Resilience and Healthy Family Adjustment in Face of Spinal Cord Injury

Exploring adjustment in a physical rehabilitation population

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Man is more than his private body.

Man is also his soul and herd.

Per Fugelli (in press)
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Oslo, November 2015
Abstract

Background. Patients living with prolonged severe physical injuries and their close family members are commonly confronted with major requirements of long-term adjustments to a myriad of post-injury changes. A substantial amount of clinical research is dedicated to assess and document increased risks of shortcomings and pathology due to the altered life conditions. However, approaches investigating resilience and positive adjustment are increasingly recognized as useful within the physical rehabilitation psychology field. Objective. The purpose of the present study is to explore long-term processes of resilience in face of a spinal cord injury within a family context. Methods. Six qualitative in-depth interviews and two focus groups were conducted with a total of 14 participants. The narratives collected were thematically analysed. Results. Narratives illustrating family adjustment and resilience were categorized into three broad themes: (1) Individual strengths, (2) Relational flexibility, and (3) Contextual influence. Findings support previous notions about the complexity of the resilience phenomenon, and additionally add new aspects to the operational definitions by emphasizing relational flexibility and the qualitative investigation of resilience as potentially useful for the future. Empirical considerations, operational definitions, and implications are discussed.

Keywords: resilience, family, long-term adjustment, physical rehabilitation psychology, spinal cord injury
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**Introduction**

Few incidents in life are believed to be as critical to human beings as the acquirement of a severe physical injury. Representing periodical or permanent loss or abnormalities in motor and sensory functions, spinal cord injuries (SCI) are recognized as one of the most severe injuries to be experienced (Bill & Harkins, 2003, Yu Chen & Boore, 2008). SCI patients are commonly confronted with major requirements to adjust to a myriad of physical, functional and medical changes (e.g., Richards, Kewman, Richardson, & Kennedy, 2010). Moreover, a substantial amount of investigations are based upon the premise that SCI constitutes increased risks of psychosocial maladjustment and levels of psychopathology due to its typically prolonged and life-changing course of nature (Craig, Perry, Guest, Tran, & Middleton, 2015; Hoffman, Bombardier, Graves, Kalpakjian, & Krause, 2011; Holtz & Levi, 2006; Post & van Leeuwen, 2012). Arguably, SCI *is* life-altering. Patients indeed report higher average tendencies of emotional and psychological struggles post injury compared to healthy controls (e.g., Agar, Kennedy, & King, 2006). However, a growing body of research has consistently revealed underlying distributions illustrating individual response variances in face of SCI. Moreover, trajectories of resilience characterizes the majority of responses (e.g., Bonanno, Kennedy, Galatzer-Levy, Lude, & Elfström, 2012; Post & van Leeuwen, 2012; Quale & Schanke, 2010). While the majority of clinical research has been preoccupied with assessing shortcomings and pathology, an emerging amount of researchers argue the usefulness of investigating positive processes and healthy adjustments in post-injury life (Bonanno, 2012; Quale & Schanke, 2010; White, Driver & Warren, 2008). The present thesis investigating life in face of SCI acquirement is compiled within a resilience approach.

**Spinal cord injury**

Caused by external physical trauma or non-traumatic circumstances (e.g., surgical failures), SCI involves one or several spine lesions impeding sensory and motor signals to cross the sites of lesions. Depending on localization and extent of injury, approximately two-thirds of SCI patients worldwide are *paraplegic*, a condition affecting both legs, whereas the remaining third experience muscle paralysis and loss of sensation and bodily function in legs and arms (*tetraplegia*) (Maynard et al., 1997; Wyndaele & Wyndaele, 2006). SCI is classified due to neurological levels of injury and could occur as periodical (*incomplete*) levels of muscle
paralysis, and loss of sensation and body functions, or permanent \textit{(complete)} conditions (Kirshblum et al., 2011; Kraus, Franti, Riggins, Richards & Borhani, 1975). Epidemiological studies indicate that young males statistically dominate the population of traumatic injury acquisition, also reporting motor vehicle accidents to represent the most stable common cause, followed by falls, sport accidents and violent acts, respectively (Bill & Harkins, 2003; Ho et.al, 2007; Bill & Harkins, Wyndaele & Wyndaele, 2006).

Although insufficiently studied in non-traumatic conditions (New, Cripps, & Lee, 2014), incidence rates are argued to be overall increasing worldwide (Furlan, Sakakibara, Miller, & Krassioukov, 2013; Wyendale & Wyendale, 2006). Moreover, recent Norwegian data supports these international tendencies (Halvorsen & Petterson, 2015). Moreover, due to considerable improvements in medical treatment in previous decades, the rate of long-term survival has increased, and thus more people live prolonged lives with severe bodily impairments such as SCI (Ma, Chan, & Carruthers, 2014). Considerable prevalence variances are documented across geographical regions worldwide, identified to range from 227 to 526 persons per million inhabitants across Scandinavian countries (Furlan et al., 2013). In Norway, SCI prevalence is estimated to be 36.5 per 100 000 inhabitants and overall increasing (Hagen, Eide, Rekand, Gilhus, & Grønning, 2009). However, although medical treatment has improved, SCI still represents a myriad of life-altering consequences. In addition to prolonged physical impairment, the elevated risk of medical comorbidities and secondary afflictions adding prominent complexities in the patients’ lives are emphasized (e.g., pain and pressure ulcers: Richards, Waites, Chen, Kogos, & Schmitt, 2004; and dysregulations in body temperature: Karlsson, Krassioukov, Alexander, Donovan, & Biering-Sørensen, 2012). Moreover, increased risk of suicide and fatalities due to lung-, cardiovascular-, and urinary diseases are documented in the population (Lidal, 2010).

Risk and vulnerability. The exposure to psychological trauma and adversity is frequently associated with outcomes of psychopathology. A significant amount of research documents that individuals who survive life-threatening circumstances are particularly vulnerable to posttraumatic stress disorder (PTSD) (e.g., Hapke, Schumann, Rumph, John, & Meyer, 2006). Thus, factors believed to put individuals at risk for post-adversity maladjustments have been extensively studied. Commonly, the characteristics of the adverse circumstances, history of pre-morbid mental health problems, female gender, and lack of social support are highlighted
Similarly, a physical trauma to the spine is predominantly associated with abnormal levels of psychological morbidity, substance abuse, and risk of suicide (Craig, Tran & Middleton, 2009). Cross-sectional studies consistently report PTSD to be more prevalent in the SCI population compared to controls, representing 10-40% of patients across studies (Agar et al., 2006; Hatcher, Whitaker, & Karl, 2009; Kennedy & Duff, 2001; Krause, Saunders, & Newman, 2010; Lude, Kennedy, Evans, Lude, & Beedie, 2004; Nielsen, 2003). Increased prevalence ratios for symptoms of a depressive disorder (Arango-Lasprilla, Ketchum, Starkweather, Nicholls, & Wilk, 2011; Dorsett & Geraghty, 2004; Hoffman, Bombardier, Graves, Kalpakjian, & Krause, 2011; Saunders, Krause, & Focht, 2011) and other types of psychopathological comorbidity (Agar et al., 2006; Hatcher et al., 2009) are also argued to put the individual at prolonged psychosocial risk. Arguably, facing chronic bodily impairments are believed to challenge one’s efforts to adapt psychologically, as personal identity, occupation, finances, social roles, and future life goals are often seriously challenged (Craig et al., 2015; Crewe, 2005; Martz, Livneh, Priebe, Wuermsen, & Ottomanelli, 2005; Schanke, 2004; Charlifue, Lammertse and Adkins, 2004; Lidal, Huynh, Tuan, & Biering-Sørensen, 2007). This is echoed in subsequent longitudinal studies investigating long-term psychosocial issues, commonly highlighting negative impacts of cultural values and beliefs about trauma and disability (Bonanno, 2004; Quale & Schanke, 2010; Schanke, 2004; Dunn, Uswatte, & Elliott, 2009). Thus, a growing amount of studies puts psychosocial aspects of post-discharge life in a significant longitudinal position. However, whereas the majority of research and “outsider” beliefs tend to emphasize SCI as potentially devastating to the lives of people involved, persons inhabiting the “insider perspective” often tend to find themselves surprised by their ability to adjust to the physical and environmental changes. Hence, when meeting a myriad of thresholds and challenges when living with persistent physical disabilities, a majority of people also experience that living a relatively normal life is possible (Dunn et al., 2009; Quale & Schanke, 2010). This diversity in perspectives and findings stresses the importance of exploring resilience within patient groups admitted to physical rehabilitation (White et al., 2008).
Resilience: development and core characteristics of the construct

As opposed to the branch of research focusing on psychopathology, resilience researchers investigate processes fostering healthy adjustments and positive adaptations across contexts of adversity (Bonanno, 2004; Luthar, 2006; Masten, 2001; Richardson, 2002). Despite a substantial lack of operational consistency within the field, the majority of resilience researchers today consider resilience to involve interactions of (1) individual psychological and dispositional attributes, (2) relational factors such as social support, and (3) external support systems (Rutter, 2012; White et al., 2008). The majority of empirical research has primarily investigated resilience by identifying aspects within individual dimensions.

Personal factors. Initially attention to the resilience phenomenon evolved several decades ago, as developmental researchers observed that children growing up in high-risk circumstances showed surprisingly high capacities of psychosocial functioning in adult life. To explain why some children adjusted better than others, the majority of researchers and clinicians draw attention to certain personality characteristics believed to serve as protective and promotive factors (Luthar, Cicchetti & Becker, 2000; Masten & Coatsworth, 1998). Thus, previous literature has commonly defined resilience as a personality trait, appearing as a relatively stable intrapersonal characteristic over time, subsequently affecting individual levels of adaptation to environmental difficulties (Masten, 2011). Over decades of empirical investigations, researchers have debated whether or not resilience as a theoretical construct should be considered as a stable trait (trait resilience) or as dynamically changing processes or outcomes (Luthar et al., 2000). As researchers further on have gained interest in resilience within adult populations, discussions of operational definitions have subsequently increased (Bonanno, 2012; Bonanno & Diminich, 2013). Reflecting the lack of consistency in operationalizing the resilient construct, researchers have defined resilience in different ways, such as the ability to flourish in face of adversity (Connor & Davidson, 2003), or as an internal motivation force (Richardson, 2002). Accordingly, resilience represents a psychological term holding different assumptions that potentially affect conducted research (Bonanno, 2012; Flechter & Sarkar, 2013). Bonanno (2012) suggests personality represents one of several important key factors in resilience, and defines the phenomenon as:

The ability of adults in otherwise normal circumstances who are exposed to an isolated and potential highly disruptive event such as threat of a close relation or a violent or life-threatening situation to maintain relatively stable, healthy levels of psychological and
physical functioning . . . as well as the capacity for generative experiences and positive emotions” (Bonanno, 2004, p. 20–21).

