

RESEARCH

Addressing Uncertainty and Stigma in Social Relations Related to Hidden Dysfunctions Following Acquired Brain Injury

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The aim was to elucidate the experiences of people with mild to moderate acquired brain injury to learn how hidden dysfunctions influence their interactions in different social relations. A focus group of four sessions with the same five informants was conducted and analysed using qualitative content analysis. The analysis revealed one main theme: the dysfunctions created hidden challenges and uncertainty in the informants' encounters with others. The main theme was illustrated by five sub-themes: uncertainty in encounters with others, an additional burden of being misunderstood, little consideration for hidden dysfunctions at work, little consideration for hidden dysfunctions from health and social services, and different coping strategies in encounters with others. The results emphasize the informants' uncertainty in unfamiliar situations while adapting to changes in their functioning and addressing additional challenges due to the invisibility, unpredictability and stigmatization of their reduced functioning and to others' ignorance regarding hidden dysfunctions.

Keywords: Social relations; Acquired brain injury; Hidden dysfunctions; Cognitive deficits; Stigma; Uncertainty

Introduction

Stroke and traumatic brain injury (TBI) are major causes of acquired brain injury (ABI) and chronic disabilities (WHO 2003; Donnan et al. 2008). Brain injuries may be categorized as minimal, mild, moderate and severe (Comper et al. 2005). Because medical advances have improved the outcomes of ABI in recent years, the impact of milder deficits is an increasing challenge (Rochette et al. 2007). Given the high incidence of mild brain injuries, a substantial number of individuals experience persistent physical, emotional, cognitive and behavioural symptoms and deficits (Marshall et al. 2012). Referring to the fact that the cognitive symptoms are often undetected and that the actual incidence and social impact of these deficits are underestimated, brain injuries are described as a 'silent epidemic' (Langlois et al. 2005; Peters et al. 2015). Cognitive and emotional deficits following mild ABI can interfere with functioning ability in many areas of life and with perceived quality of life (Edwards et al. 2006; Hommel et al. 2009; Sveen et al. 2013). Even mild ABI can cause severe challenges in daily life and have a major impact on social roles and relations (Comper et al. 2005; Rochette et al. 2007). Common symptoms and deficits of mild ABI may include headache; fatigue; depression; sleep disturbance; and impaired attention, concentration or memory (Ahman et al. 2013; Marshall et al. 2012). Although remission frequently occurs within the first hours to months following mild TBI (Konrad et al. 2011), many experience the cognitive deficits as a considerable problem even one year after an ABI (Cassidy et al. 2014; Roe et al. 2009). A number of individuals still experience cognitive and emotional sequelae even six years after a mild TBI, which also influence their daily social and working lives (Konrad et al. 2011). Changes in functioning and life situation following an ABI can also have an impact on how people see themselves and on their personal and social identities (Ownsworth 2014). The process of psychological adjustment involves becoming aware of and making sense of these changes and adapting to the consequences in functioning and life circumstances (Ownsworth 2014).

The cognitive and emotional deficits are conceptualized as invisible or hidden dysfunctions (Carlsson, Moller, and Blomstrand 2009; Jaillard et al. 2009). They can be invisible or hidden in different ways. First, dysfunctions may be

hidden in the sense that they are not detectable or visible in the appearance of the person. Second, they may be hidden in that they are not apparent to the person or readily apparent to others in the person's environment (Carlsson, Moller, and Blomstrand 2004; Stone 2005). The consequences of hidden dysfunctions may have a significant impact on relationships and the ability to participate in social activities and working life (Lawrence 2010; Lock et al. 2005). It has been argued that the far-reaching impact of such hidden dysfunctions often seems to be unrecognized (Chen and D'Esposito 2010).

Research has suggested that a lack of public understanding of the hidden dysfunctions can have a negative influence on adjustment following ABI caused by stroke (Hall et al. 2012; Sarre et al. 2014). However, little is known about the impact of ignorance about these dysfunctions (Sarre et al. 2014). Further research is required to illuminate the experiences of living with the consequences of hidden dysfunctions following ABI and how these experiences may influence relationships and social participation (Lawrence 2010). The aim of this paper is to elucidate experiences of people with mild to moderate ABI to understand how hidden dysfunctions influence their interactions in different social relations, in their working lives and in encounters with health and social services.

Methods

Design and context of the study

This study is part of a pilot project in Norway to develop an outpatient group intervention in hospitals directed at people with invisible cognitive deficits following ABI. The present study utilized a qualitative approach with focus group sessions (Krueger and Casey 2015; Morgan and Krueger 1998) and qualitative content analysis (Hsieh and Shannon 2005) to explore the experiences of people with mild to moderate ABI. During a period of nine months, a focus group of four sessions covering corresponding topics was conducted with the same five informants. The sample corresponds to those who participated in the group intervention. This article does not merely address the group intervention but rather explores experiences concerning important issues with follow-up services that have importance beyond the current group intervention and are related to how hidden dysfunctions influence different social relations. These issues represent a separate but complementary focus of the follow-up needs that are important to elucidate without exposing people to unnecessary strain.

