

How do family members of individuals with spinal cord and acquired brain injuries make sense of their experiences: A qualitative study of meaning making processes

Anne Geard^{1,2}, Marit Kirkevold¹, Marianne Løvstad^{1,2}
and Anne-Kristine Schanke²

Health Psychology Open
January-June 2020: 1–13
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DOI: 10.1177/2055102920913477
journals.sagepub.com/home/hpo



Abstract

This study explores the processes that promote coping with abruptive life changes, often experienced as life before and after injury. The concept of meaning making, was used as theoretical framework for analysis. Family members of individuals with spinal cord and acquired brain injury participated in two focus groups three to twenty years post-injury. Data was analysed using thematic analyses. Two main themes were identified: drawing upon different coping strategies and balancing family needs against personal autonomy. Making sense of an altered situation was by keeping a positive outlook, making comparisons to worst cases, engagement in activities and making room for own needs. Thus, the study illustrates that life can continue in a good manner after adversities, but requires flexibility and adjustments.

Keywords

brain injury, family members, meaning-making, qualitative, spinal cord injury

Introduction

Spinal cord injury (SCI) and acquired brain injury (ABI) are often described as a traumatic or devastating event not only for the patient, but also their families (Boschen et al., 2005; Bulley et al., 2010). Both qualitative and quantitative studies have found that these consequences may be accompanied by emotional reactions, such as grief, distress and depression, but also by physical strain, communication problems and disruption of social life (Angel and Buus, 2011; Blake, 2008; Bulley et al., 2010; Buschenfeld et al., 2009; Charlifue et al., 2016; Dickson et al., 2010; Post and Van Leeuwen, 2012; Wray and Clarke, 2017).

Family members with a role as caregivers have reported some positive aspects of adjusting to life after an injury, such as feeling appreciated enhanced family cohesiveness and the experience of observing progress in the person with injury. Many people cope well with adversity. One study found that 48 per cent of family members of persons with SCI could be characterized as resilient in the initial year

after injury. Studies have also demonstrated that the medical severity of injury does not predict psychosocial adaptation. Rather, personal attributes such as optimism, and support from family and extended networks, are of major importance both for the patients and for the whole family (Bonanno et al., 2011, 2012; Charlifue et al., 2016; Elliott et al., 2014; Mackenzie and Greenwood, 2012; Quale and Schanke, 2010).

According to Walsh (2014) how persons adjust to the consequences of injuries includes how one makes sense of and endows the life changes with meaning. Meaning making is seen as the process of how people make sense of life events, relationships and the self (Gillies et al., 2014;

¹University of Oslo, Norway

²Sunnaas Rehabilitation Hospital, Norway

Corresponding author:

Anne Geard, Sunnaas Rehabilitation Hospital, Bjørnemyrveien 11, 1450 Nesoddtangen, Norway.
Email: anne.geard@sunnaas.no



Ignelzi, 2000) and is a multi-faced phenomenon. It consists of a positive psychological process that contributes to positive adaptation processes. Some studies highlight that meaning making might allow people to become more resilient, and can reduce the feelings of distress. However, for some people, failures to attribute meaning to an event may lead to more long-term distress and counteract adaptation (Bonanno, 2013; Davis et al., 2012; Webster and Deng, 2015). Furthermore, Hobfoll et al. (2007) point out that sometimes meaning is not to be found in cognitions but rather in how the person engages in behaviours considered meaningful.

Park (2010) highlights that there is a rich body of theory on how meaning making functions in adjustment processes, but that limited empirical research has been conducted. Meaning making is a complex phenomenon. One can experience suffering and at the same time gain strength to deal with life events. Jumisko et al. (2007) investigated family members' experience of meaning while living with a person with traumatic brain injury (TBI). The family members reported both a struggle with their own suffering, but also that hope and love from the person with injury, family and friends gave them strength. Ayres (2000) explored narratives of family caregivers to people with various impairments. The conclusion was that meaning making processes depend upon the use of earlier life experiences, personal beliefs about themselves and others, and selected action strategies in daily life. According to Steger and Park (2012), meaning can be global or situational. Global meaning is a general orienting system that provides people with a cognitive framework to interpret experiences, motivate actions and structure their lives. Global meaning comprises beliefs about the world, goals they want to achieve and subjective feelings of meaning that give their lives purpose and direction. An altered life situation, such as a severe injury, may challenge people's global meaning such as beliefs, career goals, relations and identity. Global meaning differs from situational meaning, which arises when people encounter distinct challenges or adversities, and try to comprehend and assign meaning to a new and unfamiliar situation. People typically attempt to assimilate revised beliefs and goals into their existing global meaning system in order to establish consistency between the appraised situational meaning and their global meaning (Steger and Park 2012). After a severe injury, mental, emotional and behavioural efforts applied to distinct everyday situations represent meaning making at the situational level. Sometimes, but not always, this will force through adaptations in more overarching and global belief systems.