Thus, empirical efforts have been put forward to identify personality resilience, commonly associated with high levels of extraversion and openness, and lower levels of neuroticism (e.g., Sarubin et al., 2015; Schneider, Rench, Lyons, & Riffle, 2012; Zeb, Naqvi, & Zonash, 2013). However, trait resilience is argued to represent one of many pieces to the puzzle (Bonanno & Diminich, 2013). Thus, a growing body of research is compiled to investigate the more complex and dynamic utilization of personal capacities fostering resilient outcomes. In this, resilience as a process refers to the dynamic interactions of forces at play during circumstances characterized as adverse, whereas the positive adaptation in face of the process is typically described as the resilient outcome (Fletcher & Sarkar, 2013). In their review of previous resilience research, Bonanno and Diminich (2013) emphasize several personal dimensions believed to add pieces to the resilience puzzle in dynamic ways, such as the display of positive emotions. Empirical studies have documented associations between positive emotions and positive adjustment across adverse contexts (Papa & Bonanno, 2008; Fredrickson, Tugade, Waugh, & Larkin, 2003), emphasizing the positive aspects of emotional attributions, such as positive emotions, positive attitude and humor. Moreover, research has emphasized important cognitive processes related to self-perception, including self-efficacy (SE) and self-esteem. Whereas self-efficacy is commonly associated with one’s perceptions of competence and capability to negotiate with a variety of challenges effectively (Bandura, 1977), self-esteem refers to more enduring self-ascribed value fostering positive self-perceptions and increased feelings of self-worth (Ziegler-Hill, 2011). Cross-sectional and longitudinal studies have previously demonstrated strong positive correlations between coping self-efficacy and psychosocial adjustments in face of adversity (Benight & Bandura, 2004). Moreover, empirical efforts have been put forward to investigate general self-efficacy, associated with a generalized perception of agency across contexts. Quantitative studies have documented that this generalized agency are negatively related to levels of anxiety, PTSD and depression, and positively associated with levels of optimism and social support (Lusczynska, Benight, & Cieslak, 2009; Scholz, Gutiérrez-Doña, Sud, & Schwarzer, 2002). Levels of self-esteem have correlated negatively with levels of depression and anxiety (Baumeister, Campbell, Krueger, & Vohs, 2003; Ziegler-Hill, 2011). Previous research indicate that individuals with low self-esteem tend to develop strategies
that is more associated with self-protection and subsequently decreased levels of self-esteem, whereas high self-esteem tend to influence strategies building on potentials and feelings of self-worth, such as self-enhancement (Ziegler-Hill, 2011). Thus, high levels of general SE and self-esteem is considered to have positive impact on cognitive appraisal.

Previous reviews have also considered optimism to foster such as positive emotions, well-being, perseverance, and motivation in contexts of facing challenges in life (Peterson, 2000). Moreover, by adding a positive explanatory style for past events, optimism is defined as cognitive processes of recognizing positive outcomes (Peterson, 2000). Literature has also considered hope to represent positive beliefs about expectations and fulfillment in future life. Snyder (2002) defines it as: the perceived capability to derive pathways to desired goals, and motivate oneself via agency thinking to use those pathways (p.249). Although representing potential conceptual overlaps with other psychological constructs (e.g., optimism and self-efficacy), the literature has noted that hope represents a unique construct due to its agency and emotional components (Snyder, 2002; Arnau, Rosen, Finch, Rhudy, & Fortunato, 2007). Empirical data commonly report hope to serve as a buffer against depression and anxiety in various contexts, although findings are also argued to have less longitudinal effects (e.g., Arnau et al., 2007).

However, Bonanno and Diminich (2013) argue that previous literature have had a tendency to emphasize both how optimism have involved the abilities to minimize impact of adversity exposure, other researchers have additionally emphasized the importance of facing the impacts to adapt successfully. Thus, they argue that individuals who manage to flexibly change their coping styles and emotional expressions in accordance with situational demands also report lower levels of distress compared to more rigid individual. Psychological flexibility involves capacities to change behaviors and strategies to subsequently optimize responses temporally and across contexts. They additionally distinguish between coping and expressive flexibility, the latter referring to the capacity to up-regulate and down-regulate emotional expressions. Rather than considering adaptive emotional regulations as superior to emotional suppression, researchers have revealed the healthy benefits of regulating emotional expressions. Moreover, empirical investigations have made associations between expressive flexibility and resilience, documenting the capacity to foster low and stable levels of distress and positive health and well-being (Bonanno & Diminich, 2013).
Ordinary magic. By taking new approaches of quantitative data collection and analysis, Bonanno and associates have consistently revealed four prototypical trajectories of longitudinally adversity outcomes, subsequently reporting patterns of resilience to represent one of them. Subsequently, a growing body of research indicates that short-term episodes of adversity should not be considered as deterministically traumatic, but rather as potentially traumatic events (PTE’s) (Bonanno & Mancini, 2008; Bonanno, Westphal, & Mancini, 2011). Moreover, across studies investigating resilience in a number of potentially adverse contexts, the trajectory of resilience is identified as the most common human response (e.g., Bonanno, 2012). Thus, resilience is increasingly acknowledged as ordinary in nature rather than magical or evidences of human superiority (Masten, 2001).

Thus, a growing body of literature have investigated mechanisms that could be seen not as fostering either a resilient or non-resilient outcome, but instead as shaping through their nature of function and array to develop psychological resilience (Fletcher & Sarkar, 2013)

Psychosocial dimensions. Perceived and received social support have additionally shown to be routinely positively related to positive adjustment, resilience and functional outcomes of patients within the physical rehabilitation field (Chronister, Chou, Frain, & Cardoso, 2008). Whereas received support refers to the measurable support offered, perceived support refers to the perceptions of available support (Haber, Cohen, Lucas, & Baltes, 2007). Moreover, the family unit is highlighted as an important psychosocial dimension believed to represent a crucial component in post-injury adjustment processes (Walsh, 2011, 2012). In her systemic view of resilience, Walsh (2011, 2012) has emphasized the need to understand resilience as a developing and ecological phenomenon, reflecting the myriad of interactions that foster resilience in families. Subsequently, upcoming research additionally stresses the importance of investigating family adjustment as representing something more than the sum of individual processes, but additionally the functional competence and positive behavioural patterns of the entire unit (McCubbin & McCubbin, 1996; Simon, Murphy, & Smith, 2005; Walsh, 2011). In this, three dimensions are commonly identified as key components of resilience: (i) the lengths of the adversity, (ii) life stage or life phase in the family, (iii) and the use of internal or external support (Simon et al., 2005). In their conceptual review of relevant literature, Black and Lobo (2008) identified several prominent protective and recovery factors in family adjustment processes, including a positive outlook, spirituality, family member accord, flexibility, communication,
financial management, time spent together, mutual recreational interests, routines and rituals, and social support. They argue that resilient families tend to use these aspects in dynamic ways, by integrating protective and recovery factors when needed. In addition to compensate for risks, the factors also promote positive family behaviour, such as harmony, balance and security (Black & Lobo, 2008). As resilience is increasingly recognized due to processes of dynamic interactions between intrapersonal, social and environmental levels, resilience is argued to have the potential to be learned and modified. Thus, almost all people have the potential of developing resilient processes (Bonanno & Diminich, 2013). This subsequently yields resilience to be a potential construct within the rehabilitation field.

Empirical findings in the rehabilitation context. There is a shared agreement within the rehabilitation field that a magnitude of aspects are associated with long-term life post injury. A biopsychosocial model is commonly used within the rehabilitation field, facilitating investigations of biological, psychological, and social contributions within human adjustment processes (White et al., 2008). Within therapeutic interventions, this model have the potential to focus on a number of dimensions, such as individual aspects of illness and on the impact and importance of significant others. Thus, researchers within the rehabilitation field have argued rehabilitation psychology to be uniquely suited to work within the concept of resilience, believed to benefit individual processes as well as family adjustments in the context of physical adversity (White et al., 2008). Based on findings in non-rehabilitation settings, there has been a need to investigate whether persons living with prolonged physical adversity are able to return to pre-injury levels of psychological and emotional functioning (White et al., 2008; Quale & Schanke, 2010). Also, researchers have gained increased interest in investigating potential mechanisms believed to foster resilience in face of physical injury acquirement. Here, several of the previously mentioned individual, relational and contextual aspects have been identified.

Empirical research has documented positive associations between self-efficacy and resilience in face of SCI (Kilic, Dorstyn, & Guiver, 2013). Also, positive attitudes have been associated with resilience (). Moreover, mechanisms such as optimism, positive attitudes, appraisal and social support are additionally associated with resilience within physical rehabilitation (Catalano, Wilson, Chan, Chiu, & Muller, 2011; Tugade & Fredrickson, 2007; Quale & Schanke, 2010; Yorgason et al., 2010). Rehabilitation investigations have furthermore demonstrated associations between inpatient resilience and long-term outcome, emphasizing the
positive relationships between the construct and reported psychosocial outcomes (White, Driver, & Warren, 2010). A growing body of rehabilitation research serves additional empirical demonstrations of the relationship between psychological resources and functional outcomes in long-term life, such as high self-efficacy and self-esteem (Peter, Müller, Cieza, & Geyh, 2012), functional appraisal style (Kennedy, Lude, Elfström, & Smithson, 2011, 2012), and high levels of dispositional optimism and hope (Kortte, Stevenson, Hosey, Castillo, & Wegener, 2012; Quale & Schanke, 2010; Vassend, Quale, Røise, & Schanke, 2011).