The study was approved by the Norwegian REC West Research Ethics Committee (2011/1878/REK vest). The research ethics principles are based on the Vancouver Convention (ICMJE 2015). Prior written informed consent was obtained. The study involved several sessions with the same informant group over an extended period and included people with mild to moderate cognitive dysfunctions. Therefore, to maintain informed consent throughout the period, information on the purpose of the study was provided in all the focus group sessions. Information on voluntary participation and the option to withdraw from the study without consequences for future care or treatment was also repeated. No informants dropped out of the study. Anonymity is emphasized in the presentation of the data, and statements have been made anonymous because there were few informants.

Recruitment and selection

The sample included three women and two men who represented different family and life situations and work experiences. The youngest was 37 years old and the oldest 65. Four had permanent employment and work assessment allowance (AAP). One was retired. Four were married or cohabiting. Clinicians who were not involved in the study conducted the recruitment. The inclusion criteria were being of working age with cognitive deficits following mild to moderate ABI within the past year caused by stroke, TBI, or other non-progressive brain injury. A further criterion was independence in activities of daily living (ADL). The exclusion criteria were progressive disorders, substance abuse and severe mental illness. It had been 8 to 11 months since the respondents' injury at the time of the first focus group session.

Data collection

During the recruitment process, the informants provided self-reported data concerning family relations, education, work, employment status, social security benefits and their perceptions of the situation after ABI, which formed the basis of the data that characterized the demographics and social situation of the sample prior to the focus group sessions. The informants were interviewed on four different occasions. The focus group sessions occurred from September 2012 to June 2013, and the mean time span between the sessions was three months (range from two to four months). The main topics of the four sessions were follow-up needs and the focus that rehabilitation services should have after discharge from the hospital. To gain insight into the follow-up needs, the moderator facilitated open dialogue and discussion among the participants by introducing these topics and asking open-ended questions. At the beginning of every focus group session, the informants were asked how they experience everyday life and their relationship with work. The informants shared their perceptions and experiences of the influence of their hidden dysfunctions consistently during all four discussions. These experiences were related to social relations—mainly family, friends, employers and health and social professionals. How hidden dysfunctions influenced their everyday interactions and contact with other people became a recurring topic (raised by the informants) during all the focus group sessions.

Table 1: Overview of categories and sub-themes that formed the main theme: the dysfunctions created hidden challenges and uncertainty in the informants' encounters with others.

Categories	Sub-themes
<ul style="list-style-type: none"> · New and changed situations · Others' reactions · Own strategies 	Uncertainty in encounters with others
<ul style="list-style-type: none"> · Normalization and generalization · Negative labelling · Irrelevant suggestions 	Additional burden of being misunderstood
<ul style="list-style-type: none"> · Inadequate adaptation of work tasks · Too-high or too-low expectations 	Little consideration for hidden dysfunctions at work
<ul style="list-style-type: none"> · Poorly adapted information · Inadequate support and follow-up 	Little consideration for hidden dysfunctions from health and social services
<ul style="list-style-type: none"> · Withdrawing from situations · Talking about hidden dysfunctions · Utilizing professional support to explain hidden dysfunctions 	Different coping strategies in encounters with others

Focus groups have been used in previous studies of people with ABI (Lock et al. 2005; Sveen et al. 2013). The first author (IH) moderated the focus group sessions, while an assistant moderator took notes. The discussions were audiotaped. Each session lasted approximately two hours. In consideration of the informants' cognitive deficits, a break was taken midway through the focus group sessions. The participants received information about the topic in advance and were provided with pen and paper for taking notes.

Data analysis

The data were analysed using conventional qualitative content analysis, which provides a systematic method for identifying codes and themes by attempting to let new insights inductively emerge from the data (Hsieh and Shannon 2005). This method focuses on the content or contextual meaning and may be used to analyse text data obtained from focus groups (Hsieh and Shannon 2005). For this article, an analysis emphasizing the content of the focus group discussions was performed.

The analytical steps were inspired by Graneheim and Lundman (2004) and involved a process of moving back and forth between parts of the text and the entire unit of analysis. The first author (IH) transcribed the focus group discussions, helped by an assistant moderator who transcribed parts of the data. To obtain an overview, the discussions were listened to, and the transcribed text and notes from the focus group sessions were read through several times. Text concerning how the informants experienced the influence of their hidden dysfunctions in social relations, working lives and encounters with health and social services were extracted and consolidated into one text for each session. Quotations were condensed into meaning units and then abstracted into categories that were formed to closely resemble the statements of the informants. In the next phase, these categories were analysed on a more interpretative level, forming five sub-themes and one main theme (See **Table 1**).

The first author (IH) had primary responsibility for the analysis. To ensure conformability, the analysis of categories was performed in close collaboration with two co-authors (KE, SY) through a process of reflection and discussion. All the authors contributed to further analysis and development of the sub-themes and the main theme, discussion of the findings and the writing process. All the themes are illustrated with examples of statements from the informants.

Results

The analysis revealed one main theme related to the informants' experiences of how their hidden dysfunctions influenced their interactions in different social situations: the dysfunctions created hidden challenges and uncertainty in the informants' encounters with others. For all informants, the injury had caused somewhat reduced mobility, and two still experienced a visible physical disability as well as hidden dysfunctions. The hidden dysfunctions were often fatigue and impaired attention and memory. The informants found that friends, family, colleagues and others in their social networks were unaware of these invisible dysfunctions. They found the hidden dysfunctions to be more challenging to live with than the visible ones: 'The physical part, you can learn to live with that. What people cannot see, that is the tough part.' The uncertainty was connected to becoming aware of and addressing not only the dysfunction itself but also a new and changed situation with an unclear future and the challenges involved in a hidden disability. The main theme is based on five sub-themes with associated categories as presented in **Table 1** and described below.

