DOCTORAL THESIS

Everday Life While Aging with a Traumatic Spinal Cord Injury

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Everyday life while aging with a traumatic spinal cord injury

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To Dave...

Thank you for our inspiring
conversations about participation,
research and life in general!

CONTENTS

ABSTRACT

The overall aim of this thesis was to develop knowledge of participation in everyday life while aging with a traumatic spinal cord injury [SCI]. This thesis had an explorative approach, with a mixed method design: two with a quantitative method and two with a qualitative method.

In **study 1,** via a two-part postal survey, 97 participants with a traumatic SCI explored and described their leisure repertoire and how it was related to their interests, performance, and well-being. The results showed that participants were mostly interested in, performed, and experienced well-being from, social and cultural activities. Gender, age, and time since injury were more closely related than the level of injury to interest, performance, well-being, and changed performance in the participants' leisure repertoire.

Study 2 was performed by narrative interviews with eight participants to gain an understanding of participation in occupations from persons aging with a traumatic SCI. The narrative analysis resulted in a description of how they acted to participate in occupations from soon after the injury until several decades later. The results showed that their ability to act and participate in occupations changed over time due to both personal and environmental factors, and that they were concerned about their future.

Study 3 described and offered an explanation for how one man viewed meaning in his everyday life while aging with a traumatic SCI. A story emerged from the narrative analysis, which illustrated the importance for the man to be a worker and how experiences of his aging body and secondary health complications [SHC] shattered the story. Our findings show how aging with a SCI influences a person's experiences of different dimensions of meaning in occupations.

Study 4 explored and described participation in activities and the frequency of SHC when aging with a traumatic SCI. Register data were used for the 121 eligible participants, and 73 participants answered a phone survey. The distribution between men and women was 4:1, consistent with the overall prevalence for persons with SCI. The findings show that participation in activities e.g. exercise and active recreation changed in relation to time since injury. Women reported better general health than men; still SHC increased over time, and thereby negatively affected participation in activities.

To conclude, this thesis contributes with knowledge of how aging with a traumatic SCI can be a complex daily struggle in order to know how to act and continue to participate in everyday life, especially when SHC increase over time. In addition, experiences of meaning in occupations changed and occupational risk factors such as imbalance, alienation and deprivation occurred as a result of, for example not receiving sufficient and appropriate support from the society. The findings have implications for lifelong rehabilitation and provide knowledge that can guide occupational therapists in their work in enabling possibilities to participate in occupations when aging with a SCI.

Key words: activities, agency, aging, occupation, participation, rehabilitation, secondary health complications, spinal cord injury

LIST OF PUBLICATION

This thesis is based upon the following papers resulting from four studies, which are referred to throughout the different sections in the thesis by their Roman numerals:

I. Lundström, U., Lilja, M., Petterson, I., Lexell, J., & Isaksson, G. (2014). Leisure repertoire among persons with a spinal cord injury: Interests, performance, and well-being. *Journal of Spinal Cord Medicine*, 37(2), 186-192.

II. Lundström, U., Lilja, M., Gray, D., & Isaksson, G. (2015). Experiences of participation in everyday occupations among persons aging with a tetraplegia. *Disability and Rehabilitation*, published early online 37(11), 951-957.

III. Lundström, U., Lilja, M., & Isaksson, G. (2015). One man's story about his everyday life while aging with a spinal cord injury. *Submitted.*

IV. Lundström, U., Wahman, K., Seiger, Å., Isaksson, G., Gray, D., & Lilja, M. (2015). Participation in activities and secondary health complications among persons aging with traumatic spinal cord injury. *Submitted.*

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PREFACE

Even though I didn't know it by the time, this journey started about two years before I was accepted as a PhD student in 2010, when I was working at a camp organized by the non-profit organization RG Active Rehabilitation. There I met Matthew[1], who was around 45 years old at the time and living with his wife of a couple of years, and was about to become a father for the first time. Matthew was injured in a motorbike accident when he was a young adult. His spinal cord was injured completely at C6, meaning that he had no sensory or motor functions below the SCI, and limited functions in his arms and hands. He struggled with the rehabilitation for almost a year, gradually becoming independent and able to participate in for him meaningful occupations in his everyday life. He educated himself and got a job that he enjoyed.

During his own rehabilitation, he met role models from RG Active Rehabilitation and participated in a few of their camps when he was newly injured. Therefore it felt natural for him to engage in the organization and become a role model himself. Now, approximately twenty years later when facing a new phase of life, becoming a parent, he was concerned. Not only overwhelmed by becoming a father with everything that entails joy, expectations, confusion and maybe some worries, Matthew was also facing new problems with his body. For the previous two years he had been experiencing increasing muscle weakness and fatigue. He had reduced his working hours and had personal assistance in the mornings and evenings with, for example, transferring between bed and wheelchair. These new experiences raised questions of the future. Would his physical functions decrease further? What would happen next? Would he be able to handle the new role of becoming a father?

I was touched by his experiences and the situation really caught my interest; I became curious to learn more about what will happen with the possibilities to participate in occupations of everyday life while aging with a SCI. So when I was employed as a PhD student and had the opportunity to be a part of developing the topic for my thesis, the choice was given, and thereby became the destination for this journey.

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[1] Fictitious name and somewhat altered/changed personal characteristics.

INTRODUCTION

Experiencing a SCI represents a dramatic shift in life. All the occupations, even apparently simple ones in everyday life become a challenge. Rehabilitation after a SCI focuses on providing comprehensive care to prevent medical complications and on allowing persons to live active lives with the possibility to participate in occupations in relation to the new conditions (Angel, Kirkevold & Pedersen, 2009; Goodman, 1986; Sand, Karlberg & Kreuter, 2006). A number of different professionals are involved in the rehabilitation based on their specific areas of expertise (Kirshblum et al., 2007; Sand et al., 2006; Whiteneck et al., 2011). The SCIRehab project, for example, has described interventions for the initial rehabilitation based upon each rehabilitation discipline (Brougham et al., 2011; Foy et al., 2011; Gassaway et al., 2010; Hammond, Gassaway, Abeyta, Freeman & Primack, 2010; Huston et al., 2011; Rundquist et al., 2010; Taylor-Schroeder et al., 2010; Whiteneck et al., 2011). One of the professionals on the rehabilitation team is the occupational therapist who is responsible for enabling occupations and participation in everyday life. A variety of interventions are used with the aim to restoring and maintaining occupations, and also enabling the ability to compensate for a reduced physical capacity. Examples of interventions include assessing the person's physical capacity, analyzing and adapting the demands for various occupations, finding and training for new ways to participate in occupations, and prescribing assistive devices or implementing home and workplace adaptations (American Occupational Therapy Association, 2008; Foy et al., 2011; Ozelie et al., 2012).

Early mortality after a SCI was common around the period of World War II, and for a long time SCI was considered to be a relatively static condition: in other words, it was thought that persons with a SCI would maintain their functional level for most of the remainder of their lives (Trieschmann, 1987). Now, as more persons survive a SCI to a higher extent and are aging with the SCI, recent research describes a premature aging among this group. This means an earlier onset of some health conditions which usually are associated with aging (for example, diabetes and cardiovascular disease), together with an increased severity and/or higher frequency of certain health conditions in contrast to nondisabled age-matched peers (Hitzig, Eng, Miller & Sakakibara, 2011; Jensen et al., 2013).

Earlier research on aging with a SCI mainly focused on a medical perspective. Today, it is known that aging with SCI is different in relation to aging in the general population. Therefore, from a rehabilitative perspective, and thus from an occupational perspective, it becomes important to develop knowledge of participation in everyday life while aging with a traumatic SCI. Knowledge that can be of value for improving rehabilitation interventions for this group.

BACKGROUND

Everyday life from an occupational perspective

A core assumption in occupational therapy is that engagement in occupations influences well-being and health (Law, Steinwender & Leclair, 1998; Wilcock, 2006, 2007), and to start with, I would like to share some reasoning about the concept of occupation. Occupations can be seen as all the things that people do and engage in, alone or together with others in their everyday lives (Townsend & Polatajko, 2013; Wilcock, 1999). In the literature and research regarding occupational therapy, one can find the use of both occupations and activities as concepts. They are often used interchangeably even though they are not synonyms something that Pierce (2001), for example, described when trying to untangle the concepts, suggesting that occupation holds a personally constructed experience like meaning within a specific context. Whereas activity, on the other hand, offers a more general description and is commonly used when categorizing what people do. Kielhofner (2008) suggested that activities could be categorized into activities of daily living, work, and play, while others have suggested self-care, productivity, and leisure (Townsend & Polatajko, 2013). Activity is also used as a concept in the International Classification of Functioning, Disability and Health [ICF] and is there described as the execution of a task or action, and thus a classification of what people do (World Health Organization [WHO], 2002).

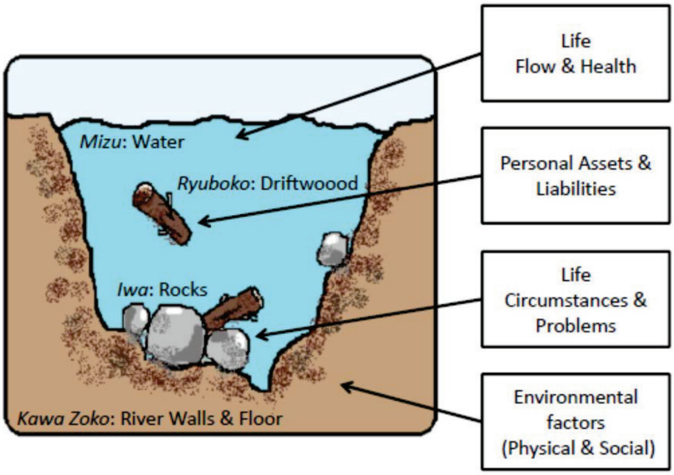
The categorization of activities mentioned above is problematic for several reasons. Some of the most meaningful occupations, like caring for one's children or a partner, for example, or meditations, cannot fit in any category (Hammell, 2004, 2009), and the same individual may define an occupation differently depending upon mood, goals, and the social environment (Hammell, 2004; Kelly & Kelly, 1994). Another way of understanding occupations has been proposed and expanded over the last two decades, with a focus on how people experience their occupations, i.e. the different dimensions of meaning. These dimensions of meaning have been described as doing, being, and becoming (Wilcock, 1999), together with belonging (Rebeiro, Day, Semeniuk, O'Brien & Wilson, 2001). *Doing* is the things we do, *being* is how we feel about ourselves and what we do, *becoming* is the perpetual process of change and development within our lives that is affected by goals and aspirations, and *belonging* is a sense of connectedness that we have with other persons, places, and cultures (Hammell, 2004; Hitch, Pépin & Stagnitti, 2014a). These dimensions of meanings have been suggested as a useful tool in occupational therapy to guide the work with clients (Hammell, 2004, 2009). This was affirmed by Hitch et al. (2014b), who stated that having this holistic perspective in both research and clinical work is important to achieve the full potential of occupational therapy. Based on the reasoning above regarding occupations versus activities, I will use the concept occupation together with the dimensions of meaning in this thesis to provide an understanding of everyday life while aging with a traumatic SCI.