By qualitative investigations, the rehabilitation has the potential to increase the understanding about resilience and positive adjustment by taking insiders’ perspective. In their qualitative study of hope in face of SCI, researchers accordingly identified that patients tended to describe the processes of hope as more important than their focus on hope when adjusting to post-injury life (Lohne & Severinsson, 2006). This could be associated with the importance of promoting realistic hopes within the context of severe and prolonged injury, as hope is argued to be presupposed by re-evaluations and recognitions of obtainable goals, and accordingly associated with situational meaning-making processes (Bergin & Walsh, 2005). Thus, the capacities to re-evaluate and develop obtainable goals seem to represent a core building block in the way individuals find their lives meaningful, not necessarily their ongoing recognitions of new limitations in life (Bergin & Walsh, 2005). In another recent resilience study, Monden et al. (2014) also investigated SCI insiders’ accounts. By using a qualitative approach, analysis revealed several important topics expressed by the participants as important to their adjustment processes, such as being a role model or inspiring others. This notion adds a new perspective to the relational aspect of resilience. As they additionally notice, previous literature have commonly reported social support within camaraderie to be important within healthy adjustment processes post injury. However, the literature serves limited understanding of the experiences of being important to other people, such as in a role modelling (Monden et al., 2014). Finally, recent literature has additionally emphasized the complexity of adjustment to injury acquisition. In their review on qualitative studies of adjusting after stroke, Sarre et al. (2013) demonstrated findings illustrating that processes of adjustments are commonly experienced as temporally changing over time due to personal, relational and structural resources. By this, the field is about to explore further the even more complex processes involved in life in face of injury acquisition. One of many complex processes may additionally involve family relationships.
Family environment and levels of functioning is argued to serve as a potential source of impact in individual rehabilitation progress across a number of medical disciplines (Martire, Schulz, Helgeson, Small, & Saghafi, 2010). For instance, in studies of family responses to traumatic brain injury, empirical studies have documented family function to be significantly related to such as levels of post-acute independence and employability (Sander et al., 2002) and to adjustment to an altered life (Power & Hershenson, 2003). However, the family system is also a vital ecosystem consisting of several relational and environmental forces at play. Major requirements of reorientations and adjustments are commonly reported among significant others who care for the person and their shared family life (Martire et al., 2010). In family research in face of brain injury, negative injury impact on family members has been documented to include psychological distress (e.g., Winstanley, Simpson, Tate, & Myles, 2006) and reduced life satisfaction (Livingston, Kennedy, Marwitz, et al., 2010). Thus, outcome trajectories in family members may also predict long-term life in face of a spinal cord injury. Qualitative research on spouses within the physical rehabilitation field have additionally reported common descriptions of initial affective manifestations and also long-term worries about the health status of their loved ones, including fear of losing their partner, feelings of helplessness, and fear and uncertainty about the future (Chen & Boore, 2008; Dickson, O’Brien, Ward, Allan, & O’Carroll, 2010). Moreover, family roles and relationships are often challenged, as injury seem to have a negative influence on family functioning (Chan, 2000; Sander et al., 2002), and also to represent more instrumental difficulties, including vocational and financial changes (Kreutzer, Serio, & Bergquist, 1994; Meade, Taylor, Kreutzer, Marwitz, & Thomas, 2004). Spouses describe the increased caregiving burden imposed upon them, as family roles and relationships change from equal to more hierarchical due to injury acquirement. Thus, the injury might additionally represent potential disruptions of family equilibrium (Dickson et al., 2010; Dickson et al., 2012; Gould, Ponsford, Johnston, & Schönberer, 2011; Kreutzer et al., 2009; Ponsford, Olver, Ponsford, & Nelms, 2003). However, by investigating insiders’ accounts, the empirical documentation also reveals positive aspects of post-injury family life. Experiences of growing stronger as a couple and developing useful strategies in daily life that are adaptive and convenient such as taking time outs, venting on emotions, rely on external support and focus on positive aspects of life have been identified (Dickson et al, 2010; Dickson et al., 2012).

In accordance with Bonanno (2004), Quale and Schanke (2010) have extended the
resilience definition to the rehabilitation setting and empirical documented resilience as the most common trajectory of outcome, representing 54 % of the sample (Quale & Schanke, 2010). Subsequently, a growing body of research using a resilience-oriented approach has investigated long-term adjustment in the physical rehabilitation setting, consistently serving new empirical findings of the four trajectories identified in studies of potentially traumatic events. Moreover, these empirical findings additionally support resilience to be the most common trajectory reported in the rehabilitation context, ranging from 53.0-66.3 % across samples (deRoon-Cassini, Manicini, Rusch & Bonanno; 2010; Lam et al., 2010; Le Brocque, Hendrikz, & Kenardy, 2010). The findings reflect a notion of resilience as a non-extraordinary response to prolonged physical adversity, suggesting resilience to be potentially useful as a construct in the context of physical rehabilitation (Dunn & Doughert, 2005; Quale & Schanke, 2010; Sarre et al., 2013; White et al., 2008).

Arguably, the family system represents a potentially fruitful psychosocial dimension in resilience within physical rehabilitation contexts. As the majority of literature seem to agree upon the notion that resilience represent dynamic interactions across individual, relational and contextual levels, family research conducted within a resilient approach has the potential to extend our scientific understanding as well as clinical practice on the rehabilitation field. However, there seems to be a paucity in research investigating dimensions of resilience and healthy adjustment within families in the physical rehabilitation context (e.g., White et al., 2008). Moreover, the majority of previous research within the field has used quantitative methodological approaches, studying levels of psychopathology compared to normative data. In contrast, studying resilience by investigating insiders’ perspective of healthy adjustments is rather unexplored (Sarre et al., 2013; White et al., 2008).

**The main aim of the study**

The present study aims to explore patients and family members perceptions of long-term processes of resilience within a family context. The study is conducted within a resilient tradition, where major emphasis is put into understanding personal, psychosocial and contextual aspects that facilitate positive and healthy processes of family adjustments and resilience following spinal cord injury. Moreover, the study takes a phenomenological narrative approach, and thus facilitates a closer look at how people living with ongoing adversity in their families reflect talk
about their lives. Dimensions of adjustments within shared life processes in the family system lies at the heart of the work presented, as I aim to explore how both SCI patients and their close family members perceive family life and talk about processes of adjusting within the context of prolonged physical adversity. As knowledge based on resilience in rehabilitation is scarce, there will be a major emphasis on exploring the complexity of the phenomenon. I wish to learn more about how individuals within families experience and act upon challenges they face, including to what degree they perceive that they have shared or individualized their efforts. Based on Bonanno’s (2004) definition of resilience, and in accordance with the rehabilitation perspective (Quale & Schanke, 2010) and what seems to foster resilience in families (Walsh, 2011, 2012), the present study defines resilience as: The multiple contributions and flexible efforts by family members facing a severe and potentially disabling physical injury to maintain relatively stable, healthy levels of psychological and social functioning in a long-term perspective, and to maintain positive emotions and a positive perception of self, the family unit, and the future. This definition alludes to three key components: (1) the presence of ongoing physical adversity within a family context, (2) the importance of temporality, and (3) the flexibility to use internal and shared capacities, as well as social and contextual supports, to achieve processes of healthy adjustments.

**Research questions.** Based on the previous notions of resilience, four research questions were presented to investigate resilience among rehabilitation patients and their families:

1. Which core themes within the tradition of resilience can be identified in the narratives among patients and their partners in face of a spinal cord injury?
2. What do the narratives emphasize as prerequisites or efforts taken in order to achieve family adjustments?
3. How do they utilize narratives to illustrate their cohesive family life?
4. What can narratives tell us about resilience and healthy adjustments in a long-term family perspective of spinal cord injury?
Methodology

Rationale for the choice of method

As a junior researcher with no insider experience about the phenomenon investigated, using first person accounts was perceived as crucial. My aim was to explore how insiders reflect upon, construct and make sense of their stories of positive family adjustment, and by this obtain a better glimpse of the construct of resilience in families that live with prolonged physical adversity. For this purpose, a methodology based on qualitative principles was considered suitable. The qualitative research approach is believed to provide access to rich descriptions of human experiences, beliefs and processes of meaning-making (Malterud, 2001). Inspired by narrative psychology, the present study highlights long-term processes of family life, including post-injury adjustment as well as accounts concerning the time of injury onset and aspects of life prior to SCI.

Narrative psychology

Representing part of the qualitative research approach, studies based on narratives belong within the hermeneutic-scientific tradition as they interpret messages through text, voice or other media traditions (Kvale & Brinkmann, 2009). Narratives are known as stories, or part of stories, consisting of past events and actions in human life believed to form a purpose, direction and meaning in human affairs (Polkinghorne, 1988; Riessmann, 1993; McAdams, 1999). Conducted within a wide range of theoretical perspectives and methodological preferences, studies using narratives usually agree within certain broad principles. First, narratives are suggested to consistently organize one’s autobiographic storehouse in a bidirectional way, using strategically selected memories to serve main goals in life. Secondly, they are integrative as they form into understandable and causal accounts of understandings. Moreover, autobiographical memories are argued to undergo temporal instability, as people typically seem to have a selective memory at the time of important life events, and additionally revise their priorities in life and accumulate new experiences over time. Finally, convincing life stories are typically constructed using knowledge about cultural concepts, and undergo both emotional and personal positions vis-à-vis the audience when they are conveyed. As such, how people form their autobiographical memories in expressions seems to be affected by both close and distant social factors (McAdams, 1999). A central aspect in narratives are the use of plots.
Narrative plots. Plots make up one of the crucial components in narratives, defined as: the conceptual structures that overlap with each other when a narrative is cohesive (Lehnert, 1981, p.293). Thus, narratives have the potential to illustrate causal events through a series of plot.

Epistemological considerations. At the heart of the qualitative approach and narrative psychology lies the principle concerning construction of knowledge. Qualitative researchers generally work on the basis that knowledge is generated due to human interactions, reflecting a post-modernistic framework (Wertz et al., 2011). Thus, narratives are believed to construct meaning and knowledge through dynamic processes over time and within the specific context (Hermans, 1999). Subsequently, the participants in a qualitative study are typically perceived as active contributors rather than just passive subjects within the research process (Malterud, 2001). In this, narratives are not believed to represent the only true story of a person’s life, as every narrative should be considered a result of a specific interaction in a specific context in a specific time (Hermans, 1999).