Uncertainty in encounters with others

Informants stated that their hidden dysfunctions led to uncertainty in their encounters with others. This uncertainty involved being in a new situation with altered functioning, and the greatest challenges were related to their dysfunctions not being readily apparent to others. The informants expressed uncertainty about whether, how and what they should tell others about their altered functioning: 'How do we face everyday life, how people react to us and how should we respond?'

Uncertainty was also related to what they could expect in their encounters with others. Several expressed uncertainty about how people would react to their hidden dysfunctions, which could make them reluctant to go out and meet others:

It's very difficult to meet other people. (...) Not being afraid to go out and meet your neighbour or just ordinary things such as doing the shopping. (...) Of course it's nothing to be ashamed of, but you feel it, many people feel it.

There was also uncertainty in how to address others' reactions to the consequences of the hidden dysfunctions, and the informants expressed a need to learn strategies to handle these reactions. Several experienced uncertainty about others' attitudes and fear of embarrassment, and one expressed, 'What should I say on the phone if I have not got a clue about what I told the person the day before? (...) I feel so stupid when I tell them exactly the same thing again.'

One of the informants found it easier to obtain feedback in communication with family members and others he was close to who knew about and showed an understanding of the cognitive difficulties: 'It's okay with my daughter, because she just says gently: "Yes, I have heard that."'

Additional burden of being misunderstood

The fact that others lacked sufficient awareness or understanding of the hidden dysfunctions was also revealed when the informants stated that they often found people's reactions to be irrelevant. Others misunderstood and misinterpreted the situation, and the informants found this to be an additional burden. They noted several examples of misinterpretation by others. One type of misinterpretation was to normalize and generalize the consequences of the hidden dysfunctions by responding as if the difficulties were normal and applied to everyone. For instance, the informants found that family and friends often replied that they also forgot things and had the same difficulties: 'I feel they're not really listening, but kind of just saying yes yes, and something about how they have the same problem too, it's quite common.'

Another type of misinterpretation they faced involved the negative labelling they felt because of their hidden dysfunctions. An example of this was that increased fatigue was perceived as laziness: "'Oh my God, are you so lazy that you have gone to bed?" It's nothing to do with that, but you're tired. And they do not understand it. That annoys me.'

A third type of misinterpretation emphasized by informants was receiving irrelevant suggestions for how to cope with their situation. In their view, these suggestions showed that others did not understand that the difficulties were due to a dysfunction after an injury that could not merely be compensated for by changing their ways of thinking. One example was the advice given to one informant to think positively: 'They said do what Monty Python says, sing the song "Always look on the bright side of life."'

Little consideration for hidden dysfunctions at work

The informants expressed a desire to work but were uncertain whether it was realistic. The uncertainty related to a lack of consideration for their hidden dysfunctions. Two of the informants in positions of responsibility found that their work had not been sufficiently adapted for them while they were on sick leave. One had been given a suggestion for working hours that did not take into account increased fatigue and necessary time for exercise and rest: 'Then, I will not get time to exercise, no time to recharge my batteries or anything at all.'

Experiences of lack of consideration for the hidden dysfunctions also meant that the informants were unsure about how they could return to work. Several expressed concern about putting great effort into a process that would not succeed. They were concerned that an excessive focus on their hopes and potential opportunities to return to work, without regard to the consequences of the injury, could lead to further loss and disappointment: 'It mustn't be like pulling the wool over your eyes, then it's better to be a realist. [...] It would be a huge let-down to go back to work and then have to give up.'

The uncertainty was also connected to worries about going back to changed tasks at work that could be either too challenging or not challenging enough. In one example, an employer had suggested new and different types of work that the informant found irrelevant. Returning to a job with much simpler work than before could be perceived as failure. The informants perceived it as an underestimation of their abilities to be offered work that they considered not challenging enough, where they could not use their expertise and past experience:

What is depressing for people going back to work is the thought that they cannot do what they used to do. So if you get an easier job, you feel it's a kind of failure.

Another informant said, 'And then you get back to work, and everybody says: "Oh, now you're back at work." And eventually you end up standing there making the coffee and doing the copying.'

Little consideration for hidden dysfunctions from health and social services

The fact that the cognitive dysfunctions were invisible and hidden also had consequences for the help that the informants had received. The informants noted several areas where they had found that health and social services did not take their hidden dysfunctions into account or ignored their need for help. A common feature of lack of consideration was poorly adapted information. The informants struggled to understand the meaning of letters and other written information from the health services and the Norwegian Labour and Welfare Organization (NAV). It could also be difficult to understand and relate to information given on the telephone. One example was a telephone call from a case worker at NAV:

She said lots of things on the phone. Could not she just ask me to come for a meeting and explain it to me? That is what the challenge is. It's not like I have broken my foot and my head's 100% okay.

Inadequate support to help the informants meet the requirements for benefits from NAV was also a common feature of the focus group sessions. They had difficulty filling in forms and composing their CVs. One of the informants had lost benefits because he had had difficulty understanding the registration card and the instructions from the NAV case worker: 'So I lost 14 days' money because of that, as I hadn't filled it out correctly.'