Next, I would like to focus on another multifaceted concept, commonly used within occupational therapy, namely participation. The overall goal within occupational therapy is to enable participation in everyday life, and thereby enhance feelings of well-being and health (Law, 2002; Wilcock, 2007). The idea of participation has also become more widespread in society at large, including policy makers, health care services, rehabilitation staff, and interest organizations for persons with disabilities (Hammel et al., 2008). One reason for this is the revised conceptual model, ICF, that WHO introduced in the early 2000s, where participation stands for the opportunity to be involved in everyday life on the basis of several domains (WHO, 2002). WHO's description, however, has been criticized by Hammel et al. (2008) as well as by Hemmingsson and Jonsson (2005) for not taking social factors such as age, gender, culture, and economic status and/or the subjective experiences into account. Built upon this critique, Hammel et al. (2008) suggested that participation is a dynamic process that involves constant negotiation and interactions with and within physical, social, cultural, and political environments. Thus, participation is a complex and multifaceted concept which holds both an objective and subjective dimension; therefore, it is a challenge to measure and capture the essence of it. In this thesis I will take on this challenge, to develop knowledge of participation in everyday life while aging with a traumatic SCI.

Furthermore, previous research notes that the experience of participation can be viewed as a person's opportunity to choose and make decisions about engagement in occupations (Borell, Asaba, Rosenberg, Schult & Townsend, 2006; Fallahpour, Jonsson, Taghi Joghataei, Nikbakht Nasrabadi & Tham, 2013; Hammel et al., 2008). Therefore, this ability to act or to be an agent can be a necessity for participation in everyday life (Bergstrom, Eriksson, Asaba, Erikson & Tham, 2014). Agency, also a multifaceted concept, is defined differently depending on the theoretical foundation, and concepts such as autonomy and independence are often linked to agency (Harper, 2000). Instead of focusing on agency as separating oneself from others and being self-sufficient, I have decided to use a sociological and gerontological definition of agency according to Wray (2004), who describes agency as a creative, generative and relational process in which persons deal with issues in their everyday lives. Thus, one could say that agency is a dynamic process that is socially and culturally constructed rather than constructed on an individual basis. Participation and also agency are considered to be important outcomes in rehabilitation when reducing the effects of symptoms and disabilities. Rehabilitation then, can be defined as the multi- and interdisciplinary management of a person's functioning and health either by treating or overcoming impaired body structures/functions and thereby participation restrictions (Stucki, Ewert & Cieza, 2002).

Another way of looking at rehabilitation and to understand participation in everyday life while aging with a traumatic SCI is to use the Kawa model (Iwama et al., 2009; Iwama, 2006/2012), which can help us gain an image of how the concepts earlier described can be placed into a wider perspective. According to Iwama (2009), this model was created as an alternative to "Western models of rehabilitation," were the individual is in focus. The underlying ideology in the Kawa model is more complex and focuses on how different contexts shape and influence the realities and challenges of person's everyday life. The name Kawa comes from the Japanese word for river. In this well-known metaphor from nature, life is understood to be a complex journey that flows through time and space like a river (Drawing 1). No matter where in life a person with a SCI is situated, an optimal state of well-being and participation in everyday life can be experienced metaphorically when that person's river is strong, deep, and flowing unimpeded. Certain structures that can be found in a river, such as, rocks (life circumstances/problems), river walls and bottom (environment), and driftwood (assets and liabilities), are all inseparable parts of the river that influence its boundaries, shape, flow-rate and overall quality. These components are inseparable in such way that a change in any one of these will entail changes in the larger context for the person aging with a SCI when it comes to, for example, experiences of well-being and/or the ability to participate in occupations: in other words, the water flow weakens. Thus, using this model in rehabilitation, the interventions should aim to enable and enhance life flow by creating or re-creating harmony (between all the structures in the person's river), by focusing on the uniqueness of every person's narrative (Iwama et al., 2009; Iwama, 2006/2012).

Drawing 1. The structures of the Kawa model.



Several are the concepts and reasoning that have been outlined in this section. Based on this reasoning, I found it important to use the concepts of occupation, meaning, participation and agency together with the Kawa model in this thesis to learn more and develop knowledge about everyday life while aging with a traumatic SCI.

To experience a spinal cord injury

In the literature, two types of SCI are described: non-traumatic and traumatic. Non - traumatic SCI can be more or less acute. In cases where an infarct or hemorrhage is the underlying cause of the SCI, function loss can occur rapidly in contrast to tumors that cause a slow and gradual decrease of functions (Holtz & Levi, 2006). Traumatic SCI is caused by an acute trauma associated with the head or spine. Motor vehicle collisions (approximately 40 – 50%) are the leading cause of SCI in many countries, followed by falls, and sports and other leisure related activities. In some countries, the USA for example, acts of violence such as shootings and stabbings are a common cause for a traumatic SCI. Research shows, however, that sports related injuries and acts of violence decline as common causes with advancing age: instead, falls become the leading cause for SCI (van den Berg, Castellote, Mahillo-Fernandez & de Pedro-Cuesta, 2010). Regardless of what caused the SCI, the level and severity of injury will cause symptoms that vary widely and thus also the need for help to participate in occupations. A SCI can be complete or incomplete. A complete SCI is characterized as having no neurologic function beneath the level of injury. With an incomplete SCI, there can still be motor and/or sensory functions beneath the level of injury. In simplified terms, if the injury occurs on the cervical spine, it will effect arms and legs as well as the trunk (tetraplegia), whereas if the injury occurs on the thoracic or lumbar spine, it will affect the trunk and legs (paraplegia) (Holtz & Levi, 2006). The incidence rate for traumatic SCI varies from between 10 to 40 cases per million each year in industrial countries (Lee, Cripps, Fitzharris & Wing, 2014). In Sweden, the incidence rate is 10 to 15 cases per million (approximately 120 persons each year), compared to 40 in North America (Holtz & Levi, 2006; Lee et al., 2014). It is mainly men who suffer a traumatic SCI and the sex ratio reflects the fact that high-risk behaviors are more common in men and especially young men. In recent years, however, the number of older persons who suffer a traumatic SCI has increased. Reasons for this may be that older persons are more active than before, but also due to the fact that degenerative changes and osteoporosis increases in the spine with advancing age, which means that even a low-energy force can be sufficient to cause a SCI (Groah et al., 2012; Holtz & Levi, 2006; van den Berg et al., 2010).

During the first years following a SCI and the initial rehabilitation, for the vast majority, improvements are seen in functions and the performance of different occupations. An explanation for this could be the increased experience of living with SCI which can mean a refinement of the techniques used when performing for example dressing or transfers and changes in assistive devices (Amsters, Pershouse, Price & Kendall, 2005; Thompson, 1999). Besides having appropriate assistive devices, sufficient personal assistance is another prerequisite for many persons with a SCI in order to be able to participate in personal care, work and leisure activities, (Hagglund, Clark, Mokelke & Stout, 2004; Saikkonen et al., 2004; Whiteneck et al., 2004). In particularly how one can successfully return to work after a SCI has received a lot of attention in earlier research, for example Schönherr, Groothoff, Mulder and Eisma. (2004) described the need for persons with a SCI to change work assignments and reduce working hours as necessary interventions. It is important to strive for work assignments that can be experienced meaningfully, since both older and more recent research has shown that satisfaction with vocational situations is usually low because of unrewarding and poor-quality jobs (Clayton & Chubon, 1994; Fadyl & McPherson, 2010; Fuhrer, Rintala, Hart, Clearman & Young, 1992; Hay-Smith, Dickson, Nunnerley & Anne Sinnott, 2013; Post, de Witte, van Asbeck, van Dijk & Schrijvers, 1998; Ville, 2005).

After a SCI, it is not unusual that persons need more time to participate in certain occupations, such as personal care and housework. In addition, it is not uncommon that there might be an imbalance in their everyday life, with reduced time spent in leisure activities each day for those working, and for those not working, an increased time for leisure activities (Gassaway et al., 2010; Schönherr et al., 2004). Research has shown that there is a decrease of participation in occupations such as active recreation and sports (Boyce & Fleming-Castaldy, 2012; Tasiemski, Kennedy, Gardener & Taylor, 2005), whereas others have identified a risk for an over-representation in occupations such as listening to music, watching TV, reading books, and computer activities (Gassaway et al., 2010; Lee & Mittelstaedt, 2004; Pentland, Harvey, Smith & Walker, 1999; Schönherr et al., 2004). Research has also focused on why persons with SCI do not participate in for them meaningful occupations. Several factors have been identified and can be summarized as either personal factors, which are related to the consequences from the SCI (Caldwell, Adolph & Gilbert, 1989; Kleiber, Brock, Lee, Dattilo & Caldwell, 1995; Tasiemski et al., 2005); factors in the physical environment such as non-accessible buildings and the lack of mobility services (Caldwell et al., 1989; Coyle & Kinney, 1990; Kennedy et al., 2010; Tasiemski et al., 2005; Wahman, Biguet & Levi, 2006); and factors in the social environment, for instance a lack of social support and attitudes towards persons with disabilities in society at large (Henderson & Bedini, 1995; Isaksson, Lexell & Skär, 2007; Kleiber et al., 1995; Price, Stephenson, Krantz & Ward, 2011). Thus at the same time as earlier research has focused on promoting independence in occupations such as personal care, and work: leisure activities on the other hand has received less attention in rehabilitation, and within occupational therapy practice (Hammell, 2004; Majnemer, 2010).

Overall, research about SCI has mainly had a quantitative approach and has to a great extent focused on the initial rehabilitation for persons with a SCI, describing how these persons can return to work, and reengage in occupations successfully. Earlier research has explored that there is a risk for imbalance in everyday life as well as between different occupations after a traumatic SCI. However, no studies were found that describe how the possibilities to participate in occupations can change over time among persons with SCI.