Meaning making may be difficult to capture. The process is often unconscious and implicit (Park, 2010; Park and Ai, 2006). However, conscious reflection on underlying values or attitudes may be activated when serious health problems are experienced, and thus render them explicit to

the person and their surroundings (Krauss, 2005; Park, 2010; Park and Ai, 2006). Two studies have explored global meaning, in persons with SCI and stroke. They found no evidence that global meaning changed in the persons with SCI (Littooij et al., 2016b). In people with stroke, they found that there was a continuation of global meaning, but their worldview, identity and inner posture could be subject to change (Littooij et al., 2016a).

Meaning making and the concept of resilience share common features, both being conceptualized as an individual-centred phenomenon that may promote positive adaptation (Davis et al., 2012). Some studies highlight that meaning making occurs within the context of relationships (Chan, 2000; DeSanto-Madeya, 2006). This applies to resilience as well, as resiliency depend not only on personal attributes, but is an umbrella term referring to both personal, psychosocial and contextual factors in individuals and families (Bonanno, 2004, 2012; Luthar et al., 2000; Meredith et al., 2011; Park, 2010; Walsh, 2017). Gauvin-Lepage et al. (2015) noted that what promotes resilience in families in the context of physical trauma and constituted positive adaptation might vary across time. They underline how the ability some have to avoid viewing themselves as victims and to exert agency contributed to positive outcomes. In addition having self-compassion skills, being satisfied with relationships and being able to applicate situationally appropriate flexibility when needed may promote resiliency (Min et al., 2013; Parsons et al., 2016; Trompeter et al., 2017; Wai and Sin, 2014).

Few studies have highlighted both meaning making and resilience in SCI and stroke families. However, one study was found exploring sources of spirituality and family resilience in dyads experiencing an SCI. They illuminated that when the families spirituality was challenged, meaning making responses were linked to outcomes such as hope, connectedness to others and gratitude (Jones et al., 2018).

Patterson (2002), Benzies and Mychasiuk (2009) and Walsh (2017) underline that beliefs, values and convictions, being part of the global meaning system, may serve as protective factors and support resilient processes. In our culture, it is quite common to consider injury as a limiting factor of quality of life. After an injury, people often divide life in two, the time before and after the injury. Thus, it is important to explore the processes that contribute to coping with major life changes and 'bridging the gap between past and presence', where meaning making, which has been little studied, was used as a frame of understanding.

In summary, despite the body of theories on how meaning making is associated with adjustment and resilience, there is limited empirical research on this topic. Few studies have considered meaning making processes in family members of persons with SCI and ABI. How family members assign meaning to their experience and which aspects of their meaning making efforts appear to influence the

adaptation process after an SCI or ABI is of interest to the rehabilitation field.

Aims

The current study aims to explore how family members of persons with ABI and SCI in the chronic phase make sense of and adjust to living with an altered life situation. There is a need to expand our understanding of how meaning plays out in family life, and this study aims to explore this.

Methods

To explore the phenomenon of family members' meaning making in an altered life situation, we chose a qualitative research design. Polkinghorne (1988) makes a strong case for the centrality of narratives serving as meaning making efforts, and that the creation of meaning is an ongoing process, which gives purpose and direction to human affairs, and thus makes peoples' lives understandable as wholes. This is also emphasized by Josselson (2011), 'the stories that people tell about their lives represent their meaning making, how they connect and integrate the chaos of internal and momentary experience and how they select what to tell' (p. 224). Narratives are embedded in the form of stories or parts of stories people tell, how persons claim identities, construe their lives and try to live up to moral demands (Riessman, 2008).

The present study comprises two focus group interviews with family members of persons with SCI and ABI who told their stories of living with relatives with injuries. Focus group interviews are considered well suited to elicit narratives by examining and sharing ideas and experiences and give a deeper understanding of experiences and approaches to topics people have in common (Kvale and Brinkmann, 2015; Sørly and Blix, 2017).

Recruitment procedures

Sunnaas Rehabilitation Hospital sent a request to former patients and family members to participate in a qualitative study of resilience in families following SCI and ABI where the person with injury previously had been in patients admitted for rehabilitation. The mailed written consent form contained the study background, the interviewers' professional background and roles in the study, and the possibility to choose whether they wanted to participate in individual or group interviews. The inclusion criteria were being older than 18 years of age, for patient's competence to give their consent and that there were a minimum of 1.5 years post-injury in order to ensure sufficient experience with family life post-injury. If the injured person or family member was medically unstable, had major psychiatric disorders or extensive ongoing substance abuse, they were excluded (see Figure 1).

The sample

Table 1 presents the demographic and medical variables of the interviewed family members and the person with injury, where the table is made in order to preserve the participants' anonymity.

The interviews

One nurse and two psychologists conducted the two focus group interviews. The first and second authors interviewed the family members of individuals with SCI, and the first and last authors interviewed the family members of individuals with ABI. To ensure homogeneity within the focus groups, the interviews were conducted with family members of persons with the same diagnoses, SCI and ABI, respectively. However, including both diagnostic groups in the analysis provided an opportunity to explore meaning making processes across diseases.

Both interviews took place at Sunnaas Rehabilitation Hospital. The recorded interviews lasted, respectively, 90 and 105 minutes. The interview guide was semi-structured to give the informants an opportunity to talk about experiences of importance for themselves and their family, followed by these questions:

1. What changes in family life have you experienced?
2. What do you do to handle everyday life?
3. How do you support each other in the family?
4. How do you view the future in light of what you have experienced?