Another consequence of inadequate support was a refusal of benefits to which the informant believed she was entitled because she looked 'okay'. 'NAV refused because I looked too healthy. [...] Next time, I will bloody well put on some awful old clothes, so I do not look like I'm okay.'

However, another had found that the case worker understood the situation and helped him fill out forms and complete his CV: 'All those questions and the CV, I did them with the man at NAV [...] We talked about all of it, we did it together.'

Lack of consideration for hidden dysfunctions was also related to the inadequate follow-up that the informants received in the hospital immediately after the injury. Several said that there was little focus on the cognitive and emotional consequences in the hospital. Additionally, four of the informants had been admitted to a rehabilitation unit where standard procedure involved the patients in preparing a multidisciplinary report (generally by the doctor, nurse, occupational therapist, physiotherapist, psychologist, social worker and, if needed, a speech therapist) before being discharged. Several acknowledged that it was difficult for them to decide what follow-up they might need later while they were still in the hospital: 'But you do not quite know what you need either.'

Different coping strategies in encounters with others

The informants stated that they adopted different strategies to address their hidden dysfunctions and the reactions of others. One strategy was to leave or avoid certain situations. One way to cope was to withdraw from social settings. Some informants had a holiday home, and some of those on sick leave chose to spend more time in the countryside. There it was easier to be active and avoid meeting other people: 'It can be a good thing to get away from the town if you can. [...] You feel less pressure, not always confronted with work or money like you are at home.'

Another way to cope was withdrawing from conversations and talking less to avoid embarrassment: 'Then, what happens is I just keep quiet, I mean I say much less. Because it's like "Have I said that before?"'

Not all the informants emphasized withdrawing from or avoiding situations to hide their difficulties. Some expressed the view that it was important to be open about the difficulties and face others' reactions. They perceived a need to talk to others about their hidden dysfunctions and said that it did not matter much if other people said something wrong: 'Actually, it's really good that people say anything at all, rather than everyone just keeping quiet about it.'

In conversations, some used strategies to determine what they had already told others to avoid repeating themselves:

I feel I'm going round and asking about it all the time, if I have said this before [...] So that I will not start telling a long story and the other person will be just sitting there: 'Oh my God, now he's repeating the same story again.'

The fact that these hidden consequences of the injury were less well-known than the physical disabilities meant that the informants had to explain them to their family and others in their network: 'The hidden difficulties, I think that is my biggest problem today. It's important for me to explain it for my family at home. They have not been aware of it.'

Additionally, some had utilized the support of health professionals with knowledge of hidden dysfunction to express, explain and provide information to their family, employer and the social services. One of the informants

had received help from her GP to explain her dysfunction to her closest family. Others had utilized an occupational therapist and a social worker from the specialist health services to help them better express the hidden difficulties in encounters with health care providers and their employer: 'When I met the doctor and NAV, it was nice to have an occupational therapist with me who could express the situation and ask questions.'

Discussion

This study explored the experiences of people with mild to moderate ABI with regard to how their hidden dysfunctions influenced their interactions with different social relations, working lives and encounters with health and social services. The findings revealed how the informants experienced hidden challenges and uncertainty in encounters with others and utilized different strategies to address their dysfunctions and others' reactions. The informants found that their greatest challenges were related to having mild cognitive and emotional changes and to how they should address the consequences of these hidden dysfunctions in encounters with others. However, they found that people in their environment paid the most attention to physical disabilities. Challenges related to the fact that these difficulties can be hidden, and thus not easily noticed and understood by others, have also been noted in previous studies (Carlsson, Moller, and Blomstrand 2009; Stone 2005).

The informants felt uncertain in many areas, one of which was whether and how they should disclose the difficulties arising from their hidden dysfunctions. The results suggest that uncertainty is a pervasive feature of the informants' situations with their families, friends and social networks. There are a number of possible explanations for this uncertainty.

The uncertainty may be seen in the light of the stigma sometimes linked to having ABI. Goffman (1968) describes stigma as a deviation from our expectations of normality; the object is therefore disparaged and undesirable. There may be special challenges related to stigma when a disability is invisible or hidden (Corrigan and Watson 2002; Goffman 1968). The results of our study suggest that cognitive and emotional changes resulting from mild ABI may be perceived as stigmatized dysfunctions. People who experience stigmatization may feel uncertain about how others will identify and accept them and perceive that they cannot tell what others 'really' think (Goffman 1968). The informants reported being afraid that others would find out about their dysfunctions, which shows that a form of downgrading and self-stigmatization can be involved in hidden dysfunctions resulting from mild injury. Other qualitative studies of brain injury from Norway have also found examples of fear of stigmatization (Nortvedt and Fagermoen 2010; Romsland 2008).

