who lived in a health care setting were excluded, just as participants with progressive forms of brain injury like Multiple Sclerosis and Parkinson Disease or metabolic diseases or neuropsychiatric disorders. People needed to experience participation problems and needed to have insight in their (eventual) cognitive impairments and their behavioural and emotional changes as a result of the brain injury in order to get included.

Regarding the focus groups can be stated that participants with more or less the same background were participating in the same focus group in order to create mutual recognition which leads to a better intensification of the data. The diversity between the various focus groups was remained as big as possible in order to take the different perspectives into account. Table 2 gives an overview of the characteristics of the participants of the interviews and focus groups.

The selection for the working group was based on the degree in which participants were able to exceed their own stories and did have knowledge of the stories of other fellow sufferers. People without this knowledge and skills could not participate in the working group.

Table 2 Characteristics of the participants of the interviews and focus groups

	<i>Interviews</i> N = 26	<i>Focus groups</i> N = 36
Age mean	46 (ranging from 27-60)	49 (ranging from 30-60)
N < 50 year	18	19
N: Women	14	19
Diagnosis		
Tumor	6	2
Stroke	8	17
Traumatic Brain Injury	11	14
Infection	1	0
Out-of-hospital cardiac arrest	0	1
Unknown	0	2
Employment		
yes	12	11
no	14	25

Data collection

The study combined various data collection methods which will be explained below.

Semi-structured interviews

In the consultation stage 26 semi-structured interviews were held. The interviews were aimed at getting information about the experienced restrictions or bottlenecks regarding participation, the perceived possibilities of participation and the needs of participants regarding participation. The conversations were furthermore aimed at getting information on how participants perceived the

concept of participation and how they evaluated their own participation in society. The stories of the participants were leading during the interviews. A topic list was used in order to check if all relevant topics were discussed. Participants were able to choose the location of the interview and most interviews were held at home. The conversations lasted about one hour, and were, if the participants agreed, audio recorded.

Focus groups

The results from the interviews were subsequently, in the collaboration stage, validated and deepened in 6 focus groups with a total of 36 participants. The focus groups were moderated by 2 academic researchers and 1 research partner. They lasted about 3 hours, including a pause. The moderators were trained in advance on how to conduct focus groups and how to use strategies to elicit and equalize participation. A structured and well suited protocol was developed and used for each focus group. The protocol and procedure were adapted to the possibilities and specific restrictions of participants with ABI. The moderators of the groups were focussed on giving each participant a voice and were using, when necessary, a round robin approach to equalize participation.

The focus of each group was slightly different. The first group was aimed at a further discussion of the analysed restrictions and bottle necks regarding participation. Participants were asked if they recognized the mentioned problems. They were furthermore asked to cluster the problems into categories. The next 4 focus groups were aimed at validating, deepening and relating these four factors. Each group focused on one factor in order to prevent an overload of information for the participants. These 4 focus groups resulted into a dynamic model in which these related factors are visualized.

Working group

During the integration stage a working group in which 8 participants with ABI were involved, was formed. These persons with ABI were able to exceed their own stories and did have knowledge of the stories of other fellow sufferers. The working group members met each others two times and the meetings were aimed at the formulation of methods and actions that may lead to the improvement of the participation of people with ABI. The earlier found barriers and possibilities to

participate and the dynamic model with participation influencing factors, were the basis for the formulation of possible methods and actions. The 2 meetings led to an overview of actions that may, according to people with ABI, based on their experienced possibilities and barriers, lead to improvement of participation of people with ABI.

Data analysis

Data analysis was part of the whole research process and outcomes from one stage steered the data collection in the next stage. The audio-recorded interviews were written out line by line resulting in transcripts. The transcripts were separately analyzed by both the academic researchers and research partners and later discussed in research team meetings. A thematic content-analysis was used.⁽¹⁵⁾ First, the entire transcript was read to identify emerging themes and sub themes. Labels were attached to the text parts related to a specific (sub) theme. Each transcript was first analysed separately. Any new emerging themes were added to the process of labelling and analysis and also adopted to the interviews analysed previously. In the collaboration stage the input of focus group participants was actively used in the process of analysis, as we invited them to cluster findings from the interviews. This classification led to the identification of 4 covering factors that may influence participation, namely: the process of recovery, support & treatment, the environment & society and at last communication and interaction.