In addition, other reflections and themes were welcomed.

Data analysis

According to Krauss (2005), the researchers' role is to create meanings from the subtler aspects of narratives that may go unrecognized by the participants using a qualitative data analysis approach. A meaning making process is often of an implicit nature (Park, 2010). Therefore, data were analysed according to the systematic analytic frame of thematic analysis (TA) where the interpretative level requires examination of the underlying ideas, assumptions and conceptualizations of the themes mentioned in the participants' narratives (Braun and Clarke, 2006).

The analytic procedure started with listening to the recorded interviews. Next, a verbatim transcription of the digital voice recordings was established. To accentuate the essence of the two group interviews, repetitive fillers such as 'hm, aaa, hm' or 'no, no, no' were removed. In addition, expressions that directly or indirectly could identify the participants by such as name, where they lived and working place was replaced with XX.

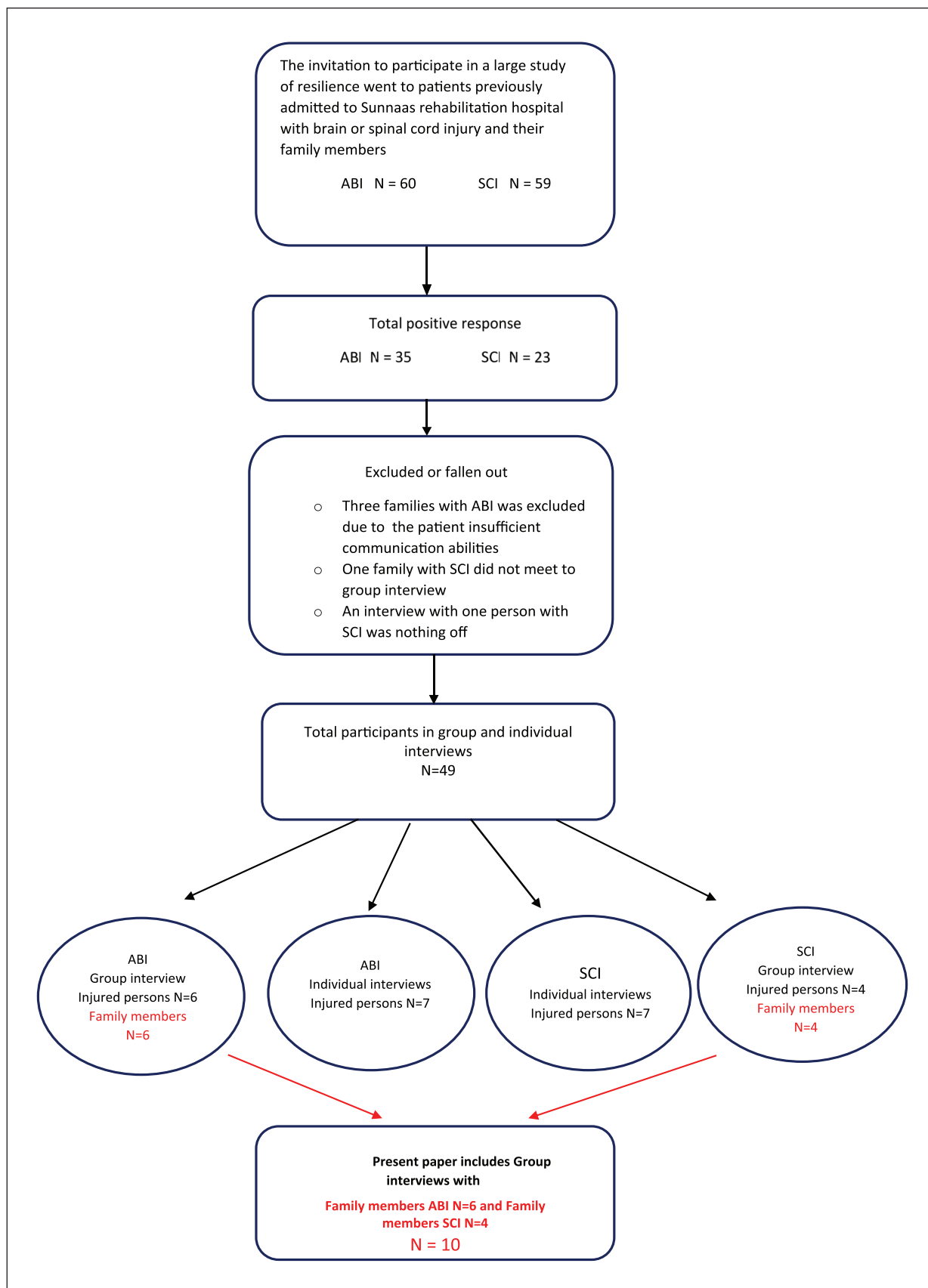


Figure 1. The recruitment process.

Table 1. Demographic variables.