We have seen examples of different ways to address hidden dysfunctions in encounters with others. According to Goffman (1968), people with unknown differences are vulnerable and must address issues related to managing information. In *The Presentation of Self in Everyday Life*, Goffman (1959) argues that people are likely to present themselves in a light that seems favourable. Because hidden dysfunctions are not readily apparent to the untrained eye, it is possible to 'pass as normal', and people must consider whether they will reveal or try to conceal their dysfunctions (Goffman 1968; Lingsom 2008). Based on a reinterpretation of Goffman, Raffel (2013) argues that whether one feels able and willing to be exposed and considers it possible and necessary also depends on the relationship and situation. We have seen that some found it easier to address their hidden dysfunctions in relationships with family members and others who knew about and showed understanding of their difficulties. Some informants on sick leave also said that it was easier to be active at their holiday home in the countryside. Withdrawing from social life may be perceived as an appropriate way to address the changed situation and daily life in the short term but can also indicate that the person wants to avoid meeting all the requirements of a normal social life that would inevitably reveal the dysfunction (Raffel 2013). Previous research also showed that young female stroke survivors worked to hide their dysfunctions by avoiding situations that they expected to be difficult (Stone 2005). Others have noted that whether one chooses to disclose hidden dysfunctions may also have implications for one's ability to maintain existing social relationships and establish new ones, which in turn may affect adaptation and rehabilitation (Jones et al. 2012).

One explanation of why the informants addressed their new situation in different ways may be related to whether they felt that stigma was attached to their dysfunctions. Based on research on self-stigma in various minority groups, Corrigan and Watson (2002) suggest that perceiving the negative reactions of others as legitimate is associated with diminished self-esteem. Not everyone seems to be affected negatively by stigma. Some may protest against a negative label or be indifferent to others' perceptions and evaluations (Corrigan and Watson 2002). We have seen here different approaches to others' reactions to the hidden dysfunctions. Some of the informants were not greatly concerned about negative reactions, while others said that they cared about others' misinterpretations and negative labelling.

However, another explanation of the uncertainty concerning whether, how and what to tell others is related to the unpredictability of the hidden dysfunctions in everyday life and whether the dysfunctions will diminish or disappear. Previous studies have argued that hidden dysfunctions can be experienced as unpredictable and sensitive to environmental circumstances (Carlsson, Moller, and Blomstrand 2004) and as fluctuating, influencing some work and life activities but not others (Santuzzi et al. 2014). The complex role of environmental factors, combined with the fact that some hidden dysfunctions can also be difficult to distinguish from normal variations, may exacerbate the challenges of addressing these consequences in working life and other social contexts (Santuzzi et al. 2014).

This study highlights the additional challenges the informants perceived concerning others' ignorance and misunderstanding regarding hidden dysfunctions. Some informants occasionally felt that other people misinterpreted their situations by normalization and generalization of the hidden dysfunctions. There may be several explanations for such reactions: Other people were not aware of the difficulties, normalized the problems to avoid stigmatization or had insufficient knowledge. Recent research has also demonstrated inadequate public knowledge of the consequences of and treatment for mild ABI and vulnerability to stigmatization (Ralph and Derbyshire 2013). The informants stated that the irrelevant responses and negative labelling they perceived due to misunderstanding of their dysfunction represented an additional burden that could exacerbate their problems. An example was that fatigue was perceived as laziness. This is also highlighted in other research. Lack of knowledge and acknowledgement from significant others can represent an additional burden to people who experience fatigue as a hidden dysfunction following stroke (Eilertsen, Ormstad, and Kirkevold 2013). Because it is reasonable to assume that the consequences of hidden dysfunctions after mild injury have received little attention, it is hardly surprising that family, friends and social networks are unaware or have scant knowledge of them.

However, it is more surprising that the informants experienced lack of knowledge and understanding in encounters with health and social services. Although there is some knowledge of hidden dysfunctions (Carlsson, Moller, and Blomstrand 2004; Marshall et al. 2012; Wilson 2002), it is clear that the informants in this study did not perceive that the support was sufficient. Our findings suggest that the problems were also invisible to employees of health and social services and that this ignorance affected the information, services and follow-up provided to the informants. Greater accessibility of information at all stages of rehabilitation has also been noted as a need by people who have experienced strokes in previous research (Lock et al. 2005). Several of the informants utilized the support of health and social professionals with knowledge of hidden dysfunctions, from the specialist health services, to express, explain and provide information to their family, employer and social services. Although it varied, we found that most of the informants experienced little consideration for the specific challenges of encountering community-based health and social services. These findings emphasize the need for a discharge plan, which concerns the cognitive challenges inherent in providing needed support and opportunities for the person to reflect on their situation and context and to create a new framework of meaning. The finding also indicates a need for more knowledge about supporting cognitive challenges in community-based health and social services.

Our study further emphasized that encounters with health and social services can increase challenges and entail additional burdens for people with mild ABI. Inadequate information and limited access to relevant health services are also highlighted in a systematic review of how stroke survivors experience a treatment burden in encounters with health and social services (Gallacher et al. 2013). This indicates lack of knowledge among health professionals, with the result that they ignore and fail to address the particular needs involved. In this way, health and social services may be contributing to maintaining the uncertainty experienced by people with ABI by failing to talk about, follow up on or take account of these difficulties in a satisfactory manner. Our results also indicate that being faced with both too-high and too-low expectations can promote uncertainty and that both of these scenarios may therefore constitute an additional burden. In relation to returning to work, the same reasons for uncertainty may apply. Poor service provision, caused by ignorance and lack of awareness of invisible or not easily comprehensible deficits, has been noted as a barrier to work participation after stroke in previous research (Lock et al. 2005).