Aging with a spinal cord injury

Earlier research (Whiteneck et al., 1992) described a survival of 32 years on average, meaning that if a person were injured at the age of 30, the estimated lifespan would be very low compared to the general population. More recent research (Groah et al., 2012) shows that today there are persons with SCI surviving into their 70s and 80s, having lived with the SCI for between 30 to 40 years. Still, longevity varies significantly according to level and severity of the SCI, suggesting that those with an incomplete SCI have the longest life unlike persons who have a complete tetraplegia and also need to use a respirator. More recent research has documented that persons with a SCI are aging faster than the general population. This means that they develop characteristic medical problems commonly associated with the aging process at a younger age than does the general population (Capoor & Stein, 2005; Groah & Kehn, 2010; Groah et al., 2012; Hitzig et al., 2008; Liem, McColl, King & Smith, 2004). A way to understand aging with a SCI has been described in a model by Menter (1993), in which the time after a SCI can be described in three phases. *Acute restoration* occurs immediately after a SCI and focus on regaining the maximum amount of functional capacity after the initial rehabilitation, *maintenance* is a lengthy phase and is characterized by a stable functional capacity, and *decline* entails a gradual onset of physical deterioration. In a somewhat similar way, earlier research showed that physical deterioration can begin as soon as 10 to 15 years after the onset of the SCI (Cushman & Hassett, 1992). McColl (1999) describes a slow decline of expected health between the first and fourth decade after the SCI; this will most likely vary due to various circumstances such as heritage, age at injury, duration of injury, and historical era at injury (Groah & Kehn, 2010).

As people are aging with a SCI, a wide range of secondary health complications [SHC] have been noted, such as: fatigue and osteoporosis (Cook, Molton & Jensen, 2011; Garland, Adkins, Rah & Stewart, 2001), pain and increasing muscle weakness in for example upper extremities (Brose et al., 2008; Waters & Sie, 2001). Also, an increased risk of repeated pressure sores (Hitzig et al., 2008) together with additional bladder and bowel regulation problems (Faaborg, Christensen, Finnerup, Laurberg & Krogh, 2008; Liem et al., 2004), cardiovascular diseases (Myers, Lee & Kiratli, 2007; Wahman, Nash, Lewis, Seiger & Levi, 2010), carbohydrate intolerance, diabetes mellitus, and obesity (Bauman & Spungen, 2001; LaVela et al., 2006; Rajan, McNeely, Hammond, Goldstein & Weaver, 2010), and also obstructive sleep apnea and sleep-disordered breathing (Biering-Sørensen, Jennum & Laub, 2009). The majority of these SHC occur with higher frequency among those with longer SCI duration (Capoor & Stein, 2005; Jensen et al., 2013; Savic et al., 2010). Further, research describes that persons with tetraplegia need increased help with personal care for, as examples, transfers, bathing/showering, and dressing at a younger age as compared to those with paraplegia (Charlifue, Weitzenkamp & Whiteneck, 1999; Liem et al., 2004; McColl, 1999). This is in contrast to aging in the general population, where persons usually remain independent and do not receive any help with personal care before approximately 80 years of age (Moore, Rosenberg & Fitzgibbon, 1999). In a later study by von Heideken Wågert et al. (2006), which included 253 persons over the age of 85 years, every other person was still independent in bathing/showering and dressing, and approximately 20% of the study population was also independent in occupations like housework and buying groceries. The image of modern senior-citizens shows an active and self-realized lifestyle, with the most distinctive feature for them being that they are independent and autonomous, without any significant illnesses or disabilities (Hockey & James, 2003; Taghizadeh Larsson, 2009).

Throughout the years there has been a great interest in studying the quality of life both for person's just finishing initial rehabilitation (Fuhrer, 2000; Post & Noreau, 2005) and for persons who are aging with a SCI. A number of longitudinal studies (Crewe & Krause, 1990; Krause, 1992, 1998; Krause & Broderick, 2005; Krause & Coker, 2006; Krause & Bozard, 2012) have identified changes over time in terms of participation in social activities, employment, health and quality of life among persons with SCI over a 35-year period. The results show desirable changes, such as increased satisfaction with employment, as well as undesirable changes, such as a decreased satisfaction with health and participation in social activities. On the other hand, Hill, Noonan, Sakakibara and Miller (2010) came to the conclusion that, unfortunately, because of a lack of consistent results and definitions, the knowledge about quality of life among persons with SCI is still limited. Capoor and Stein (2005) suggested that maintenance of health, maximal functioning, and quality of life, are three major rehabilitation goals for persons aging with SCI. At the same time, this is easier said than done when other researchers have recognized that there is still a lack of knowledge regarding for example issues related to the possibilities to participate in occupations, surveillance recommendations, benefits of different interventions, and caregiver issues (Groah & Kehn, 2010; Groah et al., 2012).

In general, earlier research focused on aging with a SCI from a medical perspective and by doing so explored a variety of SHC that can affect a person's life, thereby causing accelerated aging. In addition, an increased need for personal assistance in certain occupations has been identified. However, no studies were found that explored and described how the aging process was experienced by persons with SCI and how SHC affect their possibilities to participate in occupations. Neither were any studies found regarding rehabilitation interventions for this group and how the need for rehabilitation or support from society changes over time.

Rationale

Aging with a SCI is a challenge for the person experiencing it, but it also places new demands on health care and society. Earlier research has mainly focused on the initial rehabilitation for persons with a SCI and on interventions to successfully return to work, and to participate in personal care. However, the risk for imbalance between occupations in everyday life has also been explored. A gap of knowledge remains, since no studies have captured how participation in everyday life changes over time among persons with a SCI. In addition, when it comes to aging with a SCI, earlier research focused on this from a medical perspective, and by doing so explored a variety of SHC that can affect a person's life and cause accelerated aging. In relation to this, no studies were found that explored and described how the aging process was experienced by persons with SCI and how SHC affect participation in everyday life. An increased need for personal assistance in certain occupations has been explored, but no studies were found regarding rehabilitation interventions for this group or if the need for rehabilitation or support from society changes over time. Therefore, this thesis aims to develop knowledge of participation in everyday life while aging with a traumatic SCI. Knowledge that can be of value for improving rehabilitation in order to enable possibilities to participate in occupations while aging with SCI.

RESEARCH AIMS

The overall aim of this thesis was to develop knowledge of participation in everyday life while aging with a traumatic SCI. Knowledge that can be of value for improving rehabilitation interventions in order to enable possibilities to participate in occupations while aging with a SCI. The specific aim for each study was:

I. To explore and describe the leisure repertoire of persons with traumatic spinal cord injury and how the repertoire is related to interest, performance, and well-being.

II. To gain an understanding of participation in everyday occupations through life stories of persons aging with a traumatic spinal cord injury.

III. To describe and offer an explanation for how one man viewed meaning in his everyday life while aging with a traumatic spinal cord injury.

IV. To explore and describe participation in activities and frequency of secondary health complications among persons aging with a traumatic spinal cord injury.

METHODOLOGICAL FRAMEWORK

"Research is to see what everybody else has seen and to think what nobody else has thought." (Albert Szent-Gyorgyi, 1893-1986)

When planning and conducting research it is important to remember that there are different ways to generate knowledge, based upon the epistemological perspectives empiricism, rationalism, reductionism, and holism. This variety of ways to view the world is the foundation for different research methodologies, both quantitative and qualitative (Sohlberg & Sohlberg, 2013). One example of research from an empirical reductionist perspective is exploring and describing the underlying causes for SHC for persons aging with a SCI; an example of research from an empirical holistic perspective is describing experiences of participation while aging with a SCI. Research questions within health science are often complex, which can make it difficult to answer them adequately through the mere use of a single method (Creswell & Plano, 2010). Therefore, to combine research methods in a so-called mixed method design is becoming more common today, both in separate studies and in a set of related studies like within a thesis (Johnson & Onwuegbuzie, 2004; Mengshoel, 2012). The philosophy behind using a mixed method design has a pragmatic character due to the possibilities of combining methods, techniques, and procedures of research in order to best meet the needs and overall aim of a study or a thesis (Creswell & Plano, 2010). In doing so, it is important to understand the weakness and take advantage of the strengths of qualitative and quantitative methods to be able to combine them in a suitable way.

Quantitative and qualitative methods differ when it comes to distance and closeness between the researcher and the object or phenomena being studied (Creswell, 2009). In quantitative research, the researcher strives to keep a distance from what is being studied, by using for example a random sampling method for the participants and structured instruments/surveys for data collection. Quantitative research is also characterized by quantification and generalization. Whereas in qualitative research, the researcher alternates between closeness and distance by, for example, being a part of the data collection together with the participants being interviewed and then performing abstract analyses. For this thesis I decided to use a mixed method based on the lack of knowledge that was identified in the literature review together with the fact that a majority of research had an empirical reductionist perspective. To use both quantitative and qualitative methods could, therefore, elucidate everyday life among persons aging with a traumatic SCI from different perspectives, providing a more comprehensive understanding.

DESIGN AND METHODS

Overall design

This thesis had an exploratory approach, with a mixed method design (Creswell & Plano, 2010; Mengshoel, 2012); an overview of the different methods that were used for this thesis can be found in Table 1.

Table 1. Overview of methods used in the four studies of this thesis.

	Study I	**Study II**	**Study III**	**Study IV**
Design	Cross-sectional	Qualitative	Qualitative	Cross-sectional
Data collection	Postal survey	Narrative interviews	Narrative interviews	Register data Phone survey
Analysis	Descriptive and analytic statistics Rasch analysis	Paradigmatic analysis of narratives	Narrative analysis of eventful data	Descriptive and analytic statistics

In this thesis, it all started with an interest to learn more about participation in everyday life while aging with a traumatic SCI. A quantitative method was used in study I, to explore and get a description of the leisure repertoire among persons with a traumatic SCI. To expand the findings and be able to describe how participation in everyday life changes over time and the underlying causes for the changes, a qualitative method was used for studies II and III. In study IV a quantitative method was used to explore and describe the findings from studies I, II and III in a larger study sample. With the ambition to elucidate and provide a more comprehensive understanding of participation in everyday life while aging with a traumatic SCI, a secondary analyze of the findings from the four studies were conducted by using the Kawa model (Iwama et al., 2009; Iwama, 2006/2012).