Interviewed family members – SCI	Age	Work	The person with injury	Age	Work	Type of injury	Years since injury
2 Husbands 2 Wives	32–78	3 Fulltime 1 Retired	2 Wives 2 Husbands	31–76	2 Part time 1 Fulltime 1 Retired	2 Complete 2 Incomplete	4–20
Interviewed family members – ABI	Age	Work	The afflicted person	Age	Work	Type of injury	Years since injury
1 Mother 3 Wives 1 Male cohabitant ^a 1 Husband	42–68	3 Fulltime 2 Part time 1 Retired	1 Son 3 Husbands 1 Female cohabitant ^a 1 Wife	41–56	5 Disability pension 1 Part time	3 Stroke 3 TBI	3–13

SCI: spinal cord injury; ABI: acquired brain injury; TBI: traumatic brain injury.

^aCohabitant – having a romantic relationship but not married.

Furthermore, in the search of finding initial ideas, the text was repeatedly read, while extracting and noting sentences or paragraphs. Next, a detailed analysis of each interview was conducted to generate initial codes by searching for expressions of what may be signs of meaning making efforts, both implicit and explicit in nature. These codes sought to convey the essence of the description and examples included ‘it could have been worse’, ‘solution focused’, ‘be flexible’, ‘stay positive’, ‘take control’, ‘having strength’, ‘regain self-time’ and ‘move forward’. The next step was to collate the codes and then group them into themes, such as ‘creating a new daily life’, ‘personal autonomy’, ‘family needs’ and ‘feeling lucky’. Next, initial themes from both interviews were compared in the search for common themes. The defined shared themes included such as ‘strength surfaces when needed’, ‘being lucky’, ‘restructuring daily life’, ‘reconciling with the situation’ and ‘re-empowering the person with injury’. These themes were organized into two main themes and sub-themes as presented in the findings. The first author carried out the preliminary analysis and discussed the initial finding with the last author. Next, the transcribed interview was discussed with all of the authors where the results are reflected in the ‘Findings’ section.

Ethics

Participation in the study was voluntary, and the family members and patients provided written informed consent. In addition, the injured persons signed an agreement to their family member’s participation. The Regional Committee of Medical and Health Research Ethics of Southeast Norway (REK number 2012/1430) approved the study, and it was conducted according to the World Medical Association (2013).

Findings

The findings are presented through two overarching themes and nine subthemes that illustrate how family members

engage in meaning making efforts. First, ‘drawing on different coping strategies’ consists of five subthemes: downplaying the consequences of injury; keeping a positive outlook; making comparisons to worst cases; finding strengths within; and taking control through meaningful activities. The second theme was ‘balancing family needs against personal autonomy’ with the four subthemes: in search of a balance; making room for own needs; being motivated through relationships; and dealing with the necessary but upsetting need for professional assistance. These themes contain different strategies, such as accepting, wanting more or opting out of home care, the process of regaining personal space by safeguarding their own needs better by, for example, reinforcing and entrusting responsibility to the one with injury or the strong motivator as having something to go for.

Drawing upon different coping strategies

The family members were motivated to cope by drawing upon a range of different strategies they believed had influence on and improved their quality of life. Their exertion to cope implies that they used their conscious efforts to solve the challenges with the intention of mastering the situation. This involved downplaying the consequences of injury; keeping a positive outlook; making comparisons to worst cases; finding strengths within; and taking control through meaningful behaviours. When facing the injury-related challenges, they emphasized these strategies to variable degrees, and tried to solve their problems in a focused and persistent manner.

Downplaying the consequences of injury

Family members of both persons with SCI and ABI all described that they were confronted with and well aware of the painful realities of the injury. When downplaying the consequences they accentuated potentially positive aspects in order to minimize the negative effects of the disability.

They told that it was important to reduce the impact of the injury as much as possible and not give the injury too much space. This was in order to be able to make the most of life with disability, stabilize everyday life and reconcile with the situation. The family members described different approaches to do so. One husband, living with a wife with a complete SCI, told that

I did not focus on my wife's disability. I do not bother to worry about something that I cannot do anything about; being able to walk is only a small part of everyday life. (SCI 24b)

For others, even when painful, reconciling with the situation was a relief. When reconciling with the situation, the injury no longer was the only focus. A wife living with her husband with a complete SCI told,

The day it dawned on me that my husband would be sitting in a wheelchair, I got a lot better. I did not have to spend more effort and energy on hoping, believing and pondering over how to handle the situation. (SCI 7b)

Keeping a positive outlook

Having a positive outlook on the future appeared to be an active meaning making process and a way of approaching everyday challenges. Several family members underlined that it made sense to take each day as it comes, not ruminate too much about the past and not waste energy on what cannot be changed. They decided not to dwell on problems, and instead to highlight progress in the person with injury and 'manage the consequences together' (ABI 14b).