Methodological considerations

One weakness of the study may be the small number of informants, though this may also be considered a strength because several sessions were conducted with the same focus group. Although it would be desirable to have a greater number of informants, there is support in the literature that small samples can provide valuable knowledge (Patton 2015). In particular, if the informants are familiar with the topic of interest and the moderator knows the field, then data from only 4–7 informants may be sufficient to provide rich material (Malterud 2011). The informants in the present study had extensive experience with the current matter. With respect to purposeful sampling in qualitative research, the aim of the study is crucial to selecting the informants from whom we can learn about issues of central importance to the topic of interest (Patton 2015). Several sessions with the same informants, combined with the fact that informants became acquainted with one another through participation in a group intervention, may have encouraged openness among the group members. The informants were encouraged to discuss the topics as freely as possible in the focus group sessions, responding to and reflecting on each other's statements. It is reasonable to assume that this had some influence on the experiences that were shared. A number of topics were thus raised, although we cannot ignore the fact that other topics would have arisen if the moderator had led the discussion more actively by using a more detailed topic guide or if individual interviews had been used. The mean time span between the sessions of the focus group was three months. A shorter time span between the sessions might have been an advantage considering the mild cognitive impairments of the participants. However, the longer period gave the informants more time to reflect on topics between the sessions. Many of the findings discussed here are supported by previous studies of the experiences of people with ABI or other hidden disabilities.

No significant changes were found in the topics that the participants raised in the various focus group sessions. For example, uncertainty was an important topic raised in the first session but was equally prominent in the later ones.

Conclusion and implications

The results emphasize the informants' uncertainty about being in a new and unfamiliar situation with inadequate information and support while adapting to changes in their functioning and addressing additional challenges due to the invisibility, unpredictability and stigmatization of their reduced functioning and to others' ignorance regarding hidden dysfunctions.

The findings indicate a need for early information on hidden dysfunctions following mild ABI, including information for relatives. Health care professionals should be aware of different ways of addressing a situation of hidden dysfunctions. The findings also indicate a need for support from a longer-term perspective than only at an early stage of rehabilitation. The similarities between the informants' experiences also indicate that professionals should not only be aware of how to discuss and address hidden dysfunctions but also consider the possible implications of not mentioning or paying attention to these hidden challenges. However, there is a need to investigate this further from a broader base of experience and to include additional perspectives, such as those of relatives and health and social services personnel. There is also a need for more knowledge of needs of and additional burdens experienced by people with mild dysfunctions following an ABI in encounters with health and social services. Finally, further knowledge is needed about how information and services can be designed, adapted and applied to increase predictability and promote navigational competence and health literacy skills (Squiers et al. 2012).

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Competing Interests

The authors have no competing interests to declare.

References

- Ahman, Sara, Britt-Inger Saveman, Johan Styrke, Ulf Bjornstig, and Britt-Marie Stalnacke. 2013. "Long-term Follow-up of Patients with Mild Traumatic Brain Injury: A Mixed-Method Study." *Journal of Rehabilitation Medicine* 45(8): 758–764. DOI: <https://doi.org/10.2340/16501977-1182>
- Carlsson, Gunnel E., Anders Moller, and Christian Blomstrand. 2004. "A Qualitative Study of the Consequences of 'Hidden Dysfunctions' One Year after a Mild Stroke in Persons <75 Years." *Disability & Rehabilitation* 26(23): 1373–1380. DOI: <https://doi.org/10.1080/09638280400000211>
- Carlsson, Gunnel E., Anders Moller, and Christian Blomstrand. 2009. "Managing an Everyday Life of Uncertainty – A Qualitative Study of Coping in Persons with Mild Stroke." *Disability & Rehabilitation* 31(10): 773–782. DOI: <https://doi.org/10.1080/09638280802638857>
- Cassidy, J. David, Carol Cancelliere, Linda J. Carroll, Pierre Côté, Cesar A. Hincapié, Lena W. Holm, Jan Hartvigsen et al. 2014. "Systematic Review of Self-reported Prognosis in Adults after Mild Traumatic Brain Injury: Results of the International Collaboration on Mild Traumatic Brain Injury Prognosis." *Archives of Physical Medicine and Rehabilitation* 95(3): S132–S151. DOI: <https://doi.org/10.1016/j.apmr.2013.08.299>
- Chen, Anthony J. W., and Mark D'Esposito. 2010. "Traumatic Brain Injury: From Bench to Bedside to Society." *Neuron* 66(1): 11–14. DOI: <https://doi.org/10.1016/j.neuron.2010.04.004>
- Comper, Paul, Sean M. Bisschop, Nancy Carnide, and Andrea Tricco. 2005. "A Systematic Review of Treatments for Mild Traumatic Brain Injury." *Brain Injury* 19(11): 863–880. DOI: <https://doi.org/10.1080/02699050400025042>
- Corrigan, Patrick W., and Amy C. Watson. 2002. "The Paradox of Self-stigma and Mental Illness." *Clinical Psychology: Science and Practice* 9(1): 35–53. DOI: <https://doi.org/10.1093/clipsy.9.1.35>
- Donnan, Geoffrey A., Marc Fisher, Malcolm Macleod, and Stephen M. Davis. 2008. "Stroke." *The Lancet* 371(9624): 1612–1623. DOI: [https://doi.org/10.1016/S0140-6736\(08\)60694-7](https://doi.org/10.1016/S0140-6736(08)60694-7)
- Edwards, Dorothy F., Michele Hahn, Carolyn Baum, and Alexander W. Dromerick. 2006. "The Impact of Mild Stroke on Meaningful Activity and Life Satisfaction." *Journal of Stroke and Cerebrovascular Diseases* 15(4): 151–157. DOI: <https://doi.org/10.1016/j.jstrokecerebrovasdis.2006.04.001>
- Eilertsen, Grethe, Heidi Ormstad, and Marit Kirkevold. 2013. "Experiences of Poststroke Fatigue: Qualitative Meta-synthesis." *Journal of Advanced Nursing* 69(3): 514–525. DOI: <https://doi.org/10.1111/jan.12002>
- Gallacher, Katie, Deborah Morrison, Bhautesh Jani, Sara Macdonald, Carl R. May, Victor M. Montori, Patricia J. Erwin, et al. 2013. "Uncovering Treatment Burden as a Key Concept for Stroke Care: A Systematic Review of Qualitative Research." *PLoS Medicine* 10(6): e1001473. DOI: <https://doi.org/10.1371/journal.pmed.1001473>
- Goffman, Erving. 1959. *The Presentation of Self in Everyday Life*. New York: Anchor Books.
- Goffman, Erving. 1968. *Stigma: Notes on the Management of Spoiled Identity*. Harmondsworth: Penguin Books.