Context

The participants for studies I, II and III were recruited in collaboration with the non-profit organization RG Active Rehabilitation, providing a national distribution in Sweden. This organization has a special interest in active rehabilitation for persons with SCI in particular, for example through their outreach service which allows the newly injured to meet role models who have experienced living with a comparable type of injury and to participate in organized camps with different themes. In study IV, the participants were recruited in collaboration with Rehab Station and the Spinalis SCI Unit in Stockholm. Rehab Station offers an individualized rehabilitation with multidisciplinary teams, both for in- and outpatients. Rehab Station is the largest private health care provider in Sweden and is primarily financed by agreements/contracts with county councils, municipalities, and Försäkringskassan. In addition, persons with SCI can also apply by themselves for rehabilitation at Rehab Station. The Spinalis SCI Unit is specialized for rehabilitation and follow-ups visits after the initial rehabilitation.

Participants and sampling strategies

The inclusion criteria and samplings strategies varied in the four studies due to whether a quantitative or a qualitative method was used for data collection and analysis. An overview of the participants is presented in Table 2. Level and severity of injury together with inclusion criteria and samplings strategies will be presented in relation to each study after the table.

Table 2. Overview of the participants in the four studies.

	Study I	**Study II**	**Study III**	**Study IV**		
				RD⋆ Total population	RD GHQ†	RD GHQ PS‡
Participants	97	8	1	121	102	73
Men, n (%)	55 (56.7)	4		94 (77.7)	80 (78.4)	55 (75.3)
Women	42 (43.3)	4		27 (22.3)	22 (21.6)	18 (24.7)
Age, $\bar{x}$±SD	43.5±12.0 19 – 69	57.6±9.0 48 – 74	52	62.2±9.2 50 – 87	62.7±9.5	63.7±9.4
YPI″, $\bar{x}$±SD	7.3±5.6 2 – 31	27.1±10.4 13 – 41	35	35.5±8.8	35.9±8.7	36.3±9.2

⋆RD = Register Data. †GHQ = General Health Question. ‡PS = Phone Survey.

″YPI = Years Post Injury.

Study I

A total of 97 participants answered the postal survey in this cross-sectional study. They corresponded with the following inclusion criteria: (1) males and females with a traumatic SCI, of whom 46 (47.4%) had tetraplegia, 44 (45.4%) had paraplegia, and 7 (7.2%) did not report their injury level; (2) at least 2 years post-injury; and (3) 18 years of age or older. A simple random sampling method (Dawson & Trapp, 2004) was used to select 200 participants from the membership list; this method was used with the intention of ensuring that all members had an equal probability of being selected to participate. Ten surveys were returned due to incorrect address information, and 90 of the selected members did not respond. Three who answered surveys were excluded because two declared that they were supporting members and one had spina bifida.

Study II

The eight participants were selected through criterion sampling, which is one strategy for purposeful sampling (Patton, 2002), based on the following criteria: (1) traumatic SCI; (2) tetraplegia: two had incomplete injuries (at levels C3-4[2] and C5-6) and six had complete injuries (at levels C3-5, C4-5, C5, C6, C7, and C6-7); (3) over 40 years of age; (4) a minimum of 10 years post-injury; (5) place of residence based on geographical location to enable personal encounters for the interviews; and (6) participation in one of the so-called Retro camps, arranged by the national non-profit organization RG. These camps were designed to provide information about SHC and how these can be prevented in order to maintain and/or increase quality of life and independence while aging with a SCI. A total of 47 persons participated in the camps; 30 had paraplegia, 17 had tetraplegia, and 10 corresponded to all inclusion criteria. Eight persons returned letters with their written consent and contact information.

Study III

A purposeful sampling (Patton, 2002) was used to select William (fictitious name) from the eight persons included in the previous study. William had a complete SCI at level C4-5. The criterion for selecting him was the richness of his narrative in the first interview and therefore the potential to share more of his experiences about everyday life while aging with a SCI.

Study IV

In this cross-sectional study, 121 potential participants were identified according to inclusion criteria, among those registered at Rehab Station. Inclusion criteria for this study were: 1) men and women with a traumatic SCI; (2) aged 50 years or older; (3) neurological level C5 through L2; (4) AIS A, B, C, and D according to the ASIA Impairment Scale (Marino et al., 2003); and (5) at least 20 years post-injury. A letter containing information about the study and the survey was posted to 10 persons at a time until all 121 potential participants were contacted. A week after the letters was posted, the first author phoned the persons to answer any questions they might have, and then performed the survey with those interested in

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[2] "C" refers to cervical vertebrae, and "3-4" states the neurological level of damage.

participating in the study. In all, 9 declined participation in the survey, 10 could not be reached (e.g. due to inadequate contact information), 102 rated their general health, and 73 of them also completed the phone survey. Level and severity of injury for the total population and the participants is found in Table 3.

Table 3. Overview of level and severity of injury for the participants in study IV.

	RD* **Total population** (N = 121)	**RD** **GHQ†** (n = 102)	**RD** **GHQ** **PS‡** (n = 73)
Level of injury, n (%)			
C5 – 8	47 (38.8)	37 (36.3)	27 (37.0)
Th1 – 6	26 (21.5)	25 (24.5)	14 (19.2)
Th7 – 12	34 (28.1)	30 (29.4)	24 (32.9)
L1 – 2	14 (11.6)	10 (9.8)	8 (11.0)
AIS, n (%)			
A	69 (57.0)	60 (58.8)	41 (56.2)
B	10 (8.3)	9 (8.8)	5 (6.8)
C	17 (14.0)	13 (12.7)	12 (16.4)
D	25 (20.7)	20 (19.6)	15 (20.5)

*RD = Register Data. †GHQ = General Health Question. ‡PS = Phone Survey.

†AIS complete or incomplete injury according to the ASIA Impairment Scale.

Data collection

Surveys

Two different surveys were used for data collection in this thesis. In study I, the postal survey consisted of two parts. The first part consisted of questions related to socio-demographic variables and injury characteristics (e.g. gender, age, level of injury, the time since the injury, type of mobility device used, marital status, residential location, level of education, and employment status). The second part of the survey consisted of the NPS interest checklist (Pettersson & Selander, 1996), which consists of 20 areas of leisure activities. For each leisure activity, the participants provided self-reported answers to the following questions: (a) are you interested in the activity, (b) do you perform the activity, (c) is the activity of importance for your well-being, and (d) has your performance of the activity changed since injury? Questions (a) and (d) had the following three possible answers: yes, very much; somewhat; or not at all. Questions (b) and (c) only had two possible answers: yes or no. Participants could also add comments if needed.

The survey in study IV was based on PARTS/M-v3 (PARTicipation Survey-Mobility version 3) (Gray, Hollingsworth, Stark & Morgan, 2006), which is a self-assessment instrument designed to measure the participation of persons with mobility impairment in 24 activities, and for this study, 10 activities (Dressing, Bathing, Meals, Exercise, Leaving home, Housework (inside the home), Socializing, Leisure activities, Active recreation, and Employment) were chosen based upon findings in the earlier studies in this thesis. For each activity, questions were asked about frequency, personal assistance and use of assistive devices, and self-perceived importance, choice, control, satisfaction, and if and to what extent SHC (e.g. pain, fatigue, spasticity, respiratory diseases, cardiovascular diseases, urinary tract infection, bladder and/or bowel incontinence, pressure sores, and/or depression) affected participation. A question was added in relation to each activity to find out the underlying cause if not participating in the activity. Another question regarding commonly used transport means was added to the activity "Leaving home". At the end of the survey, the participants were asked an open-ended question about their required support in order to continue participating in the activities. Comments and/or clarifying information from the participants were documented in relation to each question.

Based on the decision to use these two instruments described above as part of the surveys, and how the concept activity was used in the instruments; activities will be used instead of occupation in relation to studies I and IV.

Register data

In study IV, demographic information (gender and year of birth) and injury-related information (level of injury, neurological severity according to ASIA Impairment Scale, and year of injury) for the 121 persons was derived from the register at Rehab Station.

Narrative interviews

Narrative method has its foundation in hermeneutical tradition which is a philosophy of science with an interest to describe and explore how persons experience the world and the meaning that persons ascribe different phenomena in the world (Mattingly, 1998). There are different traditions within hermeneutics, but the way narrative method was used in this thesis, is based on the description by Ricoeur (1991), where he describes that persons experience and understand life through the creation of stories while acting. The narrative interviews in studies II and III were conducted according to Riessman's (2007) description of narrative inquiry using a few broad questions. To begin with, in study II, the participants were asked one broad question: Tell me your story about how from soon after the SCI until today you have participated in different everyday occupations. Follow-up questions were asked about how they acted in order to continue to participate in occupations and about changes over time. A broad question was also asked regarding their thoughts about possibilities to participate in occupations in the future.

For study III, William was interviewed four times during the period of four years, 2010-2014. To address the aim for this study, and to complement and expand on the first interview, additional data were gathered consecutively through the three interviews. During all the interviews, the questions were open-ended to capture his life story about everyday life while aging with a SCI.

In both studies II and III, follow-up questions were asked according to the participants' answers, to expand their narratives in order to capture their stories.

Data analysis

Statistical analysis

Descriptive statistical analyses (mean, standard deviation [SD], and frequencies) were performed to explore the study samples and the data. Analytic statistical analyses (cross-tabulation and $\chi 2$ tests) were performed to examine relationships between demographic variables, injury characteristics, and the different questions in the surveys used in studies I and IV. A *p* value of < .05 was required for statistical significance (Dawson & Trapp, 2004). Rasch analyses (Bond & Fox, 2007) were used in study I to describe the leisure repertoires among the participants with SCI and also to test the validity for the questions in the NPS-interest checklist. The person response validity indicated that 95% of the participants demonstrated acceptable goodness-of-fit, which can be judged as sufficient based on the criteria proposed by Linacre (1991-2003) and thus not a threat to validity (Bond & Fox, 2007). In order to facilitate the analysis in study I, a dichotomization of the answer alternatives for the NPS-interest checklist was applied to the questions (a) and (d), in order to ensure that the outcome could take on only one of the following of two values: yes or no. Sub-groups were formed due to the wide range for age (19–69 years) and time since injury (2–31 years). Age was divided into two groups: age group 1 included persons between 19 and 44 years of age, and age group 2 included those between 45 and 69 years of age. Time since injury was divided into three groups based on the quartiles; group 1: 2–4 years; group 2: 5–8 years; and group 3: 9–31 years.