Quality procedures

To assess the validity of our study we used the checklist published in BMJ in 2008.⁽¹⁶⁾ The 'rock bottom' of the internal validity in qualitative research is considered the 'member check' as this procedure helps to eliminate bias.^(14,17) Individual participants received an interpretation of their interview with the question if they recognized the analysis. During the focus groups the input of participants was repeated in order to verify understanding and a white board was used to visually record a bulleted list of points. A member check was conducted with all participants at the end of each focus group to clarify, synthesize and prioritize findings and to ensure trustworthiness in representing perspectives.⁽¹⁸⁾ The findings were furthermore checked by sending a report, based on audio-tapes of the meeting, to all participants. Eventual comments of participants were incorporated. The same procedure was used for the working group.

In qualitative research the process of data collection and analysis ends when ‘saturation’ is reached.⁽¹⁴⁾ This is the point where no information is added and replication of data occurs. The point of saturation cannot be predicted in advance and is dependent on the scope of the study, the quality of the interviews and the appropriateness of participant selection. In this study saturation was reached after the interviews and focus groups. Another procedure concerned ‘triangulation’ as we combined various data collection methods. Whereas the interviews gave insight in personal experiences, the focus groups helped to broaden the set of themes and their relations. This provided us with a larger scope of information on societal participation. The analyses and results of the transcripts were compared and discussed in the different research team meetings (check coding) in order to increase the reliability of findings.

Ethical considerations

All participants who participated in our study took part on a voluntary basis and after they had given consent. Names and other characteristics of the participants were deleted. Their transcripts were not shared with their therapists or other external parties and the transcripts and tapes were destroyed after the study.

Results

Meaningful participation

The data resulted into a description of participation from the perspective of people with ABI. Participants emphasised that the quality of participation is more important than the degree of participation. Participation does not necessarily mean having a job or participating in all life domains like social activities, work, education, family life. Meaningful participation is related to playing a meaningful role in life. Participation means being part of a respectful environment in which one can fulfil meaningful roles and in which one may be himself without being rejected because of disabilities. The satisfaction with one’s role provides a sense of completeness or full-fledged participation. Participation can be partial, from the perspective of society, but full and meaningful in the eyes of the person it involves. Fulfilling one role, for instance the role of mother or spouse or employee, in a meaningful way, can give a sense of full social participation, even though one might have had many more roles in a former life. This sense of fullness is enhanced when people feel engaged and if

they can contribute to society or a larger whole. Participation is thus about *taking part, giving something and being someone* in a specific context, as can be explained by some quotes of two participants:

'Quality of life isn't only about being able to work, you also need to live! I tried to pick-up my old life: working, being a good father, being a good husband, meeting friends and family and doing some activities regarding our home[...] But I wasn't able to do all adequately and without losing myself [...] The weekends weren't enough to get new energy for the next week. The weekends were too short, if I had some social appointments or if I wanted to do some activities for myself. Live has become great since I decided to work some days less.'

'For me, it's now enough to be a good mother and wife. I'm able to clean the house, wash the children and give them all clean clothes. Doing these tasks, taking care for others, gives me a sense of worth and satisfaction.'

Factors influencing participation

The study led, as can be seen in figure 1, furthermore into the identification of 4 interrelated factors that, according to people with ABI, influence participation: (1) the process of recovery, (2) support & treatment, (3) the environment & society and at (4) last communication & interaction.

Each of these 4 factors consists of several sub-factors (see table 3) and all these factors influence each other constantly and in a dynamic way (see figure 1). Participation is a continuous dynamic process instead of a static condition. At first, these 4 factors will be explained and afterwards, the interrelation between these factors will be described.