- Graneheim, Ulla Hällgren, and Berit Lundman. 2004. "Qualitative Content Analysis in Nursing Research: Concepts, Procedures and Measures to Achieve Trustworthiness." *Nurse Education Today* 24(2): 105–112. DOI: <https://doi.org/10.1016/j.nedt.2003.10.001>
- Hall, Alexandra, Brooke Grohn, Emily Nalder, Linda Worrall, and Jennifer Fleming. 2012. "A Mixed Methods Study of the Experience of Transition to the Community of Working-aged People with Non-traumatic Brain Injury." *Brain Impairment* 13(1): 85–98. DOI: <https://doi.org/10.1017/Brlmp.2012.7>
- Hommel, Marc, Sandra Trabucco-Miguel, Bernadette Naegele, Nicolas Gonnet, and Assia Jaillard. 2009. "Cognitive Determinants of Social Functioning after a First Ever Mild to Moderate Stroke at Vocational Age." *Journal of Neurology, Neurosurgery & Psychiatry* 80(8): 876–880. DOI: <https://doi.org/10.1136/jnnp.2008.169672>
- Hsieh, Hsiu-Fang, and Sarah E. Shannon. 2005. "Three Approaches to Qualitative Content Analysis." *Qualitative Health Research* 15(9): 1277–1288. DOI: <https://doi.org/10.1177/1049732305276687>
- ICMJE (International Committee of Medical Journal Editors). 2015. "Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly work in Medical Journals." *ICMJE*, December. <http://www.icmje.org/icmje-recommendations.pdf>.
- Jaillard, Assia, Bernadette Naegele, Sandra Trabucco-Miguel, Jean François Lebas, and Marc Hommel. 2009. "Hidden Dysfunctioning in Subacute Stroke." *Stroke* 40(7): 2473–2479. DOI: <https://doi.org/10.1161/STROKEAHA.108.541144>
- Jones, Janelle M., Jolanda Jetten, S. Alexander Haslam, and W. Huw Williams. 2012. "Deciding to Disclose: The Importance of Maintaining Social Relationships for Well-being after Acquired Brain Injury." In *The Social Cure: Identity, Health and Well-Being*, edited by Jolanda Jetten, Catherine Haslam, and S. Alexander Haslam, 255–271. Hove: Psychology Press.
- Konrad, Carsten, Anne Jule Geburek, Fred Rist, Hauke Blumenroth, Bernhard R. Fischer, Ingo W. Husstedt, Volker Arolt, Hagen Schiffbauer, and Hubertus Lohmann. 2011. "Long-term Cognitive and Emotional Consequences of Mild Traumatic Brain Injury." *Psychological Medicine* 41(6): 1197–1211. DOI: <https://doi.org/10.1017/S0033291710001728>
- Krueger, Richard A., and Mary Anne Casey. 2015. *Focus Groups: A Practical Guide for Applied Research* 5th ed. Thousand Oaks, CA: SAGE Publications.
- Langlois, Jean A., Angela Marr, Jane Mitchko, and Renee L. Johnson. 2005. "Tracking the Silent Epidemic and Educating the Public." *Journal of Head Trauma Rehabilitation* 20(3): 196–204. DOI: <https://doi.org/10.1097/00001199-200505000-00003>
- Lawrence, Maggie. 2010. "Young Adults' Experience of Stroke: A Qualitative Review of the Literature." *British Journal of Nursing* 19(4): 241–248. DOI: <https://doi.org/10.12968/bjon.2010.19.4.46787>
- Lingsom, Susan. 2008. "Invisible Impairments: Dilemmas of Concealment and Disclosure." *Scandinavian Journal of Disability Research* 10(1): 2–16. DOI: <https://doi.org/10.1080/15017410701391567>
- Lock, Sarah, Lesley Jordan, Karen Bryan, and Jane Maxim. 2005. "Work after Stroke: Focusing on Barriers and Enablers." *Disability & Society* 20(1): 33–47. DOI: <https://doi.org/10.1080/0968759042000283629>
- Malterud, Kirsti. 2011. *Kvalitative metoder i medisinsk forskning. En innføring*. [Qualitative methods in medical research. An introduction]. 3th ed. Oslo: Universitetsforlaget.
- Marshall, Shawn, Mark Bayley, Scott McCullagh, Diana Velikonja, and Lindsay Berrigan. 2012. "Clinical Practice Guidelines for Mild Traumatic Brain Injury and Persistent Symptoms." *Canadian Family Physician* 58(3): 257–267. DOI: <https://doi.org/10.3109/02699052.2015.1004755>
- Morgan, David L., and Richard A. Krueger. 1998. *The Focus Group Kit*. Thousand Oaks, CA: SAGE Publications.
- Nortvedt, Line, and May Solveig Fagermoen. 2010. "Hjerneskode og selvpresentasjon. En kvalitativ studie." [Brain Injury and Self-presentation – a Qualitative Study]. *Nordic Journal of Nursing Research* 30(2): 18–22. DOI: <https://doi.org/10.1177/010740831003000205>
- Owensworth, Tamara. 2014. *Self-Identity after Brain Injury*. Hove: Psychology Press.
- Patton, Michael Quinn. 2015. *Qualitative Research & Evaluation Methods*. 4th ed. Thousand Oaks, CA: SAGE Publications.
- Peeters, Wouter, Ruben van den Brande, Suzanne Polinder, Alexandra Brazinova, Ewout W. Steyerberg, Hester F. Lingsma, and Andrew I. R. Maas. 2015. "Epidemiology of traumatic brain injury in Europe." *Acta Neurochir* 157:1683–1696. DOI: <https://doi.org/10.1007/s00701-015-2512-7>
- Raffel, Stanley. 2013. "The Everyday Life of the Self: Reworking Early Goffman." *Journal of Classical Sociology* 13(1): 163–178. DOI: <https://doi.org/10.1177/1468795X12474055>
- Ralph, Andrea, and Catherine Derbyshire. 2013. "Survivors of Brain Injury through the Eyes of the Public: A Systematic Review." *Brain Injury* 27(13–14): 1475–1491. DOI: <https://doi.org/10.3109/02699052.2013.823653>
- Rochette, Annie, Johanne Desrosiers, Gina Bravo, Denise St-Cyr-Tribble, and Annick Bourget. 2007. "Changes in Participation after a Mild Stroke: Quantitative and Qualitative Perspectives." *Topics in Stroke Rehabilitation* 14(3): 59–68. DOI: <https://doi.org/10.1310/tsr1403-59>
- Roe, Cecilie, Unni Sveen, Kristin Alvsåker, and Erik Bautz-Holter. 2009. "Post-concussion Symptoms after Mild Traumatic Brain Injury: Influence of Demographic Factors and Injury Severity in a 1-Year Cohort Study." *Disability & Rehabilitation* 31(15): 1235–1243. DOI: <https://doi.org/10.1080/09638280802532720>