Reflexivity. An important aspect of the development of knowledge within the presented framework is my ontological interests and epistemological position. Central in qualitative inquiry is the notion that the researcher’s positions and interests outline focus areas in the humble beginning and subsequently provides specific guidelines affecting the research design, choice of method, data collection, interpretation of data and dissemination of the empirical material (Guba & Lincoln, 1994). For this particular study, this includes aspects related to (1) me as a researcher, (2) the participant, (3) the alliance and (4) other characteristics of the particular data collection contexts. Thus, how I present the study and ask the questions, how I respond both verbally and non-verbally, how the participant feels that particular day, how we connect and whether or not the interviews are conducted in groups or individually are some of the aspects that affect the narratives represented (Malterud, 2001). Moreover, my role as the data collector, analyst and publisher additionally affects the stories represented in the paper. Altogether, this represents the important aspect of the continuous integration of reflexivity. In this particular study, I had to continuously ask questions about my roles and expectations in life, as well as my values and immediate perceptions of life quality and happiness. My experience concerning the insider perspective was highly limited, and throughout the study I met several possible preconceptions and beliefs related to the more familiar outsider perspective that was assumed to affect several phases of the study. Also, the participants’ perceptions of me as a member of the majority, being
physically healthy, could potentially have affected our relationship and the stories told. Thus, a crucial point during the conduct of the thesis was to properly illuminate my epistemological position throughout the research process, as this was perceived as guiding all phases in the thesis.

**Collecting narratives.** Within the qualitative research approach aiming to examine insiders’ experiences of family adjustment through narratives, in-depth interviews and focus group interviews are considered well-suited as data collection methods. As the most widely used collection strategy, the *in-depth interview* is known for its explorative advantages. By conducting a one-on-one dialogue with the subject, the researcher has the opportunity to search for detailed accounts of experiences, attitudes, and beliefs concerning the research topic (Lambert & Loiselle, 2008). Importantly, the narrative approach emphasizes that people commonly possess various understandings of the same phenomenon (so-called multiple perspectives). In-depth interviews open up for detailed narratives from each subject, whereas the researcher gets the ability to direct and guide the conversation in terms of the interview guide (Smith & Osborn, 2008). Thus, the dialogue within the in-depth interview has the potential to provide a rich material to the phenomenon investigated. (Kvale & Brinkmann, 2009). Through “tick descriptions” of experiences about family life, in-depth interviews may provide rich material to increase our understanding of the diversity existing within family processes.

As with the individual in-depth interview, the *focus group interview* is a qualitative data collection method considered well-suited to examine people’s life stories of ideas, experiences, and attitudes. Whereas in-depth interviews involve social interaction between the researcher and the participant, focus group interviews collect data from social interactions between participants coming together in groups to discuss the research topic (Lambert & Loiselle, 2007). Unlike the rather active researcher role observed at in-depth interviews, the researcher in focus groups typically works as a moderator, facilitating the exchange of opinions between participants (Lambert & Loiselle, 2007). Central to the data collection method is that focus groups facilitate interaction data among the participants, as discussions between them typically highlight both unity and diversity. Subsequently, these processes are believed to promote reflexive processes between the participants in relation to the themes addressed (Lambert & Loiselle, 2007).

**Qualitative methodological triangulation.** Moreover, the combination of in-depth interviews and focus groups is argued to be potentially advantageous as the researcher then has the opportunity to detect complementary pieces of the investigated phenomenon - if terms and
conditions of triangulation are fulfilled (Lambert & Loiselle, 2007). An important facet of integrating the two methods is not to ignore the basis for the different data collections. However, a number of studies using qualitative methodological triangulation tends to use one of the collection methods to confirm the other. Thus, by integrating in-depth interviews and focus groups, one can imagine that the trustworthiness of the data might be threatened when the basis for the different data collections are ignored and the data sets are believed to be equal (Lambert & Loiselle, 2007). Moreover, such a combination of methods might represent an underlying assumption about the *study of reality*, as it might lead us to believe that there is an objective reality out there ready to be discovered. This is an epistemological dilemma when using qualitative methods. Importantly, as I chose to use both in-depth interviews and focus groups to investigate the phenomenon of family resilience, I had to be vigilant in terms of the crucial link between study aim and purpose, epistemological and methodological foundations and the triangulation execution. Based on key concepts of triangulation approaches made in Lambert and Loiselle (2007), I chose to combine focus groups and in-depth interviews in a *non-confirmation* purpose. By doing this, I assumed that the two data collection methods would serve different accounts of family adjustment and resilience. Instead of thinking of one method as “guiding” the other (and hence unintentionally create findings that are more hierarchical proofs than different aspects of the phenomenon), I weighted them as equal in an effort to make the results more trustworthy. Subsequently, my choice of methodology reflected important aspects concerning study design, interview procedures and the process of analyzing the data material.

**Study design**

The present study was conducted at Sunnaas Rehabilitation Hospital (SunRH), and represents a sub-study within the main research project “Focus on families”. The main project aimed to explore aspects of long-term adjustments within families facing ongoing severe physical adversities in a population with spinal cord injury (SCI) and acquired brain injury (ABI). SunRH serves invaluable clinical and research expertise within the field, and represents the leading rehabilitation hospital in Norway. Due to the recognized needs for increased knowledge regarding long-term adjustments in the physical rehabilitation context, the main project was initiated and led by head psychologist Anne-Kristine Schanke, and founded by “Extrastiftelsen”. Moreover, the work has been carried out by a research team at SunRH which possesses great interdisciplinary clinical and research competence concerning aspects of physical rehabilitation.
The sub-study represents central objectives of interest in the main project, following research guidelines compiled in the project related to study design, interview guides, and main inclusion/exclusion criteria.

**Interview guides.** Two separate semi-structured interview guides were compiled in the main project and subsequently used when conducting the thesis.

*In-depth interview guide.* The guide covered aspects including pre-injury life, the circumstances of the injury acquirement, post-injury life, and participants’ thoughts and reflections about the future. Moreover, the guide covered questions about family life. Here, stories of family relationships and adjustments, including psychological, cognitive and behavioural strategies were aimed to be explored.

*Focus group interview guide.* The guide compiled for the focus groups covered aspects including participants’ descriptions of themselves, their family and pre-post experiences of change. The opening part covered their motivations for participating in the project. Moreover, the guide covered descriptions of what the families do to handle their everyday life, and how family members supported each other. Also, the interview guide added an aspect concerning how the safeguard of own individual needs was brought into the family life, and what they used to do to provide care and support to all members of the family. Further, a part of the interview guide covered topics related to the challenges faced and support received during the rehabilitation period, such as perceived challenges at different points in time, hope for the future and social and clinical support.

**Recruitment.** Participants were recruited to the main research project by using filed lists of earlier hospitalized patients. The project was approved by Regional Committee for Medical ethics, South-East Norway. Subsequently, written invitations were delivered by letter to previously hospitalized patients who met the inclusion criteria. The invitation included relevant information about the project including main aims, practical implications, information about each methodological approach, as well as information about anonymity, pros and cons of participation and ethical considerations. From a total number of 59 invited SCI families and 60 ABI families, written consent was received from 11 SCI families and 18 ABI families. A second invitation was sent to the SCI families due to the low response rate, resulting in two additional families included. In sum, a total of 54 persons participated in the main project. All participants additionally chose which of the data collection method they would prefer. 29 individuals
preferred, and were offered, to participate in individual in-depth interviews. Of them, 10 individuals represented SCI patients and partners (equally distributed), 6 represented patients having multiple traumas (SCI and ABI) and their partners, whereas the remaining 13 represented patients with brain damage (cerebrovascular accidents) and their partners. A total number of 25 people were distributed in 5 focus group interviews. One interview was conducted with 4 SCI patients, and one with their partners. One focus group included 6 persons with ABI and included their respective partners. In addition, one focus group consisted of 5 caregivers of family members with disorders of consciousness (DOC), a condition that is not compatible with interviewing the patient.

**Inclusion and exclusion criteria.** As the main project aimed to explore narratives of family resilience in adults, all participants included were adults (>18 years old) who had received treatment at Sunnaas rehabilitation hospital due to SCI or ABI, and his/her spouse or partner. In addition, as the conducted study emphasised long-term adjustment and adaption, only participants with a minimum of 1.5 years post injury were included. No criteria regarding neurological level or the extent of injury were made in the SCI group. Medically unstable patients and people with an extensive ongoing alcohol or substance abuse were excluded, as well as patients or family members suffering from major psychiatric disorders. ABI patients suffering from severity that prevented participation in a structured interview setting or precluded delivery of informed consent was also excluded.

**Participants.** The participants were representing the sample in the present thesis was selected from the families recruited in the main project. To include individuals across the diagnoses in the main project was discussed in the research team, and eventually considered to exceed the scope of this study. Hence, within the framework of the present study, I considered it most comprehensible to explore healthy family adjustment within the same diagnosis. Selection criteria were defined as follows: (i) families within the SCI population, (ii) families represented by both the patient and the partner, (iii) families with no known or expressed additional ongoing stressor. Due to these considerations, 7 families (14 participants, patients and their partners equally distributed) met the criteria. The number of participants meets the general inclusion criterion in qualitative studies (Guba & Lincoln, 1994). Demographic variables were identified and are presented in Table 1.
**Data collection.** My involvement in the data collection differed between the two collection methods. Six individual in-depth interviews, representing three families, were held. Each interview lasted approximately one hour. First contact was established prior to the interviews, by making a phone call to each patient to set a time and date for the interview. All interviews were conducted by me and held in the participants’ homes. The focus group interviews were conducted by other researchers in the main project and held at SunRH. These interviews lasted approximately one hour each. Thus, whereas I was in dialogue with six of the participants directly, the contributions from the focus group interviews in the present study are based on the job of transcribing the material.

**Data management.** The entire data material was recorded on tape using a voice recorder. I subsequently transcribed all six in-depth interviews and the two focus group interviews during the following weeks. This represented an important process as I got to familiarize with the data material. Based on assumptions of data familiarizing in Braun and Clarke (2006), it was especially important to the study that I got the opportunity to transcribe the focus group interviews, as I had not been involved in the data collection process. The transcripts were done as closely up to the spoken sentences as possible, including pauses, coughs and highlighted words, as this is assumed to make the transcriptions more suitable to the purpose of analysis (Braun and Clarke, 2006). However, sensitive information, including names and statements that could possibly reveal the participants’ identities, was anonymized. Moreover, a reflection report was written from each interview transcription as a short summary and theme overview. The reflection reports were subsequently used in group discussions within the research team working in the main research project. Participation in these discussions gave me useful inputs for further analysis. Thoughts and perspectives presented from the other researchers also increased the awareness of my own research position, thereby raising more consciousness concerning aspects of reflexivity. Moreover, I kept listening to the interviews and reading the transcripts repeatedly throughout the following months.