Figure 1 Participation model according to people with ABI

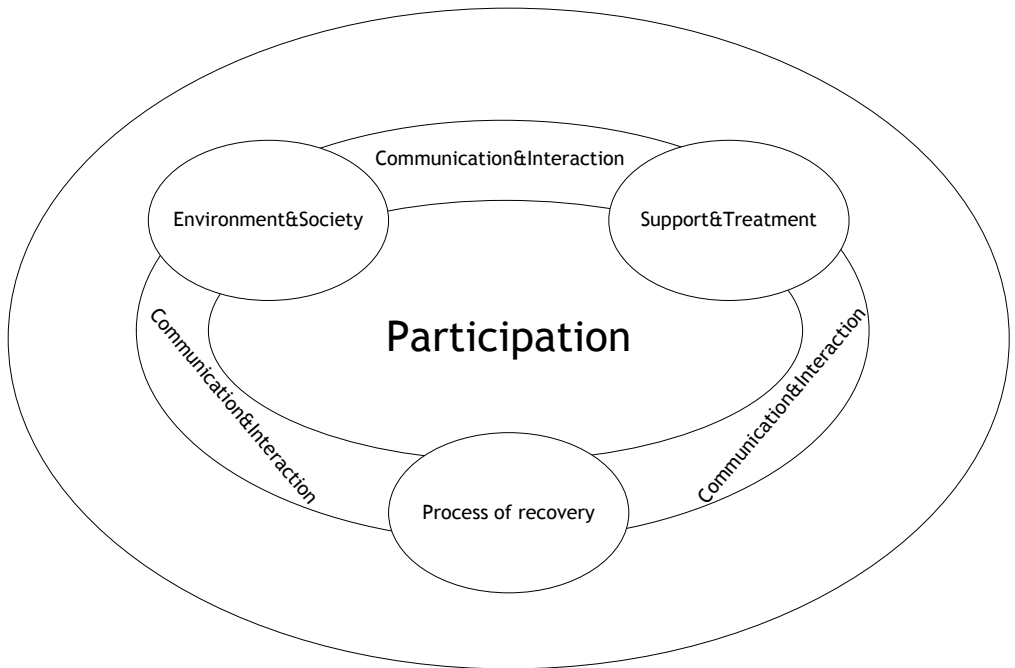


Table 3 Factors influencing participation and their sub factors

Factor	Sub factor
Recovery	Determining ABI and consequences. Process of information giving about ABI. Acceptation Emotion regulation. Relativism. Adjustment of future perspective. Will-power and persistence.
Support & treatment	Organization, structure and availability of care in the chronic phase. Attitude of and knowledge among professionals. Regulatory processes and indication.

Table 3 Factors influencing participation and their sub factors (continued)

Factor	Sub factor
Environment & society	Context-dependent restrictions. Misunderstandings, rejection and shaping of identity by (in)visibility of restrictions, apparent identifiable restrictions and judgements. Characteristics of contemporary society. Learning and development in the environment.
Communication & interaction	Communication problems due to the injury. Communication dilemmas and choices. Knowledge level of environment about ABI. Negotiating.

The process of recovery

Participants indicated that ABI and the accompanying restrictions are often insufficiently recognized, determined and communicated by professionals. Diagnoses are sometimes wrong, missing or delayed which gives a lot of problems as is also explained by one of the participants:

‘There was less and less understanding. I lost everything, my wife, my children, my job. Finally the diagnosis revealed what was happening, but then it was too late.’

Knowing what is wrong and having an explanation for the experienced problems may facilitate participation since people are able to deal with problems and to adapt positively to a certain situation, if they know about the actual situation. If people with ABI do anyhow know about their ABI, they still may feel uninformed about the consequences:

‘I was sent home with the message, “try to pick up your old life, just as you used to do”. But there comes a moment whereupon you mention that you fail, in picking up your old life. Nobody informed me about that!’

People with ABI try to go on and struggle through their lives, without knowing what is going on. This may hinder participation and may lead to uncertainty and incomprehension from the environment. Investigating and determining the possibilities and limitations is, according to the participants, also a prerequisite for acceptance and integration of the restrictions in the new identity. Not only the severity of the restrictions has an influence on participation, but it is rather the extent to which people are able to integrate the disabilities in their lives:

'I don't talk about my limitations anymore. I am now talking about the possibilities I still have. That's the progression I have already made.'

Participation is influenced by the degree by which people are able to accept their restrictions. The harder people offer resistance to their situation, the harder it will be to participate in daily life again:

'I wanted to be the old me. I resisted and wanted to be normal again!'