Family members expressed that exerting flexibility and positive thinking helped to stabilize family life and made it feel easier to deal with injury-related changes. A wife with a husband with a complete SCI expressed as follows:

I feel we have come to a place where we manage to do a lot. We have a cabin in the mountains, and since my husband depends on a wheelchair, it is a challenge with all the snow. Of course, there are some restrictions, but we will not let that stop us from going to the cabin. Besides, we have technical aids to make it easier. (SCI 7b)

Focusing on positive aspects instead of on problems was particularly challenging when experiencing severe consequences of an injury. In spite of this, thoughts were conveyed on the importance of looking for the positive: 'It is a little more difficult to find the positive' (SCI 7b), 'yes but you just have to find them' (SCI 4b). The mother of the young man living with severe stroke shared some thoughts regarding her outlook for the future:

My son can wake up in the morning and tell me, 'tonight I have been on a long hike up the mountain'. I think that it might be

positive with all he experienced when he was healthy. Now he can experience it again in his dreams. (ABI 21b)

Family members argued that looking for the positives was a shared responsibility, 'we must help lifting up one another when one of us experiences something to enjoy' (SCI 7b). A family attended a ski event for children for the first time after the accident. The husband was frustrated and only focusing on that he could not get out on the tracks with the children having to stay in the finish area in his wheelchair. His wife told how she tried to point to the positive sides of the situation:

It must be an amazing experience to finally see your kids skiing, getting to the finish line and get a prize. (SCI 7b)

A mother told that her son says he lives for his children but asks, 'What kind of a father am I? I cannot follow up anything of what they do'. She told that she responded by focusing on all that he could do that made sense:

Then I said yes, but you are with them and can look at them and you can talk to them, you can praise them and say such as this and that. (ABI 21)

In a more implicit way, another example of positive thinking was illuminated when injury-related changes had to be accepted. A man accepted the fact that he no longer could pursue his own need for structure the same way as before. His cohabitants (the person he lives with in a romantic relationship without being married) stroke caused no physical consequences, but resulted in struggling with remembering, being much more unstructured, and the inability to work. This affected how their home environment appeared and was especially challenging with many children in the family. Even if challenging his preferences for structure, he expressed his basic value that one must accept that things change. He meant that it was a necessity to reconcile with the situation to achieve a best possible everyday life. He also made sense of how the family in this specific situation fits into a broader context of life:

We must simply acknowledge being a slightly different family. We must accept that there is a little more chaos and a little messier than at the neighbours'; it just has to be that way. (ABI 9b)

Making comparisons to worst cases

Another approach appraising the situation positively, was reporting reasons for feeling lucky. This was an often-used phrase among the family members when comparing something that could have been worse. They talked of it as a survival strategy conveying hope for, or optimism about, a chance of a positive future. This may be one way of not letting the situation become too overwhelming. It also seemed

that enhancing reasons for feeling lucky was an attempt to promote positive emotions in the family. A wife of a person with SCI expressed, ‘he received excellent first aid that fortunately prevented the worst-case scenario of losing my husband’ (SCI 8b). Another young wife with toddlers and a husband with a complete SCI felt lucky when ‘being able to stay together as a family when hospitalized’ (SCI 7b). Other talked of feeling lucky when an injury to the brain gave fewer consequences than feared, as a wife told, ‘we are lucky that my husband can walk and only struggles with concentration and finding a new identity’ (ABI 14b). The husband of a wife facing many limitations told, ‘luckily, she can use her mobile phone to stay connected’ (ABI 6b).

Both a young and an older husband established a narrative where they felt relatively lucky since all could have been worse, after all. The meaning making process, however, and the role it plays in their adjustment process, probably has some common characteristics even when the life situation differs. For the older husband where surgery had left his wife with a severe SCI, the reality was that much in their life was in order. This included a good life with children and grandchildren. He felt lucky being older, which he felt gave a different perspective on life compared with those being younger:

You get a broader perspective on things when you get older. It became necessary to move from our house and we were lucky to find an apartment in the same area we had lived for 40 years, where our many friends also live, something that I think is very important, as they take care of us and we them. (SCI 4b)

The young husband and his wife were new sweethearts when the accident occurred where she got a complete SCI. They had to make important decisions that were crucial to the future such as whether they should continue to be a couple. The husband told that he felt lucky because he was still young and strong enough to carry her and was given the opportunity to mould their future life plans according to the needs provided by the injury:

We are lucky because I am much bigger than my wife is, so I can carry her when needed. It would have been difficult if it were the opposite. I also believe that we were lucky when building our new home and thus being able to customize the house to our own needs. (SCI 24b)

Finding strengths within

Another way of handling the consequences was how the family members established narratives in which they saw themselves as being strong. They defined having what it takes to cope and approached the challenges with the belief that people have strengths that surface when needed. In a dialogue among family members experiencing an SCI, they all stated that being in this specific stressful situation made

it clear to them that they possess resources in the form of strength that previously was not obvious to them:

Although we have different backgrounds, we have much of the same experiences (SCI 7b). What one finds out is that people are quite strong after all (SCI 4b). That is exactly how it is (SCI 8b). We manage what we have to manage (SCI 4b). Yes, there is something about when it becomes a reality (SCI 8b). Yes. It is as if you have no choice (SCI 4b). Yes (SCI 24b). Yes, that is how it is (SCI 7b).

The participants illustrate a meaningful, and to them, somewhat surprising realization that emerged from the situation caused by the injury. It was an expression of acknowledging that you can handle stressful situations, beyond the scope of earlier experience. Believing in having the strength to fight the injury-related obstacles was also talked of in a more implicit way as ‘taking it step by step’ (ABI 2b, 14b) and ‘we are focusing on here and now’ (SCI 4b, 7b).