**Analysis.** The analysis was conducted thematically following main principles in Braun & Clarke (2006) as well as holding my methodological position in accordance with Lambert and Loiselle (2007). In the analyzing process, the narrative perspective evolved through investigating the thematic steps by emphasizing plots constructing meaning. Based on the narratives given
when answering the questions from the interview guide, main items were identified as meaningful to each participant’s narrative.

**Ethical considerations**

In qualitative research, ethical issues are common and should be taken into account. Investigating potentially vulnerable families by using qualitative approaches represents additional issues of ethical considerations. Due to close interaction between the interviewer and the interviewee, in-depth interviews might trigger personal accounts and trigger emotional reactions. In the present study, the individual in-depth interviews were held in the families’ homes, with a main aim of the researcher to act friendly and trustful. This atmosphere potentially encourages participants to self-disclose, revealing intimate information and emotional burdens not necessarily revealed in other circumstances. According to Demi and Warran (1995), such experiences could be seen as potentially stressful or embarrassing to some participants. As I was only conducting the in-depth interviews, the ethical considerations were most primarily considered during the interaction with these participants. This also included the awareness of me as a non-clinical psychology student, thus lacking appropriate clinical tools to handle or even potentially discover potential triggers. Thus, I had to bring with me my limitations as a potential therapist during the in-depth interviews. Clinical psychologists were part of the research team and offered follow-up clinical conversations when needed.

Relevant to the study is also the challenges potentially arising when family members identify problems that nobody can fix. A spinal cord injury is not reversible, and everyday challenges could potentially become a heavier burden when the participants once again are confronted with a situation they have to live with every day. This also includes how the participants view their situation regarding help and support (Demi & Warran, 1995).

Confidentiality is a major ethical concern when studying sensitive or stigmatizing topics (Demi & Warran, 1995). Accordingly, all data revealing participants’ identities was safely stored and secured in lockers with access only by the research team.

To minimize such methodological and ethical challenges, the main project (thereby also the present study) emphasized two primary ethical concerns noted in the literature; the importance of informed consent and considerations of the risk-benefit ratio (Demi & Warran, 1995). All families received a written letter with information about the project and the potential risks and
benefits following participation. This was meant to give full information about their eventual participation, and the family members were allowed to withdraw from the study at any time. The risk-benefit ratio of the main study was crucially evaluated within the research team, concluding that the benefits exceeded the potential risks.

**Results**

Based on the research questions and the process of identifying core items in the data analysis, three overarching themes emerged: (1) *Individual strengths*, (2) *Relational flexibility*, and (3) *Contextual meaning-making*. Although the themes are described separately, they should be understood as mutually influential in dynamic manners. All participants are represented in the themes, although they considered different aspects more relevant to their lives than others did. Stories of healthy adjustment additionally covered a wide range of sub-themes and topics, and were generally more elaborate than stories of risk and vulnerability. However, the plotlines of resilience and vulnerability were also combined into coherent and meaningful narratives. Moreover, accounts illustrating negative events and unhealthy processes were generally more contextually embedded, and more represented in the focus group interviews than in in-depth interviews.

**Individual strengths**

A significant amount of plotlines was based upon the utilization of individual psychological strengths. The majority of persons considered intrapersonal dimensions as crucial to healthy adjustment processes individually, but also within shared family contexts. Narratives illustrating *stable and innate* personal characteristics were commonly used as causal explanations of adjustment processes over time, including qualities such as openness, sociability and decisiveness. However, an equal amount of stories illustrated processes of discovering unexpected psychological strengths in overcoming challenges in their life prior to injury onset, that had led to personal development and later came into use. 6B explained how her mother’s illness and handicaps throughout her childhood and youth represented major sources of adversity, but how she retrospectively considered her processes of overcoming these obstacles had made her stronger and more confident when her husband was injured:
6B: What I brought with me in life was that being handicapped is no big deal. Because I was so used to it, that wasn’t the end of my world. (…) I have also been extremely conscious about my heritage. Oh my! That has been a huge thing. But I don’t think I am that kind of a person anyway. I have been very, very conscious about that. That [my children] were not to be exposed to the same as I was.

In her account, 6B explained both how she developed confidence in adjusting to core practical challenges represented by 6A’s handicaps, but even more important how her childhood experiences of growing up with a mother engrossed in illness rather than providing care for her child had shaped her into a warm and caring mother herself. She subsequently compared her relationship with her mother to the ones with her children, the prior one characterized with a break up whereas the latter ones continued to grow stronger.

Whereas some accounts specifically illustrated the use of individual strengths in injury-related contexts, an equal amount of stories illustrated utilization of strengths across different settings, serving general use of individual strengths. 6A highlights this as he emphasizes his capacity of being a good interlocutor:

6A: I think I must have the ability to listen to people. When they talk about their problems and stuff. (…) We have talked and talked and talked. Especially about her bad relationship with her mother. I think we spent our first ten years together by talking and talking.

By serving emotional support to his wife when needed, he subsequently created a warm and stable family climate. Moreover, developed and subsequently confirmed over time and across contexts of challenges, his self-esteem as a good listener increased.

Emotional stability. A common aspect was the emphasis on emotional stability as buffers. Some described how they experienced getting injured as a minor emotional difficulty:

2A: Actually, I never felt depressed or anything like that. (…) I never actually reflected upon the negative things, as I observed physical improvements as quickly as I did… Within a week, I could get out of bed. It was no option for me to…it was like - the grater the effort the better improvement. A few days later, I could use the toilet. (…) Of course, I held a firm grip on such evidence.

2A illustrated initial experiences of motoric skill and proper pain relieving medication dominated his initial focus of attention, leading to high levels of decisiveness and training motivation. He subsequently paired his evidences of physical improvements with important pre-injury experiences of adversity, driving his training motivation to even higher levels, subsequently causing stable positive emotions over time. However, the majority of people shared accounts of significant concerns about survival and uncertainties about future life due to injury acquirement.
3B explained her overwhelming emotions due to her perceptions of loss of dreams about the future when her husband was heavily injured:

3B: You get pregnant, right – and you immediately start making plans about the future. Plans including your children - what you would like to teach them. Right? (...) But suddenly it’s more like… “That shall I do, this is probably possible, and is there even a chance of doing that?” (...) From having a life all planned, you really have to start all over again.

Although the majority illustrated plots representing severe initial emotional challenges, they retrospectively referred to evolved capacities to exhibit stable emotional patterns on a long-term basis. Some explicitly explained their innate abilities to use humor as an emotional buffer:

7A: I make a lot of fun about these things, because I think… Well, I have no problems with seeing the funny sides about it. Because when I am handicapped or disabled or paralyzed or… I love that people make fun of it together with me. (...) I think we can make fun about most things in our lives.

Moreover, subjects illustrated how they over time had turned into experts of preventing emotional struggles through detecting circumstances that could potentially trigger feelings of shortcomings. Two of the participants explored their use of actions and mental strength when their physical handicaps inhibited their abilities to join their families at social events:

5A: Actually, I really enjoy being alone sometimes as well. I enjoy my own company. I am a person who –
3A: - Yes, yes, yes! Me too! If I got something to potter with, it’s great being alone at times.
5A: Yeah! When I’m all alone and I can cook - ooooh, I can cook whatever I want!
3A: Or go and by yourself a tasty burger! [People laughing.]
5A: Noo way, I cook delicious food and open a bottle of wine [laughs].
3A: Well, I maybe grab a couple of bears and watch whatever I like on TV.

Others highlighted that they possessed a mental strategy enabling them to switch from a deficit-based focus toward an emphasis on well-preserved, ordinary qualities:

6B: I don’t look at him as ill. Well, sometimes I might look with those eyes, and then I realize how ill he has become. Right? Then I can feel a growing pain inside of me. So I consciously choose to put that drawer away. I close it. Because I can’t see any point in... It doesn’t help me even a tiny bit. I choose to look at his healthy soul, the one from his neck and up. Right, there’s nothing wrong with his head. That is how I focus - that he is a wonderful man, although he is crooked and paralyzed.
Accounts additionally added new dimensions to their stories, as they reviled the complexities of processes in family relationships. In her story, 3B explained how she and her husband first found themselves at different places, but later understood his perspective:

**3B:** I remember the first period when he was hospitalized. I read all these glossy magazine stories. The first one more utopian than the other. About people chained to the wheelchair who got up again. They had travelled to the U.S. to receive treatment. I remember telling him: “3A, I’m afraid of flying, but we’re going to the U.S.” [Laughs]. [Int: How did he respond?] He got really angry. (…) And that actually surprised me a lot, because he used to be such a fighter. (…) But, of course, he realized a couple of thing that I didn’t back then.

3B evaluated their lack of communication and tendencies of building different perceptions about future lives as emotionally challenging. However, through her plotline, she could retrospectively recognize their shared processes of reuniting a shared perception of possibilities as strengthening and stabilizing her emotional life. From this, she had built further competence in her personal life, subsequently contributing to more adaptive strategies in daily life.

**Building on potentials.** A prevailing sub-theme constituted the participants’ utilization to recognizing positive potentials in their lives. Here, subjects served plots of causal explanations of openness and creativity to explore their post-injury potentials and possibilities. For some of them, potentials were recognized through physical improvements and increased autonomy. For others, primarily those acquiring complete injuries, the mental capacities to focus on potentials on other aspects of life were highlighted identified. One of the patients, a female with complete SCI, explained her decision to focus on the presence and not the future:

**5A:** I rarely think ten years ahead. That’s too far ahead, or – no. I take one day at a time. And I have become quite an expert in…in doing so, by making this particular day pretty good. Then, tomorrow I try to make that day a good day. By doing so, maintaining hope gets easier. Because it’s easy to have hope for one day at a time.