Acceptation is also about handling feelings of shame, dependency and confrontations. Participation may be easier if people are able to overcome their feelings of shame:

'I didn't dare to bicycle but now I have bought a helmet. In the beginning I had a sense of shame: I look odd, but I'm not interested in the reactions of the environment anymore and I have gained freedom by bicycling around.'

A better acceptance and handling of feelings, may improve participation. This is also the fact for the level by which people are able to tone down, to place their restrictions in perspective and to get another point of view regarding their lives:

'I'm not able to do many things anymore, but nobody, even a normal person, is able to do whatever (s)he wants.'

Relativism helps people in order to enjoy other things or in another way which may facilitate participation:

'Now I'm saying: small is fine.'

'The old me and the old situation aren't there anymore, but the acquired brain injury gave me another thing, a present: TIME! It gave me time, time to discover myself and time to spend with my child. I don't have to hurry anymore, day after day.'

Participation is also influenced by will-power and persistence:

'You have to dare to take your time, day after day.'

Support & treatment

Participants stressed that professional support and treatment are necessary to learn to cope with the restrictions due to ABI. They experienced a lack of care in the chronic stage of their recovery process. In this period they became deeply aware of their restrictions which results in an increased need for help:

'Only then you start to realize the real impact of the injury and at that moment there is no support at all.'

Support in order to cope with the restrictions and to accept these, is needed in order to participate. Participants miss professional support, feel the provided care is too fragmented and (too) difficult to find. They often have to take initiative themselves in order to find and get appropriate care, which is often difficult because of their restrictions:

'You have to be in different places for different questions. Finding your way around is a nightmare.'

The accompanying, ever changing, formal rules to receive technical resources or (psychological) support make it even more difficult:

'If you finally know the rules, a new one pops up, that's for sure!'

Participants, furthermore, mentioned a lack of knowledge among professionals. They often felt misunderstood by professionals, and their symptoms were sometimes wrongly interpreted and diagnosed. Also, the attitude of professionals hinders participation according to participants. The use of jargon, missing information or information on the wrong moment, and not listening give rise to feelings of being treated unequal, which subsequently hinder the coping and acceptance process and therefore indirectly the participation process:

‘Why don’t they talk in normal words? It’s all about me after all, isn’t it?’

Environment & society

Participation is only possible in a certain environment. The environment and society, therefore, at least partly influence on the participation of people with ABI. People with ABI have, in order to participate, to learn how to deal with their restrictions and how to accept these in a certain way. This is experienced as a search process in which the environment plays a crucial role. Participants declared that they want to develop new interactions with and experiences in their environment. The environment is seen as a place where they can learn, and exceed and remove their boundaries in order to participate. This leads to growth and self-confidence:

‘You can actually do more, than you thought you would dare, so you just have to do it.’

Learning to know the boundaries is not easy because the restrictions are strongly influenced by the environment and context at a specific moment:

‘Whether or not you are able to do something depends on the environment. It’s not the activity or action as such, but rather the situation and context that matters most. Sometimes you are able to do an activity and sometimes you are not.’

The context dependent restrictions may, together with the invisibility of the restrictions, give rise to misunderstandings and feelings of being rejected:

'People don't see anything at all. I'm looking quite normal. The environment finds it, therefore, hard to understand my problems and the changes in my possibilities.'

Misunderstandings and feelings of being rejected are also influenced by prejudices about brain injury. People with ABI may feel rejected because of these prejudices. They also may have feelings of needing to adapt in order to overcome prejudices. Having to adapt may lead to feelings of not being yourself:

'You are not allowed to be the one you actually are.'

The identifiable restrictions give rise to feelings of not being understood:

'My friends often say: "Don't worry, we all forget more and more since we are getting older."'

The misunderstandings and feelings of being rejected and misunderstood may hinder participation since it may keep people at home in order to prevent these reactions.

People with ABI have, furthermore, to deal with a society that does not always meet their needs and possibilities. The contemporary rapid, individual, stimulus-rich, unstructured and competitive society, full of rules that require a pro-active attitude of people, hampers the participation of people with ABI:

'Things go quite well as long as I feel no pressure, but only a small amount of pressure from my environment gives me a lot of stress. I know what to do and how to do it, but I'm not able to do it. It stagnates!'