Some ABI family members approached their challenges by showing strength through their activities that was needed to stabilize everyday life. One wife told that she was the one keeping her husband’s spirit up and that ‘one must be resourceful to get what one needs’ (2b). A husband told, ‘I got many new tasks that was demanding but still I handled it well’ (6b). Some family members struggled more, such as the mother of the son with a stroke, who in addition took care of the whole family’s needs. She implicitly demonstrated her strength by sustaining a sense of meaning as a supporter and when attempting to accomplish valued goals, such as securing a good life for her son:

I am the anchor and the driving force in protecting and supporting the whole family. I will challenge the community service as long as needed to secure adequate help for my son. (ABI 21b)

Taking control through meaningful activities

The process of making meaning was sometimes more evident in how the family members responded to the challenges and their choice of being engaged in different meaningful activities. Their efforts included such as organizing and maintaining a daily rhythm, and doing nice things that felt meaningful: ‘we went to the opera as soon as possible after the injury, because we love it’ (4b). Keeping up meaningful content in life within the family, the social relations and preferred activities was of importance. A wife told that their recreational activity before the injury was skiing. Regaining the activity had taken time, but her husband’s condition improved and now the couple enjoyed skiing together:

We loved skiing together before. It has been difficult to encourage him to go skiing because he was scared due to his balance problems . . . However, this year I noticed a change.

He actually got more balance . . . he is very good at exercising and now we can go skiing together again. That I did not believe would happen. (SCI 8b)

They told how they took control by creating ‘a new chapter in life’ (ABI 2b, 6b, 14b) when bridging the gap between the old life and new life with disability, and making the best of it.

The family members expressed their beliefs of possessing capability to take control and create these necessary bridges to adjust. One wife expresses that

My husband has lost some of his identity, as he no longer can keep his work for over 30 years, but we are working towards new common goals so I believe that it will work out well. (14b)

They also tried to achieve emotional control by regulating their feelings towards the consequences of injury. One wife told that

It has been a long journey with many emotions due to the brain injury being a complicated terrain to understand. It was an important process to acknowledge and accept that life is as it is.

Balancing family needs against personal autonomy

Over time, the family members had come to terms with the inevitable need to safeguard their own personal autonomy alongside family needs. Their initial appraising of meaning of the event was for a long period enmeshed in showing commitment to the one with injury, solving practical challenges and providing support. This was described as emotionally challenging, and they thought of it as an imbalance between the focus on the person with injury and their own needs. The family members described their effort in balancing family needs against personal autonomy, as both a search of a balance and making room for own needs. Furthermore, how they were being motivated through relationships and how some dealt with the necessary but upsetting need for professional assistance.

In search of a balance

A common sentiment that described the imbalance in family life was ‘everything has been about my wife’s problems for a long time’ (ABI 6b). In addition, a young wife of a man with memory problems after a TBI described that she used so much energy on trying to compensate for his cognitive problems that she started forgetting herself:

I forget my own things because I have to double check everything my husband does. (ABI 12b)

To make sense of the situation, they expressed thoughts about recapture a better balance in family life. The family

members showed important skills that improved their concern for themselves. They believed that they needed to include better their own needs as family members, but it also involved extending the focus back on the family as a whole. They re-empowered the person with injury by handing over responsibility. Making demands was about facilitating and promoting a feeling of mastery in their partners and restoring equal roles. One wife recounted how her husband with an SCI often said, ‘I am in a wheelchair, and I can’t do that so, you have to’. His wife illuminates a meaning-based coping strategy when cognitively changing her interpretation of the situation from ‘doing for’ to challenging her husband:

So, I have become a bit stricter towards him. He manages to do much more than he thinks himself. Clearly, there are limitations, but he must contribute with things he can do. When he feels that he has mastered something, such as helping the kids brushing their teeth, it feels like a big relief to me . . . I see that it benefits us all. He is proud when he has been alone with the kids. (SCI 7b)

A husband told that he did what he could for his wife but

It is not durable in the end. You have to make demands. Otherwise, you go under yourself. (4b)

In the process of finding a balance, two of the wives expressed their belief in fighting against role changes. They emphasized the importance of not seeing their spouses as patients but as the person, they are. Furthermore, to hold on to the relationship as a couple, not just by helping,

I think it is important to see him as more than just a patient. He is, for us a lover, a father, a brother, a son, etc. (7b)

Must not look at him as a patient. After all, it is my husband. It was a different role and I am trying to . . . not make it our relationship. (2b)

Making room for own needs

Most of the family members found it difficult to safeguard personal needs up against meeting family needs. The approaches varied on how they made sense of and solved these problems. When family members were to balance their autonomy, they found it sensible to create physical and mental spaces. A wife with a husband with a brain injury concluded, ‘I can’t look after the whole world, but I work intensely with myself, to admit that I can’t look after everyone’. She also integrated the stressful situation by signing up for group meetings for family members to get attention and mutual understanding. For her, it made sense talking with others (ABI 14b). Other ways included making room for nourishing their own needs, for example, taking

‘trips with girlfriends’ (SCI 7b, 8b) or ‘fishing with buddies’ (ABI 9b). A wife told that

I’ve started to take some of those rooms back both physically and mentally. I travel to our cabin to write for a week, all by myself. (2b)