One persistent finding was their narratives describing the use of re-interpreting reference frames in their lives by using downward comparison, comparing with the worst case. The most heavily injured patients reflected upon his shared his coping strategy by emphasizing his potentials and preserved resources rather than limitations:

**7A:** Not everybody have lived as I have done. (…) And of course they got disappointed when they don’t find employment. Some of them have not had the courage or self-confidence to date and have girlfriends. It could be in one or the other way. Uhm… It’s probably a part of the overall picture here.
For some, pre-injury experiences had already changed they frame of reference when facing injury later in life. One of the female partners explained how wheelchairs were a natural part of her life prior to meeting her partner:

7B: I think I never draw my attention to the chair. I think I’ve always seen the person. And 7A is a very interesting man. Through his occupation he has developed into a very intelligent and knowledgeable man. (...) I think he represented some perspectives I found interesting.

Further, she additionally describes how her experiences also was transmitted to her children before she met her partner:

7B: My children and their families have felt the same way. They grew up with me, you know. So they have joined me, driving wheelchairs and drained urine bags and stuff. They grew up this way.

In her account, 7B explains how her life before meeting 7A served her important insider perspectives to her personally, but also to her family, making the transition to live with a heavily injured partner into appreciating his unique contributions in her life rather than focusing on his handicaps. However, many participants explained that their focus on potentials had evolved through challenging post-injury processes. 3B illustrated how her life changed dramatically the day she allowed herself to interpret the family situation in a different way leading to reconciliation:

3B: The day I finally realized that 3A would never be able to walk again, I felt a lot better. Then I didn’t have to… Yes. You waste a lot of energy on hopes, beliefs and brooding. “How am I going to do this” and stuff. What I really should have focused on is a whole lot of different things. Such as how we could make the best out of our situation. So to yearn after things that isn’t there… I… Well, we developed a whole new peace together. I used a lot of time in that process. But we got a much better life the day I finally realized our actual situation.

From being driven by her emotional need to see her husband physically recover, she was eventually able to reformulate her hopes and dreams in accordance with the new conditions in ways that improved the family life. In many ways, the story illustrated a crucial process that she used as an important turning point when talking about it in retrospect. Her husband described the process in his way, focusing on a remote hope, however, not overshadowing his daily living:

3A: I have realized – I actually did quite early on. When I received the message at the hospital saying I would never be able to walk again. Because my injury was quite severe. And for them [the doctors] to explain that the very first day, telling me that there’s no
hope…well… I feel that I have… I have this distant hope anyway. That science someday will help me. So that I can walk up the isle the day my daughter gets married. In 15-20 years. I don’t believe much in it, but I need some of that hope too.

In this way, 3A explains his capacity to balance between the current reality and a future hope, adding an important aspect to the notion of potentials, hopes and dreams. Thus, participants did not uncritically adapt perceptions of potentials to form optimism and positive expectations, but they additionally balanced their evidences of potentials together with previous experiences and a current now to define their future potential.

**Cultivating self-preserving qualities.** A core aspect in the narratives was illustrated by the importance of personal beliefs in documenting human agency. All except one participant showed confidence in own efforts, and deliberately explained how they were able to install behavioral and mental strategies into action in order to handle the demands in everyday life. Like a number of patients, 3A described his needs and strategies to take breaks or time-outs from the injury:

3A: I usually go to bed quite early. I have a TV in my room, and often lie down on my bed with the computer in my lap while I watch something on TV and stuff. At these times, you don’t think about it… There and then, everything is like it used to be like.

Moreover, a number of accounts additionally explained how pre-injury experiences in life contributed to foster their agency and cultivated their ability to make proper choices. 2A reflected upon how a previous injury in life had forced him into quit his job at a young age, subsequently start a process of retraining to a new occupational field. As he once again was injured, he was again forced to change his occupational dreams and directions due to new physical limitations. For him, his many years as a student had turned him into a person who simply could not sit down and start all over again:

2A: I can’t bear to start all over again as a student. There’s nothing tempting enough. What triggers me and my motivation, and what is in accordance with my values at this point in my life, is actually to start working.

A second important aspect was their sense of agency in the need for social support, typically described through friends, but also external family members. Interestingly, accounts differed significantly across individuals. One of the male patients, 4A, explained how he was able to make use of different friends at different times to serve important needs in his life:
4A: I have different networks of friends. That is, I have different kinds of friend. Well, I have friends that are linked to my spiritual belief. So… That is… That is extremely important. I have never been at the gym with them or anything like that. And I don’t need to.

Representing a general observation throughout the narratives, 4A illustrated how his perceptions of social support were a source of strengths, contributing to personal agency and also strategies that could serve personal growth over time.

Relational flexibility

A considerable amount of plotlines referred to perceptions of marital relationships and the family as a functional unit. Participants commonly described daily structure and family climate prior to injury onset, and moreover how the SCI had represented various forms of changes in these aspects in the short and long term. Some participants emphasized more life-changing processes than others, typically illustrating changes in function-related roles in daily chores and activities. Also, stories of changes in marital balance and family dynamic were highlighted, where the majority of accounts consisted of plotlines referring to positive changes over time:

4B: You know, it was so easy for him to ask me: «Can you get this and that for me, please?» So I eventually had to become a lot stricter. It was so easy for me, you know. Instead of watching him spending hours to do it himself. That was dominating in the beginning. And even a bit now… So. I try not to do too much. There is no help in that. (…) After all, he isn’t my patient. He is actually my husband.

Participants with young children or grandchildren typically added plots of injury impact on hierarchical relationships (such as increased partner responsibility in the household) as well as egalitarian ones (such as lack of coherence in wheelchair associations). Moreover, the aspect of injury impact on family relationships additionally involved external family to nine participants, primarily related to balancing perceptions of (in)dependency to their parents. Across multiple plotlines describing lived family life, a core concept within these narratives was their emphasis on being part of a mutual, dynamic family exerting mental and behavioral flexibility across time. For many of the participant, relational flexibility was seen as crucial in their stories of family adjustment, and will be more thoroughly described below divided into two sub-themes.

In addition, the underlying aspects of family identity and culturally constructions of normality were perceived as driving their plotlines of flexibility in meaningful directions.
The leading perception of family identity was recognized due to the number of participants who intertwined their own life-stories with their partner’s, and subsequently how these stories had contributed to their shared stories of lived family life prior, during and after injury acquirement. One of the male patients explained:

6A: It has never been allowed to cry out and like: “Look at me and how bad life treats me”. That has never been allowed, as easy as that. And gradually, it has been like this – no matter how sick you may feel, you still are not allowed to make life a living hell to the people around you. (…) Because that was what her (6B’s) mother did to her! She was chronically ill and affected everybody around her in a very negative way. So, we have been very conscious about the fact that you can feel as sick as you want, but you don’t go around and affect your surroundings.

Moreover, accounts described the SCI as representing primarily practical challenges, focusing on other ordinary family matters like most other families. This could typically involve their mutual affections and emotional connection, but equally important their everyday quarrels and disagreements, marital “ups and downs”, and non-injury related challenges and masteries within the family context. Thus, within the family relationships, there was a common drive in their stories underlining shared thoughts about who they were as families over time and across contexts both as an ordinary family and a family with special challenges they had to handle.

**Negotiation of barriers.** Flexible behavior were consistently illustrated by using plots concerning re-arrangements of roles and routines in the family unit. Commonly, mutual flexible behavior were perceived as crucial to the family’s capabilities to recombine functional roles in ways offering an overall positive function to each family member. Several plots described family organizing patterns, typically constructed by using family history and shared perceptions of togetherness. Through the stories, important aspects of their family’s way of organizing roles, relationships and behavior before, during, and after injury onset was emphasized. In this, negotiations of injury barriers was a crucial aspect of concern.

A number of stories illustrated how the injury had represented initial confusion and disorientation towards roles and individual functionality. However, accounts described how they used flexible manners to investigate and negotiate over time to create clarity in which projects they had to leave, change or could keep. Thus, they experienced processes of negotiation about breaking barriers over time. Although emphasizing barriers that was overcome, a noticeable amount of stories were also concerning vulnerability when these barriers were not. One of the
male patients explained how post-injury life involved non-negotiable barriers due to his
inabilities to form a relationship with his newborn son:

3A: I had no capacity to pick him up myself… For us, the opportunity to establish a
relationship has been very limited. Until recently. Now as he is starting to walk, and he
climbs up in my lap by himself. Finally, we have the chance to get to know each other.
But this has been quite difficult for me.

3A shared his vulnerability in the context of parenthood and the tough reality of barriers. To him,
the injury represented some irreversible obstacles, as he was injured at a critical time in his life.

Whereas several stories illustrated the vulnerability of facing rigid conditions, a
significant amount of stories also consisted of plots describing how new behavioral strategies and
organizing family patterns were used to challenge perceived barriers. Some of the participants
described the importance of recapturing pre-injury shared activities and time together spent in
meaningful ways. 2B explained how she and 2A were able to regain their shared hobby
representing a crucial component in their perceived family levels of functioning by initiate
behavior and challenge his role as disabled:

2B: I was sort of thinking: “If I can manage to polish everything and get him out on the
see again, and if he is able to steer, then we can try to get out there again….try to get out
there.” So I went down there and polished the boat. And he did his part - dragged himself
down there on his crutches. [laughs.]

Whereas some of the families were able to recapture previous activities, others investigated
potentials to change some of the rules within previous activities:

1B: We have developed a work distribution in our daily life where I am the performing
part during cooking, whereas 1A has the role as Hellstrøm. That’s what I use to say.
[laughs.] So, the chef sits down and points her fingers around. [laughs.] «A little bit of
this, and a little bit more of that.» [laughs.] And that works well. [Int: Was it like that
before too?] No, she was the responsible in the kitchen prior to the injury. [laughs.] But I
think it is nice to cook, so there’s no problems in that area.

Moreover, a majority of stories additionally illustrated how participants investigated new and
more appropriate activities after injury onset:

6B: We have bought ourselves a tandem bike, did he tell you? (…) We bought it to, you
know, do something physical together. So I take the front seat and he sits in the back. In
the beginning, he was supposed to follow my lead, but he was really wobbly! I was afraid
we would fall off. However, eventually he has realized that I am the boss on that bike.
In addition, a number of accounts were describing how they were capable of dynamically organizing their family roles and relationships due to perceptions of having obligations surpassing own needs:

1B: She decided for herself quite early that she would not turn into a bitter old grandmother sitting in a wheelchair. I think that was a very… And she has accomplished that. I believe our situation back then – that was just simply something to go for.