Communication & interaction

Participants stressed at last, that factors regarding the communication and interaction with others have an influence on their participation. Communicative limitations have important implications for participation. Aphasia or neuropsychological changes, such as concentration- or memory problems and personality changes, affect the communication and therefore participation:

'People often have problems understanding me, but they pretend to understand me. Maybe that's the hardest part of it!'

'I'm not that distinguished anymore and sometimes a little bit blunt.'

Communication is important to express your wishes, possibilities and limitations, but also needed to form and confirm your self-image. Painful situations arise when these processes get complicated because of the injury. People have the feeling of not being taken seriously, not being respected, not being recognized, being underestimated, being stigmatized or being put into a corner as if they no longer count. Social and work contacts and contacts with professionals often become more difficult as people struggle to express themselves:

'People don't understand your brain damage. But you can't even understand it your self, so how to explain it to others?'

The invisibility and lack of knowledge about brain damage in society also has an impact on participation. Participants want to inform their environment but are faced with doubts how to inform the environment about restrictions:

'People don't understand ABI if you try to explain it. It is hard and a real struggle: what to tell and what not to tell? People think you are crazy if you tell them too much. But if you tell them too less they don't understand you either.'

This means that people with ABI continuously negotiate with themselves and their environment. Having a false image and false hopes and denial of the restrictions of people with ABI has a major impact on the way people interact with people with ABI and on the participation of people with ABI. It may give rise a great sense of loneliness:

'Almost nobody knows what it means to have brain injury, so almost nobody understands me'

The interrelation

The above mentioned factors and sub factors at least partly influence the participation of people with ABI. As these factors also interact in specific ways in each individual with ABI participation is to be considered as a continuous, dynamic and complex process. It is impossible within the context of this paper to mention all the relations between the factors. Yet, the following may illuminate the complex dynamic interrelation. Participants stress that the organisation and the availability of care influences their process of recovery. Paradoxically, finding the right care is more easy one has a clear diagnosis and knows ones restrictions. Knowing ones restrictions makes it easier to maintain oneself in society and to cope with misunderstandings and rejections from the environment. Communication also becomes easier if one has accepted limitations and integrated these in ones identity, and this may in turn remove or reduce misunderstandings, rejections and prejudices of the environment. Vice versa environmental responses influence the way and degree in which people with ABI are able to be open and fair about their restrictions and creatively explore their possibilities. This spiralling process can both move upwards or downwards, and result in a low level and quality of participation if problems in the process of recovery, the support and care, the interaction and communication with others, and environment and society occur.

Actions in order to improve participation

Above mentioned description, explains the personal and environmental factors and how their dynamic interaction influences the participation of people with ABI. The participants of the working group generated several actions in order to remove barriers and facilitate the participation of people with ABI. In order to counter the downwards spiral the most important action according to participants concerns the development of better structured, continual and sequential care. Secondly, the collaboration among professionals in the field is considered crucial to share and develop new knowledge, skills and treatments and protocols and to improve the implementation of scientific knowledge. Sharing of knowledge and experiences among people with ABI is also mentioned, for example, by having contact with fellow-sufferers or by developing a structured buddy-system. Finally, participants prioritize a media campaign in order to create the correct image-forming of ABI in society.

Discussion

Meaningful participation

This article was aimed at the description of meaningful participation and particular barriers and facilitators for societal participation as experienced among persons with ABI. Our study revealed that people with ABI related meaningful participation to being oneself and part of a respectful environment in which one can fulfil one or more meaningful roles. These findings are corroborated an earlier study in which the investigators also found that participation is more than fulfilling tasks and making decisions. The participants in that study stressed that participation also means ‘being engaged in meaningful activities’, ‘doing things for others’ and ‘belonging’.⁽¹⁹⁾ Our participants reported the same meanings when they talked about the value of contributing to society, taking care of others and feeling connected. Participation thus refers to autonomy (being self-sufficient and independent), but in relation with others. This is known as relational autonomy in the field of bioethics; we need others to actualize our autonomy in terms of a positive development.^(20,21)