Being motivated through relationships

Several family members thought that having something to go for was a strong motivator, where, for example, both children and grandchildren were described as being essential in meaning making processes in everyday life. Taking care of the children is an important common action in a family and focusing on the children made sense:

Of course, I spent an incredible amount of effort on being positive, on being up and going. It was primarily for the kids because they have been the most important thing from day one. (7b)

I think it was an inspiration to my wife that we had ten grandchildren, because she decided very early on that she would not become a grumpy, old grandmother in a wheelchair. It was simply something to go for. (4b)

Another motivational aspect was that they wanted to support family members out of love. A young wife expressed that

I felt sorry for him, he was not an old person when the accident happened and that it was when life was supposed to begin. We had two young children and just built a house. (7b)

Dealing with the necessary but upsetting need for professional assistance

The family members shared their thoughts on both practical and emotional concerns about such as securing family routines, privacy and independency. In the process of making sense, all participants were weighing the family needs for professional assistance against their own reluctance towards receiving help. To find meaning in this specific stressful situation was described as difficult when it intervened with family life. It collided with what they wished to maintain or may have had as a desired outcome. They based their reluctance on the feelings of losing control, feeling invaded, interference with family routines and having strangers in their homes. The need for professional assistance varied, and some opted out by doing the practical chores themselves, although it ‘felt like a triple job’ (ABI 9b). The young wife with a husband with a complete SCI told that they decided to manage without help because receiving help was upsetting for the children and that it did not feel right for their family:

In our situation, the fewer strangers we need to let into our home (laughs), the better it is. The kids wondered who they were . . . I thought it was very difficult. I do not know how much a housekeeper, for example, had helped me either . . . but we have a family that has been very helpful . . . Especially my mother, she has seen my needs. (SCI 7b)

Depending on healthcare professionals was experienced as difficult also by others, involving strong feelings of being invaded by home care personnel and ‘personally experiencing a period of being in a deadlock’ (ABI 6b), due to losing privacy and control in his own home. One husband with a wife with an incomplete SCI told it was a process to accept and collaborate with the professionals. They had to learn to relate to home care, to function as a family in everyday life, despite being reluctant:

I thought it was intolerable in the beginning when strangers were coming into our home and into the cupboards getting towels (laughs). The people coming are nice and helpful and eventually we have gotten used to the fact that this is how it is. You have to be cooperative to get to this point. (SCI 4b)

On the other hand, one family was in the situation of fighting for adequate professional assistants for their son. Their son lived alone and the more adequate help, the easier it was both emotionally and practically for his parents. His mother told that

He needs help from professionals, we are elderly and do not know for how long we can take care of him. (ABI 21b)

Discussion

The present study explores how family members of individuals with SCI or ABI engaged in meaning making processes with a focus on what both groups emphasized as promoting adjustments in their families. The family members all confirmed that some of the negative consequences had been or still were present, confirming knowledge that has already been highlighted in both qualitative and quantitative studies (Angel and Buus, 2011; Blake, 2008; Dickson et al., 2010; Post and van Leeuwen, 2012; Wray and Clarke, 2017).

However, the family members also told of what had promoted positive family adaptation. They highlighted the need to be flexible in order to find the best possible solutions to challenges in everyday life. According to Bonanno (2013), people need to be flexible in the deployment of coping strategies for effective coping when facing various types of situations. The mental strategies described by the participants illustrate their efforts to deal flexibly in order to maintain a positions as active and solution-focused agents, and to be able to persevere in dealing with their family situation. The ways in which the family members

made the most of life with a disability by downplaying the negative effects and feeling lucky illustrate a capacity for mental flexibility.

Refraining from negative rumination over a situation is a positive cognitive mechanism, which mediates resilience (Wai and Sin, 2014). Expressions such as ‘not ruminating about the past’ were one way family members substantiated their belief that staying positive and downplaying negative effects were important.

The interviews comprised families in different situations regarding age, diagnosis and physical and cognitive sequelae. However, the family members displayed common ways of creating meaning such as believing in a need to reconcile with the situation. This is consistent with resilience research showing that strategies to ‘make the best of it’ are common among humans faced with adversity. Sales et al. (2013) and Walsh (2017) highlight the importance of the way in which one makes sense of adversities. They underline that a reconciliatory approach includes the propensity for adjustment by restoring a state of normalcy that serves as a buffer against resignation and helplessness.

When emphasizing positive aspects of the situation, one stance taken by the family members was that they felt lucky. This did not include ascribing positive meaning to the disability itself or to the change in family life, but rather, that it could have been worse. This is consistent with Wiseman (2004), stating that people who feel lucky might contribute to their own good fortune by envisioning how things could have been worse, by not dwelling on negative events and by taking control of the situation. This perspective overlaps with the perspectives of meaning making. Furthermore, creating one’s own perception of luck requires various skills, such as creating self-fulfilling prophecies via positive expectations, and making lucky decisions. Belief about being lucky is also part of our global meaning (Park, 2010; Steger and Park, 2012). Some family members felt lucky as they accentuated positive qualities such as receiving excellent first aid services that had prevented the death of their family member. Again, this perspective has common features with resilience theory, underlining that strong positive value and conviction constitute protective factors, which in turn promote resilient trajectories (Benzies and Mychasiuk, 2009; Patterson, 2002; Walsh, 2017). The family members probably show an underlying propensity to value the positive aspects of life through statements such as ‘feeling lucky’. The tendency to perceive themselves as lucky might also be interpreted as a cognitive emotion regulation strategy, where focusing on positive reappraisal helps promote resilience (Min et al., 2013).