- Romsland, Grace Inga. 2008. "Erfaringer fra et rystet selv: om å leve med kognitive vanskeligheter etter ervervet hjerneskade." [Experiences from a Shaken Self: Living with Cognitive Difficulties after Acquired Brain Injury]. Phd diss., University of Oslo. Accessed 29 May 2013. <https://www.duo.uio.no/handle/10852/30013>.
- Santuzzi, Alecia M., Pamela R. Waltz, Lisa M. Finkelstein, and Deborah E. Rupp. 2014. "Invisible Disabilities: Unique Challenges for Employees and Organizations." *Industrial and Organizational Psychology* 7(2): 204–219. DOI: <https://doi.org/10.1111/iops.12134>
- Sarre, Sophie, Cara Redlich, Anthea Tinker, Euan Sadler, Ajay Bhalla, and Christopher McKeivitt. 2014. "A Systematic Review of Qualitative Studies on Adjusting after Stroke: Lessons for the Study of Resilience." *Disability & Rehabilitation* 36(9): 716–726. DOI: <https://doi.org/10.3109/09638288.2013.814724>
- Squiers, Linda, Susana Peinado, Nancy Berkman, Vanessa Boudewyns, and Lauren McCormack. 2012. "The Health Literacy Skills Framework." *Journal of Health Communication* 17(3): 30–54. DOI: <https://doi.org/10.1080/10810730.2012.713442>
- Stone, Sharon Dale. 2005. "Reactions to Invisible Disability: The Experiences of Young Women Survivors of Hemorrhagic Stroke." *Disability & Rehabilitation* 27(6): 293–304. DOI: <https://doi.org/10.1080/09638280400008990>
- Sveen, Unni, Sigrid Ostensjo, Sara Laxe, and Helene L. Soberg. 2013. "Problems in Functioning after a Mild Traumatic Brain Injury within the ICF Framework: The Patient Perspective using Focus Groups." *Disability & Rehabilitation* 35(9): 749–57. DOI: <https://doi.org/10.3109/09638288.2012.707741>
- Wilson, Barbara A. 2002. "Towards a comprehensive model of cognitive rehabilitation." *Neuropsychological Rehabilitation* 12(2): 97–110. DOI: <https://doi.org/10.1080/09602010244000020>
- WHO (World Health Organization). 2003. *The World Health Report 2003: Shaping the Future*. Geneva: World Health Organization.

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