**Positive family (re-)interpretations.** Participants typically illustrated cognitive flexibility within the family relationship context. Several participants described experiences of increased partner togetherness and even growth due to their ways of handling new challenges as a team. Central to these stories was the constructions plotlines that captured pre-injury stories and baseline relationships, turning them in to agents who were able to detect and fulfill individual and shared needs. 2B explained how she and her injured partner had turned into a strong team in the initial time post-injury, making them take shared risks which subsequently strengthened their post-injury interpretation of togetherness:

2B: We were told that he could not be discharged before he could walk the stairs. [Laughs]. And that was sort of what we needed. So then we snuck out to practice in the hall at Sunnaas. He walked the stairs while I stood behind, ready to catch him if he fell. (...) [Laughs]. At least I had to try. I guess I would’t have managed to catch him if he had actually fallen. [Laughs.]

During her interview, 2B explained her abilities to make sacrifices to meet her partner’s needs, and moreover how 2A had met some of her most significant needs at the time he got injured. Subsequently, their abilities to mutually build on these experiences to shape strategies that was more due to their own need than following straight-lined recommendations, they further built their positive interpretations of togetherness and family competence when they succeeded. Some of the participants additionally reflected upon their choices in life, retrospectively evaluating them as positive to their long-term family growth:

5B: You never know what could have happened if she never got injured. You know… Because, when it happens, you instantly get so close right away. [Int: In some way, it affected how your relationships developed?] Yes. It did. Because it was sort of... I travelled down here to visit her. And when you do that, you sort of get much closer. You never know what could have happened if we had just continued goofing around at the student pub… [Laughs.] You never know.
Also, the focus groups additionally added an important aspect of re-interpretation as they discussed their experiences with each other, revealing perceptions of family competence and as potentially resources to other families:

3B: When I am out skiing with the children, it is with an ambivalent feeling. You instantly feel sorry for him because you know he really wants to be the one who takes the lead.
4B: Have he tried one of these…
3B: - You know what, he has actually requested to get one of these sledges from the Norwegian ski federation. (…)
4B: Yes. Because we know a guy who is also injured. He uses his sledge a lot.
3B: Yes, that is something we really look forward to. (…) 1B: Is he strong in his biceps?
3B: Yes, he is.
5B: It is extremely heavy. My wife borrowed one once. (…) She had a great time, though. Thought it was so funny. Because she got out… Without any motorized assistance.
1B: You should probably find a quite flat area in the beginning, you know.
3B: Yes, we probably will. [Laughs].

Contextual influence
SCI was found to affect a number of individual and family arenas. Many accounts was emphasizing the importance of social support outside the family arena, such as camaraderie and neighborliness. One of the female patients explained the importance of her social network and neighborhood as one significantly important aspect of being able to adjust to her new apartment when they had to move due to her disability:

1A: Luckily, we were able to live in the same neighborhood. We didn’t have to leave that part of town. I have lived there my entire life, so I have all of my friends there. And today we live in an apartment complex. Senior apartments. There are 46 apartments there. And everybody have at least reached our mid-sixties. And there’s a lot of vigorous 80 year-olds among us as well.

Patients and partners additionally reported different practical “uncontrollable” limitations related to levels of injury. The most heavily injured families described substantial limitations in the winter seasons, as some of the patients became almost prisoners in their own homes. Their lack of autonomy due to the weather and snow could subsequently affect mood and family climate. However, the majority of accounts describing challenges were not related to levels of injury specifically, but more due to contextual elements. By referring to thresholds recognized within aspects of occupation, finance and the health care system, participants emphasized a majority of
challenges to their positive adjustment and family function. A male patient explained how he quit his job after a decade:

7A: I was tired of the nursing help always came too late in the morning so that I missed – uhm, if I missed the car that was waiting to drive me to work. And I was tired of this car arriving too late to my work place. I was tired of looking for handicap toilets and to have to run around in meetings at places where I didn’t know how these things were like.

To 7A, the sum of a myriad of contextual challenges together made him more frustrated as no of these elements seemed to get better over time. For him, being in a life phase where work was an essential part of his daily life, these contextual elements played a crucial role in his functional status. Moreover, a female partner explained why her family chose to cancel nursing help offered from the social system:

3B: To live everyday life with homecare nurses in our home – in our situation, uhm, we were never able to start our day until 10-11 a.m. When they had time to come over and… Yes. And new people came every day. Our kids began asking who they were and, like: “Are they coming to fix daddy this time?” So well... No. It felt totally wrong to us in our situation.

To 3B and her family’s adjustment process, the home nursing that was offered to them clearly did not meet their needs at the time. Representing a number of accounts illustrating adjustment difficulties, 3B perceived the help system as being a source of frustration instead of the support it was supposed to represent, and subsequently explained this due to her family’s life phase.

The focus groups were more concerned about contextual challenges and thresholds related to life phase than the participants in the in-depth interviews. Throughout the focus group interviews, participants went into discussions, comparing different life phase conditions, and also sharing their own experiences of family life transactions subsequently uncovering new and old life phase conditions:

3A: This has put a large burden to my wife’s shoulders. Because I don’t manage to do as much around the house as I used to. So… Yes. This affects our relationship.

5A: I felt different about it during our first years. (…) Things were different when the children were young, because they needed more of the physical help. Young children need a lot more physical help. Because as they grow older they manage to do things themselves. Then it’s more than enough that you are present and that you are a driver and helps around in that way.
By evaluating the fit between “uncontrollable” aspects and their life phases, participants could also recognize the times the contextual elements were sources of opportunities. Subsequently, a number of accounts additionally illustrated feelings of being lucky:

1B: Both of us had retired at the time she was injured. So I can see we were in a fortunate situation back then. We had had our children and our grandchildren. That part was, kind of, okey.

Moreover, risk and protection were not described exclusively as discrete entities. 3B describes how her young children cause increased grief and vulnerability in her adjustment process, but at the same time serve protection from giving up:

3B: A lot of grief is involved when you have two young children. [Silent. Cries.] (…) Although you have to stay positive and embrace the opportunities in life, it still involves major limitations to the children. (…) [Int: What did you and 3A do to handle this?] Well… Arguably, with two children - you just have to. Although you simply just want to lay down and quit, you have to get up every morning. Of course, I spent a lot of energy being positive, to get up and be a mom. My children come first. They have been the most important thing from day one.

Representative to a number of stories, 3B’s account shows how the same contextual dimension of family life, in this situation being their life phase, may occur as risk and protection within the same family.

Discussion

The aim of this thesis was to investigate insider perspectives of family life in face of a severe chronic physical injury. More specifically, the research questions intended to explore individual accounts of positive adjustment processes and resilience in families where one of the members had a spinal cord injury. The majority of studies in this field have primarily taken a deficit-based position when investigating long-term aspects in face of severe physical injuries, where quantitative assessments of psychosocial maladjustments and pathology has contributed to identify risk factors for negative outcomes (e.g., Quale & Schanke, 2010; White et al., 2008). This has been argued to represent a dominating societal belief about living with disability, commonly referred to as the outsider perspective (Dunn & Dougherty, 2005). By analyzing six in-depth interviews and two focus group interviews, a number of plotlines illustrated complex resilient processes that were both in accordance with previous studies and expectations in this
study. Moreover, the findings also highlighted potentially important processes that have not been of much primary interest earlier, including the aspect of relational flexibility. Three overarching themes emerged from the narratives, representing individual, relational and contextual dimensions within the process. However, the themes were closely interacted and sometimes hard to separate. This finding contributes to the current discussions on how to conceptualize resilience and healthy adjustments in families faced with severe injuries (Sarre et al., 2013).

**Individual capacities and strengths.** Some accounts went more into details than others, and in-depth interviews were, as expected, the ones serving the richest descriptions of lived life prior, during, and after injury onset. Additionally, other accounts were more contextually embedded, typically collected in the focus group interviews as the exchange of opinions and experiences between participants were constructed by referring to societal norms, in accordance with the intention of focus groups. Importantly, the overall narratives collected across methods and participants were identified as illustrating aspects of some core thematic dimensions. Thus, the two data collection methods served equal accounts within different aspects about the phenomenon investigated, subsequently increasing the validity of the findings (Lambert & Loiselle, 2007). In line with prior resilience research on the field (e.g., Monden et al., 2014), one important findings was the considerable amount of stories that illustrated personal capacities. Here, narratives illustrated participants’ emphasis on individual characteristics they believed were sources of strengths in both individual and family processes. Previous studies have investigated potential predictors of resilient outcomes, reporting several aspects including positive emotions and high self-efficacy (Peter et al., 2012), and optimism and hope (Vassend et al., 2011) to serve as potential predictors for long-term functional and psychosocial reports. Several plotlines consisted of stories about using their capacities from hospitalization to the presence. However, by exploring the complexity in their stories, temporally changing processes were additionally recognized, as the majority of participants emphasized how life could be characterized with “ups and downs”. This was often explained due to changing environments, perceptions of society norms and important aspects of their life phases. Sarre et al. (2013) have highlighted the temporally changing character of post-injury adjustment processes. In their study of previous literature, they identified complexity to the dynamic long-term processes. In accordance with this, the current findings also illustrated that the participants did not only explain their useful individual strengths, but also utilizing and dynamically changing expressions of such capacities.
over time. In other words, although some plotlines consisted of what seemed to be perceptions of innate and stable personality traits, their changing capacities to dynamically develop and utilize individual strategies and strengths were highlighted as important. Previous qualitative findings have suggested how the development processes, such as the dynamic construction of hope (Lohne & Severinsson, 2006), are as important to post-injury adjustment as dispositional capacities. The current findings support this notion and also indicate this to be present for a number of capacities. Moreover, the findings also illustrated how some of the participants underwent individual processes that were meaningful to them, whereas others also emphasized crucial processes of finding shared perceptions of attainable goals in relationship with their partner. Thus, the relational dimension served as an additional source of evolving individual strengths and capacities in a dynamically changing environment. Finally, this focus on personal characteristic and internal capacities in the study seem to reflect and support previous research that has put a considerable amount of effort in to investigate the individual dimension of resilience (Bonanno & Mancini, 2013). The findings indicate that individual capacities and personality are a part of a bigger puzzle.