Another important finding was entrusting responsibility to the one with injury to promote independency and restore equal roles. This is a deliberate process described as meaning-related strategies by Park (2010). The strategies could be beneficial for both the family member and the injured person because they address both practical and emotional

issues and promote coping and sharing of responsibility. The study exploring sources of spirituality found that meaning making responses were linked to outcomes such as connectedness to others (Jones et al., 2018). This has similarities to findings in the present study even if the family members did not explicitly accentuate spirituality, for example, when they described being motivated by close relationships.

In addition, the family members used different meaningful behavioural strategies to deal with challenges such as organizing and maintaining a daily rhythm and make the best of life. This is consistent with Hobfoll et al. (2007), pointing out that some find meaning by engaging in behaviours considered meaningful. According to Bonanno (2013), Davis et al. (2012) and Webster and Deng (2015) meaning making allows people to become more resilient and can reduce the feeling of distress and may promote their effort in making the best of life.

The above-mentioned strategies also illustrate similar results to those of Ayres (2000) who highlighted that in a meaning making process, family members select action strategies as organizing daily activities, anticipating caring obligations, setting priorities and managing their own affective reactions. The findings show family members engagement in meaning making efforts related to how they adjust to changes in family life. How they make sense of and endow their life changes with meaning includes such as what they believed in and what they thought was important to focus on. This was found in cognitions about meaning and in how they engage in behaviours considered meaningful. The family members did not directly express or indirectly show specific signs of that their global meaning had changed. This relates to studies by Littooij et al. (2016a, 2016b) showing no evidence of changes in the global meaning in persons with SCI. Further, among people with stroke, there was a continuation of global meaning, although their worldview, identity and inner posture could be subject to change.

Limitations and strengths of the research and further development

The present study comprised two focus group interviews with 10 informants. The limited number of participants may affect the generalizability of the findings; however, the interviews provided a varied and diverse material that contributes to illuminate important issues regarding meaning making processes in families that live with the chronic consequences of physical and cognitive injuries.

We acknowledge that this study only reflects the family members’ perceptions of family life after an injury, for example, when they feel that there have been improvements allowing normalization of activities. We do not know how the injured person would have responded, or whether this development was actually perceived as improvement on the injured person’s behalf.

To analyse the interviews, we have used TA and acknowledge that while the methods benefits from being flexible, TA may also lead to inconsistencies in the way themes are established due to lack of an inherently theoretically based analytic language (Braun and Clarke, 2006). Gauvin-Lepage et al. (2015) noted that what promotes resilience in families in the context of physical trauma and constituted positive adaptation might vary across time and thus longitudinal studies are warranted. In the present study, a cross-sectional design has been used, but the strength is that the families have three to twenty years of experience living with the consequences of injury. In addition, Bonanno (2013) states that qualitative data may offer a ‘valid window into the process of resilience even with a cross-sectional design’ (p. 150). It would also have been interesting to interview families from the two diagnostic groups together to explore if direct exchanges of experiences between family members of individuals with ABI and SCI would further elucidate commonalities and differences related to aetiology.

A strength of this study is that it highlights what may contribute to positive outcomes in family members of persons with both SCI and ABI, information that is sparse in the existing literature. The study also has theoretical and clinical implications that can inform rehabilitation staff of meaning making processes and help establish interventions for families living with injury-related consequences. It is important that clinicians understand that people establish a coherent set of meanings and belief systems after a critical life situation, because this is essential to their adjustment over time.

Conclusion and clinical implications

The study brings knowledge about how family members make sense of their experiences with family life in the chronic phase of severe injury. The family members’ stories illustrate how they make the best of a changed life situation and establish a balance in the family. This requires agency and decision making to the best of the unique family systems involved. To explore the concept of meaning making offers a window to the understanding of human mastery and adaptation. In addition the concept has relevance for clinicians knowing that meaning making processes in the family members may support adjustment for the family system. In the acute and early rehabilitation phase, injured persons and their families often report that it feels like their life has been ‘divided in two’, one before and after the injury. However, the present study shows that over time, life somehow tends to “bridge the gap” between the past and the present, although things continue to be different. This is also paramount for healthcare professionals to be aware of as they often see the patients primarily during the acute and post-acute phase. Thus, it is important with evidence-based

knowledge that can encourage healthcare professionals to tell families that there is a hope and that many things will fall into place in their lives, although it may take several years. In this way, health professionals can contribute more strongly to promote long-term resilience and adaptation.

Acknowledgements

The authors are grateful to all the family members who participated in the research by participating in the focus group interviews. The authors would also like to thank the collaborating staff at Sunnaas Rehabilitation Hospital for help with participant recruitment.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Personskadeforbundet LTN and the Norwegian Extra Foundation for Health and Rehabilitation supported the study through EXTRA funds (grant no. 2015/FO5572).

Related presentations

There have been no previous presentations of this paper.

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