In this light it is worth noting that (returning to) work was not mentioned as the most important aspect of participation. Other studies have shown that return to work can be seen as important since it is an indication of psychosocial recovery after ABI. Work positively influences rehabilitation, quality of life, social integration, the situation at home, leisure activities and patient’s financial situation.^(22,23) Our study shows that participation is about ‘being part of’ and ‘fulfilling (a) meaningful role(s)’. Work may provide such a context, but paid work also includes responsibilities, work pressure, negotiations with employers and sometimes colleagues who are not very empathic and flexible. In such circumstances paid work requires so much energy that people may become drained. The fatigue intrudes in their personal lives and social contacts. It can be a struggle to find out which values are most important in a situation, and sometimes a new balance in life is found by giving up one’s working career, a process that is well known from the literature on chronic diseases and disabilities.^(24,25) Rehabilitation and policy should therefore not be solely focused on returning to work, but on supporting people to regain a valuable role and on taking part, giving something and being someone in a specific context. Such support should include a

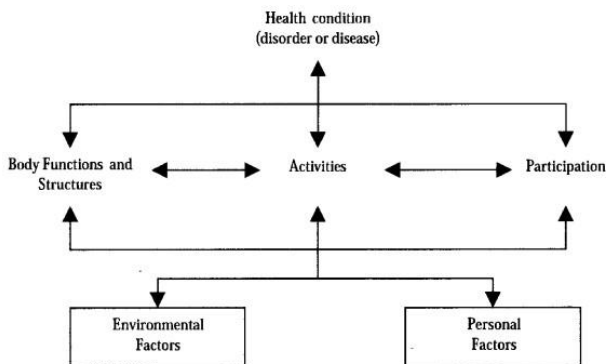
conversation and deliberation (not just an advice) to come to an understanding of the personal values that matter in one's life.

In addition to this the measurement of participation should not solely be focused on return to work. The validity of results increases if participation is measured with a generic participation instrument that covers both objective and subjective participation and that is feasible for use in clinical practice. The Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-P) meets these needs⁽²⁶⁾ and may therefore be used more frequently.

Factors influencing participation

A model with interrelated factors that influence participation was made together with people with ABI. This model shows, just as the ICF-model (see figure 2) that participation is not solely influenced by individual factors or contextual factors. The level and way of participation is determined by the interaction of individual and contextual factors.

Figure 2: ICF Model



The presented model from the perspective of people with ABI does therefore have some similarities with ICF-model. The ICF-model states that participation, after the onset of a health problem, may not only be infringed by disturbances in body functions and structures and the resulting activity limitations, but also by contextual factors such as environmental and personal factors.^(5,6) The patients' perspectives and the specific sub elements of their model can be seen as a further

and complementary fulfilment of the contextual factors of the ICF since it draws attention to more specific aspects affecting the participation of people with ABI, such as the place of contemporary society and lacking positive images of ABI in society. This also yields for personal factors as our model places emphasis on the resilience of people with ABI. Resilience can be described as the possibility of human being to live a good life and to develop their selves in a positive and socially acceptable manner, despite hard circumstances.⁽⁷⁾ More attention for the sources of resilience among people with ABI is therefore important in order to promote their participation. Also interaction and communication is found to be of great importance according to the participants in our study. Implicitly this is also part of the ICF model. Our participants call on professionals and society to take this more seriously into account when dealing with people with ABI.

The model, presented here, also places the severity of the neuropsychological or physical limitations in perspective. Our participants acknowledge that ones health condition does have an influence on participation, but state that this influence should not be exaggerated. Coping and acceptance of the restrictions and a positive adaptation (resilience) to these restrictions seemed to be much more important than the actual limitations. An earlier study state, in line with the ICF-model, that the severity of the restrictions influences the objective participation.⁽¹⁾ Our study reveals that there is no direct relation between the severity of the restrictions, participation and subjective well-being. Experiencing one's participation as valuable, leads to an improvement of subjective well-being regardless the severity of the restrictions. Another study showed the importance of contextual factors on participation and well-being.⁽⁶⁾ Our study also stresses the influence of contextual factors and other factors, but it does mainly stress the dynamic interaction between personal factors like coping and acceptance, the physical and cognitive restrictions, interaction and communication and environmental factors; together these factors influence people's participation and well-being.