For the analyses in study IV, a decision was made in the research group to use the questions regarding: frequency, personal assistance, if pain, fatigue, and/or SHC affected participation and the underlying cause if not participating in the activities. To facilitate the analysis, age was divided into two groups based on the retirement age in Sweden (65 years): group 1 included persons between 50 and 65 years of age and group 2 included those between 66 and 87 years of age. Time since injury was also divided into two groups: 20–35 years and 36–55 years, to retain two comparable groups regarding size. The level of injury was divided into four groups: group 1 included C5-8; group 2, Th1-6; group 3, Th7-12; and group 4, L1-2. SHC was divided into pain, fatigue, and other SHC, the latter including symptoms such as spasticity, respiratory diseases, cardiovascular diseases, urinary tract infection, bladder and/or bowel incontinence, pressure sores, and/or depression. Answers from the open-ended questions and comments from the participants were compiled in relation to each question, and used to expand the understanding of the data.

Narrative analysis

In study II, a *Paradigmatic analysis of narratives* was used in the way that has been described by Polkinghorne (1995). An inductive approach was used; something that has been recommended in areas or around a phenomenon when there is a gap of knowledge (Elo & Kyngäs, 2008). At first, the transcribed interviews were read numerous times to gain a sense of the overall data. Next, the coding process began by identifying significant events for each participant, events that could describe changes and/or turning points in the participants' stories about how they participated in everyday occupations immediately after their SCI, about how their participation changed over time, and about how they acted in order to enable participation. Then, in order to get an overview of the identified significant events, these events were sorted and organized into possible emplotments for each participant. The possible emplotments for each participant were then compared, in order to allow for the exploration of commonalities among the different emplotments, which led to the discovery of common themes. All through this process, the emplotments for each participant and the exploration of commonalities among them were discussed and tested by the first and last author. Different interpretations were considered by going back and forth to the original transcribed material. This process outlined above was repeated until the emplotments were arranged in the most-appropriate themes to accurately capture how participation in everyday occupations changes over time while aging with a SCI. The final themes presented in the results are the authors' interpretations and represent just one description of many possible ones. The second and third author read the drafts for the manuscript and gave constructive feedback regularly throughout the writing process.

In study III, a *Narrative analysis of eventful data* was used for the analysis, the outcome for which is a life story or a storied episode of a person's life (Polkinghorne, 1995). Initially, all the transcribed interviews were read several times to obtain a sense of the overall data. Next, the first author began the search for significant events in William's stories that matched the purpose of the study. The significant events were separated from the text and organized chronologically, in order to create a story with a beginning, middle and end. Then, a process called "narrative smoothing"

(Spence, 1986) was used in order to exclude irrelevant data that did not contribute to the story. The events were used to outline a story that could give a possible explanation to William's experiences of aging with a SCI. Next, the first and third author compared the outlined story to the unused parts in the narratives, i.e. events not used to determine whether any of them could further enhance the understanding of the changes that occurred in the Williams's life. Next, to gain a deeper understanding of the complexities and to find a suitable plot, the first author conducted a "to-and-fro movement" between the emerging story and the unused parts; some events were excluded and others were added to be able to tell his story. In the final story, a description was provided as to how one man experienced meaning in everyday life when aging with a SCI. William's story was separated into five parts that cover the time from when he got injured until today. The first and last authors had a constant dialogue during the analysis process, and the second author asked analytical questions to ensure that the first and last authors adopted a self-critical stance.

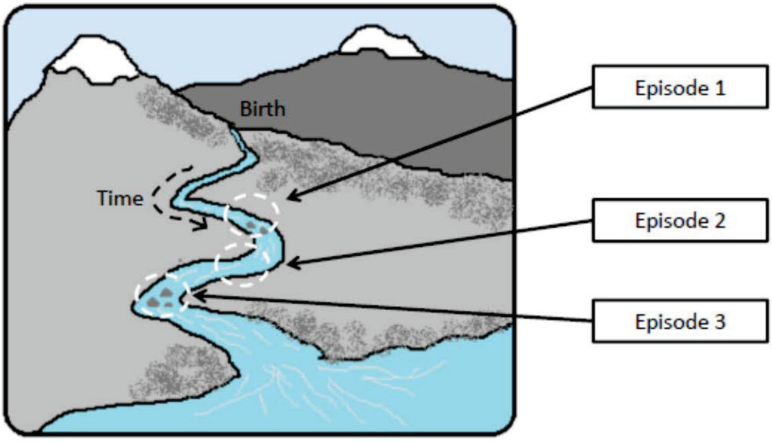
Second analysis of the findings

A deductive content analysis (Elo & Kyngäs, 2008), built upon the Kawa model (Iwama et al., 2009; Iwama, 2006/2012) as a categorization matrix (Marshall & Rossman, 2010), was used for a secondary analysis. The reason for choosing the Kawa model was based on how the model describes life as a complex journey that flows through time and space like a river, a metaphor well suited to the overall aim of this thesis. Initially, the findings from the four studies were read several times to gain an understanding of the overall findings. Next, both qualitative and quantitative findings from each study were categorized using the structures (rocks, river walls and river bottom, together with driftwood) in the Kawa model in order to get an image of how the structures influenced the rivers' boundaries, shape, flow-rate and overall quality, and thereby get an overview of the participants' everyday life. Built upon this analysis, three episodes were distinguished in the findings since time since injury, and these episodes will be used as metaphors to illustrate participation in everyday life among persons aging with a traumatic SCI. It is important to remember that the findings in the thesis are built upon my interpretations. No reflective dialogues were performed with any of the participants to value the structures based on size and location, together with the relationship between them. At each episode, a drawing will be used to illustrate both structures that can obstruct and enable the water flow in the participants' rivers.

FINDINGS

This thesis had an explorative design with the overall aim to develop knowledge regarding participation in everyday life while aging with a traumatic SCI. Three episodes will describe participation in everyday life while aging with a traumatic SCI (Drawing 2). Episode 1 illustrates when the participants experienced a SCI and the immediate years afterward, an episode characterized by recreating flow of their river. Episode 2 represents the span of time where the participants have lived with the SCI for approximately 10 to 20 years, experiencing a river in harmony. Episode 3 is the period when approximately 20 to 55 years have passed since the SCI and the participants experiences a river with impeded flow and a life in disharmony.

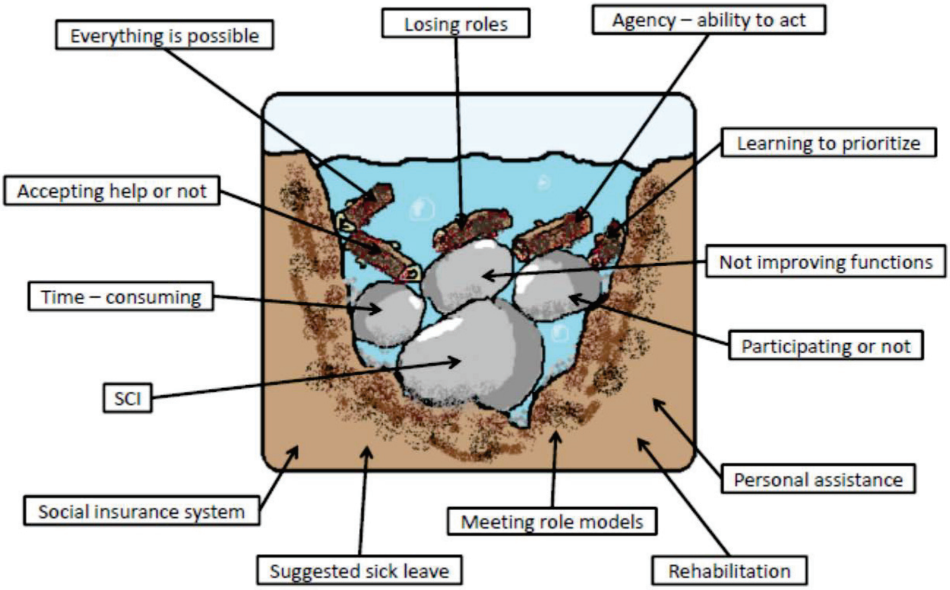
Drawing 2. Three episodes described in the findings.



Episode 1 – Recreate flow in the river

Experiencing a SCI caused a sudden change of flow in the participants' rivers, creating a dramatic shift in the possibilities to participate in occupations and thereby experience well-being (I, II, III), (Drawing 3).

Drawing 3. A river after a traumatic SCI.



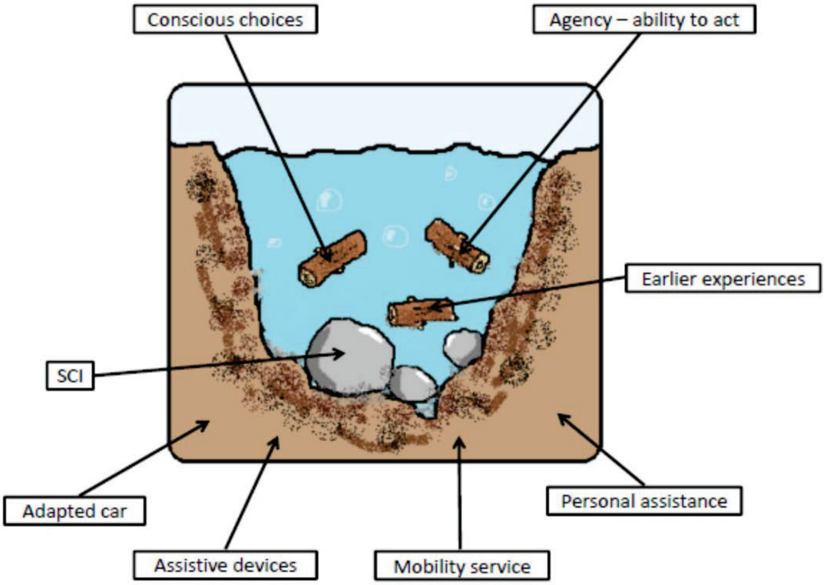
The participants highlighted the importance of a rather long period of initial rehabilitation which gave them "enough time" to adapt to the consequences of the SCI (II, III), and was a first step in restoring the water flow in their rivers. However many of the participants chose to resign from training once they no longer improved their physical functioning or experienced any progress in the rehabilitation (I, II, III). A common reason was that they did not find the training meaningful any longer. At the same time the decision to quit was associated with frustration (II, III). In spite of this, participants did learn how to perform for example dressing and transfers more efficiently by refining their techniques (II). In addition to ordinary rehabilitation, meeting with well-matched role models inspired participants to try out both new and old occupations, not letting the level of injury be a hindrance in their everyday life (I, II, III). These meetings were an important part in increasing the water flow in the participants' rivers, since the participants realized that much was achievable and that it was possible to act to participate in occupations even though some took longer to perform, some had to be performed in an altered way, and some had to be prioritized (II). The participants enjoyed to participate in social and cultural occupations as well as wheelchair rugby (I, II, III), but experienced a changed performance in, for example, camping (I). The ability to act was developed over the few first years after the SCI and became an important asset that could be used in a variety of situations to remove obstructions in the participants' rivers and/or erode the constraining surfaces of river walls and rocks, thereby enhancing well-being and participation in their everyday lifes (II, III).