**Flexibility.** Their personal beliefs about themselves as active agents in their own lives formed a considerable amount of narratives. Throughout their stories, patients and partners described their perceived personal competence to achieve important goals, and also referring to values associated with these competences and the drive and success they made. Decisiveness in training, or educational and occupational choices were some of the illustrating aspects. However, a crucial finding was their emphasis on personal competence across life arenas, commonly supported in previous studies (Luszczynska, Benight, & Cieslak, 2009; Scholz, Gutiérrez-Doña, Sud, & Schwarzer, 2002). A core aspect of agency was their capabilities to exert flexibility in terms of action, emotion and mental strategies to preserve emotional stability in their individual and shared family life. Likewise, their flexible utilization and perception of social support was additionally described as crucial in a number of stories, including external family members as well as friends and network. Both their individual flexibility to secure emotional stability, and their use of support outside the family, is in accordance with previous literature (Bonanno & Dinimich, 2013). However, accounts also described experiences of rigidity and reduced social interactions outside the family. Subsequently, the narratives reflected their evaluations of these differences, furthermore illustrating their experiences of associating such capacities and strategies
with positive adjustment processes, whereas the lack of them were associated with more vulnerable periods in their lives. Also here, a number of accounts additionally illustrated how capacities might evolve and change over time and also how they were intertwined in more complex relational and contextual dynamics. Life phase was commonly explained to add additional complexity, such as when culturally valued norms of parenting could not be met. Such circumstances were explained with decreased agency and flexibility, and also increased levels of vulnerability. However, participants additionally explained how they were able to appreciate positive life transactions due to increased levels of agency when new family phases were more in accordance with their perceptions of roles and family life. In sum, a number of accounts illustrated the importance of being flexible due to perceptions of self and their family. However, investigations of their complex stories of life processes also revealed a number of dimensions commonly interfering with their perceptions of agency and flexibility in uncontrollable ways, but also sometimes contributing to increased sense of appreciation.

Thus, their emphasis on individual capacities and strengths constituted an important part of the findings. However, their emphasis on strengths when describing shared adjustment within their family unit was equally important. Although some of the participants explicitly emphasized their innate abilities (e.g., their sociability), the majority of subjects constructed stories of adjustments based on a cohesiveness in their lives, involving the flexible relationships within the family unit.

**Relational flexibility.** When exploring insiders’ accounts, their plotlines illustrated a number of pre-injury and post-injury dimensions, such as stories of individual childhood, partner’s pre-marital experiences, and important turning points in the family in post-injury life. Thus, a complexity within their processes were revealed that would arguably be more difficult to assess by quantitative methods and statistics. Bonanno has emphasized the importance of the temporal elements of psychological resilience, and measuring pre-morbid levels in order to investigate the phenomenon properly (Bonanno, 2012). Through the accounts, pre-injury levels of individual and family functionality constituted a significant part of the plotlines, as the participants tended to explain their processes by using a sense of cohesiveness that referred to individual and shared pre-injury processes. Thus, investigating the resilience phenomenon within the family context added considerably amounts of complexities to how baseline or pre-adversity functioning should be conceptualized.
The notion above leads up to one of the most crucial findings in the study, the importance of relational flexibility. Literature has previously emphasized the crucial importance of coping and expressive flexibility. The individual capacities to flexibly shift between coping strategies and mental expression due to situational demands appears as a key mechanism in resilience in adults and children (Bonanno & Diminich, 2013). However, findings in the present thesis additionally document how patients and partners express and illustrate flexible behaviors and cognitions within a relational context. In addition to accounts illustrating individual strengths and flexibilities perceived as crucial to both individual and family processes of adjustment, accounts also referred to aspects of relational flexibility through plots describing a number of underlying aspects and conscious strategies. First, participant’s utilization of relational flexibility was commonly evident by their ongoing negotiations of barriers, as well as their emphasis on mutual dependency, and their sense of family responsibility. This dimension appeared to be overall separated from individual strengths, as the plots reflected a behavioral and dialogue based reciprocity. Their capabilities to change routines and daily structures, and do re-arrangements of functional and emotional roles together as a team were some of the most elaborative illustrations. In addition of explaining their strategies, they also illustrated how they based their sense of meaning along the way by incorporating individual and shared post-injury, pre-injury and even pre-marital dimensions. Secondly, underlying aspects of family history and identity, as well as social norms of normality were believed to shape their stories. Crucial findings here were their use of perceiving positive family interpretations, strategies of downward comparison, as well as their emphasis on ordinary family life. This latter is also crucial to the insider-outsider-distinction. To talk about “ups and downs” over the years of living with injury in their family could potentially reflect a need to illustrate their lives as normal in all manner – not only normal as being functional at all times. Moreover, the majority of stories (of both good and bad days) were also told within non-injury contexts. Thus, it became evident that the majority of patients and partners did not necessarily focus their main attention to the injury and prolonged physical limitations. Instead, they tended to explain how they as a family were a functional unit due to unique contributions on different arenas in their family life, such as being a good interlocutor.

Finally, the importance of being of value to others was also revealed to have crucial effect on the expression of relational flexibility. Monden et al. (2014) recently identified the aspect of being a role model or a source of inspiration as important when investigating the insider
perspective. The current findings support the notion from this study, as several of the stories illustrated how the role as a parent, a grandparent or a friend constituted decisiveness and motivation to reach goals and hope for a better future. Moreover, being part of the SCI population, patients and partner arguably illustrated their needs to share their good or bad experiences with other patients and partners to serve as inspiration or increased competence.

Walsh (2011, 2012) has emphasized the need to understand resilience as a developing and ecological phenomenon. Here, family negotiation and commitment are two of many predictors of functional family outcome. These predictors could potentially be pieces representing the relational flexibility aspects, as they could refer to interactional processes reflecting behavioral and emotional components. In sum, relational flexibility seems to represent a core aspect of the participants’ processes when describing individual and family adjustments within the physical rehabilitation field. Moreover, the connection between negotiations, family identity, social cues of normality and relational flexibility seem relevant.

A major debate within the resilience field has been about the lack of consistency within conceptualizing, operationalizing and defining the phenomenon (Bonanno, 2012; Flechter & Sarkar, 2013). Previous literature has emphasized the need to investigate pre-adversity functioning (Bonanno, 2012; Bonanno & Diminich, 2013). Investigating the resilience phenomenon within the family context added considerably amounts of complexities to how pre-adversity functioning should be conceptualized. Due to family members’ accounts including individual and shared pre-injury processes and experiences, as well as their temporally dynamic ways of interact together, new pieces seem to be added to the puzzle. The present study has argued the reasons to consider resilience to be a process, not only a static outcome. It furthermore supports the leading assumption of considering resilience as a theoretical construct where individual, relational and contextual dimensions interact in a myriad of ways, subsequently being modifiable and potentially learned (White et al., 2008).

**Study limitations.** As the present study was conducted within a qualitative approach, one should be careful with generalizing the findings. This points to the importance of considering narratives as constructed in a particular context. Moreover, a crucial aspect of the study was to use a methodological triangulation associated with significant epistemological challenges (Lambert & Loiselle, 2007). By establishing a clear standpoint in the use of both in-depth interviews and focus groups, the study’s objective was to expand the knowledge base and to
provide an even richer data source than by using one of the methods. Eventually, this was done with an aim to increase the validity of the study. Moreover, the study investigated narratives from both patients and their partners within this triangulation. The risk of making one of the methods more leading to the other is however present. My role as the data collector in the in-depth interviews could also potentially have affected the methodological position. However, by analyzing the data back and forth over a considerable number of months could be beneficial.

Moreover, it is an interesting discussion to suggest that some of the invited families did not respond, subsequently rising the question of what could potentially be characterizing these families in contrast to the participating families. Moreover, some of the families were careless about which data collection method they participated with, whereas others specifically requested either in-depth or focus group interviews. This was, with no exceptions, people who agreed to participate in in-depth interviews. This could potentially affect the study in several ways. First, one could suggest that participants who agreed to share their stories in a group of others were more extraverted and sociable, subsequently leading to shared accounts representing more of these accounts in the focus group interviews. Second, one could suggest that people only agreeing to share their stories within a more intimate context could potentially be more vulnerable due to their reluctance in sharing experiences in a group setting. This could also potentially impact the findings to be more in-depth on vulnerabilities, as the in-depth interviews were the ones with the most elaborated stories. However, this seemed not to be the case, as the people in the in-depth interviews explained their reluctance with the fact that they had to be transported to SunRH to join the focus group, which was not in compliance with their time schedule.

**Research implications.** The present study investigated a sample from a specific population living with spinal cord injury in their everyday family life. The results support a number of previous findings, and moreover extends the operationalization of the term by adding new topics to the field. Thus, it would be interesting to explore narratives of healthy adjustment in different patient populations in the future. In addition, investigate narratives from different family members, including children, parents or other individuals considered part of the family unit, would be of great interest. By including more members of the family, individual, relational and contextual mechanisms could potentially be highlighted in new and developing ways. Finally, the present study overall supports the association between the questions one choses to
pose and the accounts of adjustments that will be revealed. Thus, future rehabilitation research focusing on strengths and healthy adjustments rather than shortcomings and pathology have the potential to add valuable understandings to the dominating scientific and society belief about human responses to physical adversity.

**Clinical implications.** To initiate talk about positive adjustment and strengths in face of injury fostered a number of narrative constructions. By facilitating more to investigate positive dimensions and mastery within this population could be potentially useful. In this, including family members and also investigations of cognitive, emotional and relational flexibility could serve as useful tools in the future.

**Conclusion**

By investigating narratives of positive family adjustment within a rehabilitation setting, a myriad of individual, relational and contextual aspects were illustrated and explained to represent integrated mechanisms in individual and family processes. The findings serves additional contributions to the resilience field, as it considers resilience as a process that develops over time, and that living with chronic consequences of the injury poses ongoing challenges to the patients and their significant others. The latter potentially results in less uniform resilient processes, where individuals at times experience adapting as difficult, and at other times experiences living with the injury as less problematic. Of equal importance, when studying resilience in families, the crucial aspect of relational flexibility adds a prominent understanding to the field. By investigating positive processes in families, the present thesis shows that the way people relate to each other also needs to undergo flexible adaptations. In addition, by applying a study protocol intentionally probed for positive strategies and relational experiences in the questions, the study managed to obtain very interesting narratives on how the participants perceived development of positive processes, both individually and relationally. Thus, the study illustrates that the theoretical basis of the study largely influences the narratives that become evident. As such, the current study adds valuable information to a research tradition that aims at explaining not only risk factors and negative outcomes, but also processes that underlie positive developments.
References