The presented model suggests that participation of people with ABI can be enhanced, through the development of actions and improvements in all the distinguished, but related factors. The members of the working group determined, based on the results, some concrete advices and priorities in order to facilitate the

participation of people with ABI. They listed the development of better structured, continual and sequential care and collaboration among professionals as one of the top priorities. The process of diagnosis of (the causes and consequences) ABI and treatment after the phase of rehabilitation is now often experienced as a problem, as can be concluded from our study and an earlier study from 2008, which subsequently hampers the participation. People with ABI will be better able to develop a sense of acceptance if they know their diagnosis. A regional chain of professionals - i.e., medical, nursing and therapy staff - who together, as a network, warrant integrated and coherent treatment and care for people with ABI in all phases - i.e., acute, rehabilitation and chronic - of the ailment, is considered necessary. Earlier research has shown the advantages of structured sequential care for stroke patients. This kind of care organisation led to better multidisciplinary collaboration, better care after hospital admission and improved exchange of knowledge⁽²⁸⁾ and better health effects for patients.⁽²⁹⁾ The negative side-effects of fragmentation of chronic care in general are also well-known. A recent study showed that fragmentation can be characterized as a multi-factorial problem having a mixture of consequences ranging from less severe to very severe.⁽³⁰⁾ In minimizing fragmentation needs of patients should be taken as a starting point.⁽³⁰⁾ One might expect that the above mentioned advantages of structured sequential care will also occur if the organisation of care for people with ABI in general, is structured like this. Furthermore, one might expect that the new organization of care may also lead to a better and faster determination of ABI and the restrictions of people with ABI and less false diagnoses.

Strengths and limitations

It might be argued that the perspective of people with ABI, differs from that of professionals.⁽¹¹⁾ The patient's perspective does therefore have clear surplus value in addition to professional's perspectives.⁽²¹⁾ This study was specifically focused on the perspectives of people with ABI as professional perspectives on participation have already been documented. We do, however, acknowledge that integration of scientific, practical and experiential knowledge may lead to new perspectives and that these parties need to work together to jointly develop solutions. Another limitation may be the sample and external validity of our study. Despite many attempts we did not reach many people from minority groups, like people with a different ethnic-cultural background and younger people with ABI. They may have

specific additional problems and needs, and we recommend research into this area. The sample size of our study was relatively small compared to a quantitative study, but quite large for a qualitative one as it combined a series of interviews with a set of focus-groups and gatherings with a working group which enabled us reach quite a few people with ABI (70 in total), in subsequent rounds of validation. Qualitative research does nevertheless never pretend that the results can be unthinkingly generalized to other situations. Despite these limitations can be concluded that readers should assign the information to their own context and by doing that, they can co-operate with facilitating the participation of people with ABI.⁽³¹⁾

For this study we composed a mixed research team of academic researchers and patient research partners. We felt that this team composition had several advantages also listed in the literature such as enhancing the study design and dissemination of findings, preventing jargon, establishing trust and reckoning diversity.^(11,32,33,34,35) Joining in people with ABI in the research team was also giving in by the desire to explore possibilities for creating a welcoming environment within the research society. In other instances this has led to personal growth and empowerment of the research partners.^(11,32,33,35) In our team one of the persons with ABI went through a similar process of empowerment, ultimately resulting in a publication of her personal story in a professional journal.⁽³⁶⁾ This is not to say that this was a smooth process for the team. Timely reflections on our collaborations helped to deal with challenges.

Conclusion

Studies on the level of participation of people with ABI indicate that their involvement in society is limited. Our study corroborates this finding, and draws attention to the quality of participation and the personal and environmental factors that, in interaction, may hinder or foster the societal participation of people with ABI. Although the ICF-model also stresses the general influence of such factors, our study resulted in a specific description of the dynamic interaction of factors (personal recovery, environment & society, care & support and communication) grounded in the experiences of people with ABI. As such our study provides complementary and more particular insights which may hinder or facilitate the participation of people with ABI.

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