One situation in which the participants acted to enable participation was returning to work. They valued and expressed the importance of having a job early on after the rehabilitation, even though professionals in society suggested the participants to accept sickness compensation. Thus, through their own acting, they were able to find suitable educations and thereafter employment that they found meaningful; it was essential when applying for employment to be able to compete with others under the same conditions (II, III). Most of the participants were working part-time (I, II, III) right from the start following the initial rehabilitation, mainly handling administrative duties (II, III). The choice of working part-time was based upon the experience that for example personal care was more time-consuming (II). Early on after the SCI, many of the participants realized their need for personal assistance in order to be able to participate in certain occupations. This was accompanied by complex emotions, and some participants were surprised to find that it was easier than expected to accept the help, whereas others could not come to terms with it (II, III). One reason for this dichotomy could be the different ways in which the personal assistance could be arranged: formally, by the municipality or private assistance companies, for example, or informally, by relatives/family members. It was not always an easy choice. Using the latter, for example, could mean losing a role such as spouse. Therefore, deciding about arrangements for personal assistance was another situation in which the participants had to act and thus get their everyday life working smoothly with help/assistance from others (II, III), in order to avoid having their water flow impeded.

Episode 2 – A river in harmony

Whereas the first episode was characterized by recreating the water flow in the participants' rivers and participants taking control over their everyday life again after experiencing a SCI, the second episode represents the period approximately 10 to 20 years after the SCI. Life seemed in harmony and the participants' rivers had an unimpeded water flow; participants experienced a state of and feelings of confidence (Drawing 4).

Drawing 4. A river with an unimpeded water flow; a readiness to act.



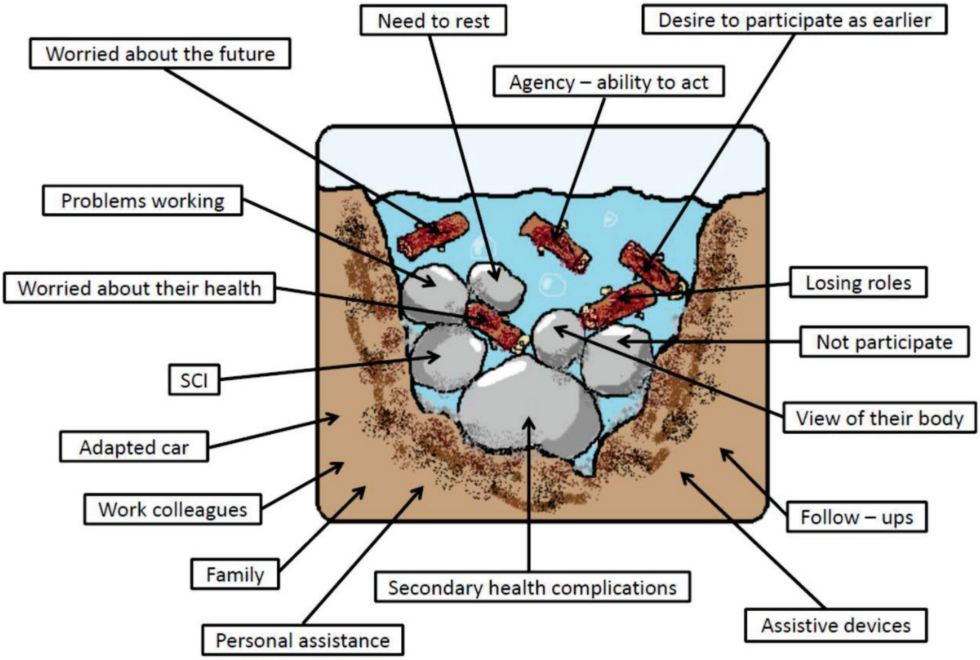
The participants had reached a comfort zone were they knew how to compensate for the SCI in their everyday life, thus keeping the water flow strong. Everything seemed possible and the participants never really hesitated to participate in occupations either on the home front or traveling abroad, relying upon earlier experiences from participating in occupations (II, III). Nevertheless the participants made conscious choices about which occupations to participate in, instead of trying to prove that everything was possible as was more common during the first few years after the SCI (II). They prioritized to participate in occupations that they found meaningful and less demanding. Many resigned from occupations that demanded a lot of planning and/or were not frequently reoccurring, or that included risks for injury such as wheelchair rugby (I, II), finding other ways to exercise (I, IV). To be able to participate in occupations out in the community on their own terms meant that they highly valued their adapted cars, as well as the possibility of using mobility service when so needed or desired (II, III).

The participants had to be observant to a few structures in their rivers that could, if participants were not acting proactively, cause the water flow to weaken and thereby affect their participation and sense of well-being. Their ability to act was an asset that helped them, when needed, seek out updates, educate themselves, and sometimes fight to obtain certain assistive devices or to solve issues with personal assistance (II, III, IV). Beyond that, this episode was characterized by control and confidence, representing a comfort zone (II, III). The participants experienced a bright future and a sense that there would be opportunities for them to develop in a variety of ways (III), keeping the water flow strong in their rivers.

Episode 3 – A river with impeded flow

If the second episode was characterized by a life in harmony and the patients' rivers had an unimpeded flow. With the third episode, approximately 20 to 55 years after the SCI, participants started to experience an increasing disharmony in their everyday life, as the water flow weakened due to several structures in their rivers (Drawing 5). This consequently created problems for them to participate in occupations and, therefore, influenced their well-being.

Drawing 5. An impeded flow; fewer possibilities for participation in everyday life



The changes were slow and barely noticeable to begin with; for example, daily routines such as personal care and transfers started to take longer (II, III). A gradual onset of a variety of conditions and symptoms occurred, some of which the participants were already familiar with, but which changed in character: small pressure sores emerged where there earlier just would have been a redness (III, IV).

Other SHC experienced included pain in for example shoulders, progressive muscle weakness, spasticity, fatigue, sleeping-disorder breathing/apnea, and/or prolonged time for bladder and bowel care (II, III, IV). Participants' changing health gave rise to worries and they tried to act in several ways to increase the water flow in their rivers, for example by reducing their working hours and adding a rest day between work days. Work was important for them because it fulfilled a social aspect of life different from other friendships and social interaction, involving collaboration and solving problems with colleagues (II, III). At the same time the rigidity of the sickness compensation system which consists of fixed steps (0, 25, 50, 75 or 100%) did not always allow for the changes the participants wanted in order to be able to continue working (III), and would thereby impede the water flow more.

One way in which they tried to act to be able to continue working and still have energy to participate in other occupations was to make tougher priorities governing which occupations to participate in (II, III, IV). For example, the participants chose not to participate in exercise and active recreation/leisure activities (IV). Another way participants acted to try to increase the water flow was to just participate in one occupation at a time, such as not both dining out and visiting a theater or a cinema the same evening (II, III). In making these decisions, the opinions of family members as to what they enjoyed doing were important, even though there was a worry of falling short as, for example, being a father and/or a husband (III). The participants experienced an increased need to rest and more time to recover from occupations (II, III). Some participants applied for personal assistance, say for housework, in order to save energy for other occupations when they were no longer able to act successfully to compensate for the physical deterioration. However, such applications were usually rejected (IV), causing the water flow in their rivers to decrease even more. On the other hand, the participants who already had personal assistance became aware of the need to apply for increased help before turning 65 years of age. After 65, any extra help needed would be granted by home care services due to laws and/or governmental policies; the uncertainty over how that would work caused additional worries (II, IV), something that also affected the water flow negatively.

Driving an adapted car had been a great asset for participating in community-based occupations and was associated with a tremendous degree of freedom. By this time some participants had quit driving, due to muscle weakness for example, whereas others were worried about what would happen when they were no longer able to drive (II, III). Additionally, it was not only the deterioration of their physical capacities that could create a problem for driving, laws and/or governmental policies made it not possible to apply for another adapted car after the age of 65 years (II). At the same time, participating in certain community-based occupations was no longer obvious because of feelings of self-contempt due to changing bodies and physical deterioration (II, IV).

As all these changes were taking place and the water flow was impeded due to several structures, the participants pondered whether using assistive devices or having personal assistance at an earlier stage as a preventive action would have changed their situations. At the same time they knew that this was not possible due to how the laws and/or governmental policies are constructed (II). Further, the participants wished that they would have received information about aging with a SCI at an earlier stage, along with information on how to be observant for signs of physical deterioration and where to get appropriate interventions (II, IV). They also missed regular meetings with a multi-professional team (IV). The lack of choice and control, limited possibilities of acting in the same way as earlier, and the experience that their physical capacities were constantly changing made their everyday life a balancing act and a state of disharmony, which in turn led to feelings of uncertainty and anxiety for the future, something that further impeded the water flow in their rivers.

DISCUSSION

Overall, this thesis contributes with knowledge about how participation in everyday life while aging with a traumatic SCI can be a complex daily struggle to know how to act and continue to participate in occupations, especially as SHC increase over time. Furthermore, the participants' experience of meaning in occupations changed, and occupational risk factors such as imbalance, alienation and deprivation followed as a result of for example not receiving sufficient and well-suited support from society. These main findings will be discussed and implications for praxis and rehabilitation will be considered in relation to the discussion of the findings.

To act and participate in occupations

To start, the findings are in line with the three phases of physical functioning following the onset of a SCI as described earlier in a model by Menter (1993). At the same time, the findings contribute with knowledge about how agency and participation in everyday life change over time in relation to these phases. The findings show how persons early on after experiencing a traumatic SCI were able to recover/regain their ability to act and be an agent in their everyday life and thus participate in desired occupations. These findings are in line with earlier research on how agency and participation are closely linked (Bergstrom et al., 2014; Borell et al., 2006; Fallahpour et al., 2013; Hammel et al., 2008). Thus, a long initial rehabilitation and meetings with well-matched role models in particular, played an important role in how persons with a SCI developed a driving force to act and participate in occupations, and not let the SCI hinder their everyday life. This is comparable with earlier findings which showed how meeting other persons with SCI increased the self-esteem and perception of possibilities and capabilities in persons after a SCI (Daniel & Manigandan, 2005; Kennedy, Taylor & Hindson, 2006). This established the foundation for how persons with a SCI for a long time can have an everyday life just like everyone else, starting families, educating themselves, and having a job. However, the findings also show how persons early on after their SCI can be restricted in their possibilities to participate in occupations due to not having the same rights to obtain assistive devices prescribed, as laws and guidelines vary greatly between municipalities. In addition, for those in need of personal assistance, the findings indicated that for example the way on how the support was organized could further constrain participation in everyday life. This means that there is a risk for persons with a SCI to not have the same occupational rights as able-bodied persons (Whiteford, 2010; Wilcock, 2006).

The findings show how, after approximately 20 or more years post injury, participation in everyday life can change as a result of SHC. Worth mentioning is that these changes in participation can be slow and barely noticeable to begin with. Earlier research has explored and described several SHC, such as increased pain in the shoulders, progressive muscle weakness, fatigue, sleeping-disorder breathing/apnea, pressure sores, and/or prolonged time for bladder and bowel care, together with a premature aging (Biering-Sørensen et al., 2009; Cook et al., 2011; Faaborg et al., 2008; Hitzig et al., 2008; Hitzig et al., 2011; Jensen et al., 2013; Liem et al., 2004; Waters & Sie, 2001). In the findings, these were also the SHC that negatively affected persons' possibilities to participate in occupations.

As SHC increased, the findings also show how participation in everyday life became more of a balancing act because strategies used earlier were no longer working. Thus, the balancing act came to involve a constant negotiation of the person's competing needs and values in relation to and within physical, social, cultural, and political environments, something that is line with the description of participation by Hammel et al. (2008). With this came, too, the difficulty to act in order to compensate and find new strategies to participate in occupations, as participants found that their conditions were constantly changing. Findings that are in line with Wray's (2004) and also Brah's (1996) descriptions that the ability to act is not fixed and can change continuously due to several different circumstances, but also contributes with new knowledge of how agency and participation in everyday life while aging with a traumatic SCI can be experienced as a complex daily struggle. While these findings are similar to how both participation and the ability to act have been described as dynamic processes, it is also possible to make comparisons with the Kawa model and how all the different structures in one's river are described as inseparable parts, determining its boundaries, shape, flow-rate and overall quality, and thus the experience of well-being (Iwama et al., 2009; Iwama, 2006/2012).

Within this daily struggle to continue to participate in occupations, the findings show how persons had to choose more carefully which occupations to participate in, as they experienced an increasing need to recover and/or save energy for certain occupations. One common strategy was to try to make these decisions based on how they experienced meaning in occupations, which can be compared with how Hitch et al. (2014b) emphasized the importance of understanding all the dimensions of meaning. The findings show how work and being a worker was experienced as meaningful and important early on after the SCI. Work was also closely related to belonging and becoming: it is a place to go to, where one's competency is needed and one can collaborate with colleagues and develop both as an individual and as part of a working group. One might expect that this should be supported by society, but the findings show that the sickness compensation system could cause problems since there is no possibility of getting an individualized work time based on the person's ability. This is something that can lead to a risk of occupational injustice, especially occupational alienation and deprivation (Hitch et al., 2014a; Nilsson & Townsend, 2014). In addition, the findings showed how other laws also complicated their everyday life. It was not possible to increase personal assistance, for example, or get an adapted car after the age of 65 years, something that can cause social exclusion and restrict possibilities to participate in for example certain community-based occupations. Furthermore it was not possible for a person to have two different types of electrically powered wheelchairs for a transition period. Thus, the findings indicated how persons aging with a traumatic SCI cannot participate in occupations on the same terms as others, leading to occupational injustice, which can cause further stress in their everyday life.

Implications for praxis and rehabilitation in society

Based on how the findings describe the complexity of participation in everyday life while aging with a traumatic SCI, it is of key importance to look at rehabilitation and what can be done to support these persons to continue to participate in occupations. The initial rehabilitation and the importance of a multi-professional team are well described (Sand et al., 2006; Whiteneck et al., 2011). Annual follow-ups are usually made throughout the years after a SCI, however, there is a lack of knowledge regarding for example suitable surveillance recommendations (Groah & Kehn, 2010) and the findings emphasized the need for regularly held meetings with multi-professional teams. The advantage of meeting with different professionals is that a person's everyday life can be highlighted from a variety of perspectives; it is then easier to identify problems in early stages and have a proactive approach. This is especially important as the findings showed that persons do not necessarily know where to get the right support. The findings also suggest providing information about aging with a SCI at an early stage, including how to be observant for signs of physical deterioration in order to act proactively with appropriate interventions. When working with rehabilitation for persons aging with SCI; health maintenance, minimization of SHC, maximal functioning, and quality of life, together with enabling participation are described as important (Barker et al., 2009; Capoor & Stein, 2005). Nevertheless, there is a lack of knowledge regarding the benefits of different interventions related to participation in occupations and caregiver issues (Groah & Kehn, 2010; Groah et al., 2012). Some researchers have suggested that an active lifestyle and exercise can prevent SHC and are important for a healthy perspective among persons aging with a SCI (Buchholz et al., 2009; Ginis, Jetha, Mack & Hetz, 2010; Hicks et al., 2011; Rimmer, Chen & Hsieh, 2011; van der Woude et al., 2013). Of course it is important to find ways to decrease the effects of SHC so that persons can continue to participate in occupations, but the findings in this thesis show how persons no longer participated in exercise and active recreation due to SHC or the increasing need to save strength for other occupations. The implication is that it is not possible to only focus on improving physical functions because that can further increase their feelings of self-contempt and imbalance between occupations. For this reason, I would like to propose the use of the Kawa model (Iwama, 2006/2012) as another way of looking at rehabilitation for persons aging with a traumatic SCI, in order to recreate balance in their everyday life.

The ideology in the Kawa model can be of interest, as it provides another approach to rehabilitation by focusing not just on the individual as a distinctly defined self, and somewhat superior to the environment, which is commonly seen in Western social contexts as well in rehabilitation (Iwama, 2005; Kielhofner, 2008; Townsend & Polatajko, 2013). Using the Kawa model can serve as a tool when meeting clients and when listening to their narratives about participation in everyday life; it is possible to get a comprehensive picture of the client's occupational situation, and can also enhance the client/therapist interaction (Carmody et al., 2007; Paxson, Winston, Tobey, Johnston & Iwama, 2012). However, it is important to remember that further and more comprehensive research is needed to be able to test the usability of the Kawa model for persons aging with a traumatic SCI. The Kawa model has been described as culturally sensitive (Iwama et al., 2009; Iwama, 2006/2012), but I also believe this model can be sensitive for the complexity, imbalance and stress persons seem to experience in their everyday lives when aging with a SCI. Groah et al. (2012) asked for new standardized measures to improve assessments of changes in health, function and participation across life span. Based on the experience of using PARTS/M-v3 for the data collection in study IV, this instrument might be useful for the purpose mentioned above, even if more research and evaluation might be needed on how to make the best use of it since it has been identified as long, and to some extent, complicated (Magasi & Post, 2010). On the other hand, the findings show that the complexity that this group has experienced when participating in everyday life can be difficult to capture with a more standardized instrument.

Besides using the Kawa model initially when meeting persons aging with SCI, I believe that there are other interventions that we as occupational therapists can do, in order to help these persons to continue to participate in occupations. Based on what the occupational situation looks like for the client, the findings have implications for the need to also do more specific assessments in relation to, for example, pain and fatigue, or the increasing need to save energy for certain occupations. Interventions like energy conserving techniques, prescribing assistive devices and/or adaptations in the environment can be useful to enable new ways to participate in occupations, something that has been proven effectively for persons with for example multiple sclerosis (Mathiowetz, Finlayson, Matuska, Chen & Luo, 2005; Sauter, Zebenholzer, Hisakawa, Zeitlhofer & Vass, 2008). Still, research is needed to test the effect of these interventions for persons aging with a SCI. Moreover, with the findings showing a complex struggle to continue to participate in occupations and an imbalance in everyday life, this can, according to earlier research cause stress (Hitch et al., 2014a), suggesting the need to recreate balance and harmony in the everyday life (Håkansson, Dahlin-Ivanoff & Sonn, 2006). One way to establish balance and harmony can be to use the Redesigning Daily Occupations – program [ReDO] (Erlandsson, 2013) that has been developed for persons with stress-related disorders, but has also been suggested for additional populations where persons experience difficulties in organizing their daily occupations.

In addition, the findings have implications for the importance to be observant for which dimension of meaning in occupations is most prominent, in order to know how to plan for interventions; this is in line with earlier research regarding persons with multiple sclerosis and how one or more dimensions can be more prominent at different times in a person's life (Hitch et al., 2014b; Månsson Lexell, Iwarsson & Larsson-Lund, 2011). As a complement to occupational therapy and other rehabilitation interventions, I suggest, based on the findings, that persons aging with a SCI could find meetings with well-matched role models useful in finding solutions for how to handle participation in everyday life. Such meetings could be arranged both by non-profit organizations and/or within rehabilitation settings, where it might be of value to mix groups with persons experiencing aging with different neurological diseases.

To conclude the findings show how persons' possibilities to continue to participate in occupations while aging with a SCI not only depend on the interventions from either occupational therapists or other members in a multi-professional team, but also on how the social insurance system and laws/governmental policies for assistive devices, personal assistance and adapted cars are arranged. The way it is arranged today can, according to the findings, mean that persons aging with a SCI do not have the same opportunities to be a citizen with all that implies, or to be socially included like everyone else.

IDEAS FOR FUTURE RESEARCH

Based on the findings that have been presented and discussed in this thesis, I would like to give my suggestions and ideas for further research. First of all, it is important to learn more about changes of participation in everyday life from a longitudinal perspective, both for persons aging with complete and incomplete SCI. There is also a need to compare the findings from this thesis with SCI populations internationally. Further, to help recreate a balance in everyday life, it is important to test the usability of the Kawa model as a foundation for regular follow-ups for persons aging with a SCI, and also to create an intervention program based on the Redesigning Daily Occupations-program [ReDO]. Moreover, it is important that the multi-professional teams working with these persons have knowledge of their rehabilitation needs throughout the life span. Therefore it is of great value to explore interventions that can be effective. For example how the use of assistive devices and energy-conserving techniques can decrease pain and fatigue when participating in occupations. In addition, from a health-economic perspective, it is important to test whether the use of assistive devices and/or personal assistance can be cost-effective as preventive strategies. Furthermore, from a societal perspective it is essential to explore and describe if and how a flexible sickness compensation system, based on the individuals' actual capacity, can enhance a person's opportunities to continue to work and thus provide them with a better economic situation. These suggestions of research can enhance the possibilities for experiencing agency, participation, and well-being in everyday life among persons aging with a SCI.

ETHICAL CONSIDERATIONS

All studies were performed according to the Swedish law for ethics in research (SFS 2003:460). Studies I, II and III were approved by the Regional Ethical Review Board in Umeå, and study IV was approved by the Human Ethics Committee in Stockholm, both located in Sweden. In accordance with the law mentioned above and the ethical guidelines and recommendations by the World Medical Association (WMA, 2008), I made the following ethical considerations when planning and conducting the four studies in this thesis.

Information and written consent

In all the studies the participants received written information about the aims and implementation of the studies. Information was also provided detailing that participation in the studies was voluntary and that the participants had the right to end their participation at any time without giving any explanation. Since the participants in studies I and II were recruited through the non-profit organization RG Active Rehabilitation, a complementary letter from the organization was attached. The complementary letter explained that the organization had provided the contact information for members and was supporting the studies. Further, the members were guaranteed that they were in no way obligated or compelled to participate and that, regardless of their decision, they were always welcome to participate in the activities of the organization. Persons who were interested in participating in study II returned their written consent and phone numbers, upon which, I contacted them by phone and gave oral information about the studies and answered any questions.

Anonymity and confidentiality

Participants in all studies were informed that the collected data would be handled in such a way that no one besides me and my supervisors at Luleå University of Technology would have access to it; audio files and transcripts were stored on password-protected computers, whereas paper copies for surveys were kept in a locked and secured place. The participants were ensured confidentiality, which means that when presenting the findings it will not be possible to recognize/identify particular persons or places in the separate studies or in the thesis. The participants in study I became anonymous for me throughout the research process since no one contacted me with any questions for clarification regarding the study and/or the survey. This was possible since the surveys were not coded in relation to the membership list, as no reminders were sent out. The document with the members' contact information that was used for randomly selecting the participants was kept in a locked place in the organization's office until it could be destroyed once the decision was made that no additional members should be contacted. As pertains to study IV, an authorized person at Rehab Station identified persons matching the inclusion criteria, and completed a list with contact information and information about age, level and severity of injury, year of injury and time since injury. The list was picked up at the Rehab Station by one of the supervisors at Luleå University of Technology and has always been kept in a locked and secured place, when not being used.

Privacy and a comfortable interview situation

All the interviews in study II were performed through personal encounters; the time and place for the interviews were chosen in accordance with the participants' wishes. Similarly, the participant in study III decided the time and place for the four interviews that were held with him; two of the interviews were performed in person, and two by phone. The narrative interviews focused on participants' experiences of how their ability to participate and act has changed over time, due to SHC for example, something that evoked memories from positive and negative events from their lives. These experiences of joy and sorrow are important in their stories and have been gathered in order to develop knowledge of participation in everyday life while aging with a traumatic SCI. It is important to create a calm and relaxed atmosphere where the participants can feel comfortable, and minimize feelings of inconvenience. I was able to do this by being responsive, showing empathy and respect for the participants' stories, and informing the participants that they could take a break during the interviews if needed. Worth mentioning is that I had met the participants before the interviews performed in study II, since I worked as a leader at the Retro camps arranged by the RG Active Rehabilitation. Participants received this information in the complementary letter from the organization. The fact that we had met before seemed to influence the interview situation positively. The participants seemed comfortable when it got silent in the room, and they could share their feelings of joy as well as sorrow. When coming to the end of the narrative interviews in studies II and III and in the phone survey in study IV, participants were informed that they could contact me by email or phone with any questions or thoughts that the interview/phone survey might have raised. A couple of participants did choose to write emails after the interviews in study II to share additional thoughts. I answered these emails until the participants ended the correspondence. When performing the phone survey in study IV, I referred a number of participants to appropriate health care contacts for questions about recent symptoms that had occurred.

Overall, by valuing the risk of harm and taking those considerations into account and, when needed, taking necessary precautions, I believe that the knowledge provided from the four studies and this thesis will exceed the possible risk of negatively affecting the participants through their participation.

METHODOLOGICAL CONSIDERATIONS

This thesis contributes to the understanding of participation in everyday life while aging with a traumatic SCI. It is important to remember that throughout the process of planning and conducting research, several decisions had to be made, decisions that in turn can affect the findings in one way or another. This thesis had an explorative design and a mixed method was used to answer to the overall aim. The benefit of using a mixed method is that it adds breadth and depth of understanding of the phenomena being studied, together with corroborating the findings. In addition it counterbalances against the weaknesses inherent with using one method by itself (Creswell & Plano, 2010). Since it is possible to find methodological considerations in relation to each of the studies in this thesis, I have chosen to do a more general methodological consideration here even though a few specific areas will be highlighted as well.

To start, I would like to say that using both quantitative and qualitative methods has been a great learning experience and I am looking forward to continuing to develop these skills in future research. I can definitely see the benefits of using a mixed method design since the research questions within this area are complex. When conducting a mixed method, either in a study or in a set of related studies such as within my thesis, it is important that the researchers have knowledge of and experience in using both methods (Creswell & Plano, 2010; Klassen, Creswell, Clark, Smith & Meissner, 2012). All of the researchers involved in these four studies have broad experience in using qualitative and quantitative methods, together with a diversity of experiences related to SCI. This was useful in for example studies II and III in the way the first and last author were involved in the process of analyzing the data. Authors two and three, on the other hand, asked questions to help us adopt a self-critical stance, but also regularly gave constructive feedback, helping to increase the trustworthiness of these studies.

In studies II and III, narrative interviews and analysis were used, and several arguments motivated this choice. First, listening to the story of an individual gives a more complete understanding of how participation in everyday life has worked so far, and what the expectations are for the future. Secondly, a narrative method keeps our focus on the individual instead of the disability (Franits, 2005). In addition, the narrative method has been proven successful in earlier research among persons with a SCI (Isaksson & Prellwitz, 2010; Smith & Sparkes, 2005) and also in aging studies (Phoenix, Smith & Sparkes, 2010). There is always a possibility that the participants narrate a limited story, although this consideration seemed unlikely since all the participants shared stories of joy as well as sorrows and showed their feelings in relation to certain parts of their stories. An advantage of using a narrative method was that it opened up aspects of participation in everyday life while aging with a SCI that would not had been captured with semi-structured questions.

A cross-sectional design was used in studies I and IV, a design that is common and which provides a "snapshot in time" of the situation being studied. This method can, if not used correctly, result in misleading information (Adkins, 2001; Dawson & Trapp, 2004). Studies I and IV had an exploratory approach, and therefore it was suitable to use cross-sectional studies to get a description of the present situation and thus a starting point for further research. When conducting research about participation and aging with a SCI, it is important to remember that there are several variables, such as current chronological age, level and severity of SCI, and time since injury, that may affect the results and thus limit the possibilities to generalize the findings. The next step can be to use a time-sequential design since it adds a longitudinal component to the cross-sectional study (Adkins, 2001). Surveys are generally used in cross-sectional studies and were too in studies I and IV. A common problem with survey research is obtaining a sufficiently large response rate. The response rates turned out to be, broadly, 50% in study I, 60% for the phone survey in study IV, and 80% for the general health question; these rates are considered acceptable based on the recommendations in the literature (Dawson & Trapp, 2004). The use of PARTS-Mv3 in study IV could have had problems with non-responsive bias (Dawson & Trapp, 2004) if it had been used as a postal survey, since Magasi and Post (2010) identified the instrument as long and to some extent complicated. The decision to use PARTS/M-v3 in a phone survey was therefore successful since all surveys were completed.

The surveys used in studies I and IV were based on already existing instruments. There is a risk in using existing instruments and also in adapting them for surveys since there can be serious implications for reliability and validity when used for example on a different population (Meadows, 2003). The NPS-interest checklist had not been used to survey persons with SCI, and thus information regarding the validity of the instrument among this group of persons was lacking. A series of Rasch analyses using the software FACETS (Linacre, 1987-2006) was done to investigate the four questions in the NPS-interest checklist. This method has been increasingly used in rehabilitation medicine for testing both new and existing assessments and questionnaires (Tesio, 2003). Due to the fact that the goodness-of-fit statistics were evaluated as acceptable, the analyses provided evidence of the validity of the NPS-interest checklist for measuring interest, performance, experience of well-being, and changed performance of leisure activities for persons with SCI. In study IV, PARTS/M-v3 was used as a survey. The choice of using this instrument was based on the fact that it includes questions regarding both the objective and subjective dimension of participation, something that is recognized as one of the strengths of the instrument (Magasi & Post, 2010). The original version has been tested as a reliable and valid measure of participation, with good internal consistency and stability (Gray et al., 2006). The translation of PARTS/M-v3 into Swedish and the adding of three questions were done in cooperation with Professor David Gray, who was one of the creators of the instrument and also a co-author in the manuscript for this study. Continuous discussions were held in the research group before a final version was completed. The final version was tested on four persons matching the inclusion criteria for study IV. No difficulties or problems arose in the testing procedure.

I used the Kawa model (Iwama et al., 2009; Iwama, 2006/2012) for the secondary analyze of the findings from the four studies. The advantage of doing so was that it gave a more comprehensive understanding of participation in everyday life while aging with a traumatic SCI. At the same time, one has to remember that no reflective dialogues were undertaken with any of the participants to value the structures based on their size and location or the relationship between them. This is an important step when using the Kawa model in clinical work, where it is usually used with one client at a time, thus enabling a client-centered approach. However, Iwama (2006/2012) does describe that the client does not necessarily have to be a single person, but can also be a collective. Another advantage is that, by trying this out in this thesis, I have shown the important to further evaluate the use of the Kawa model as a foundation for regular follow-ups for persons aging with a SCI.

Last, but not by any terms least, something needs to be said about my pre-understanding. In all research but especially when using qualitative methods, it is important to clarify one's pre-understanding in order to not let it influence the data analysis or other aspects. My clinical experience as an occupational therapist has been basically from primary care centers and the number of persons that I met with a SCI could be counted on one hand. My experience in meeting with and working together with persons who have experienced a SCI developed during my years working as a leader for different camps organized by RG Active Rehabilitation. My interest in being a part of this organization and my curiosity to learn more about SCI came after I took a weeklong course about wheelchairs in 2005. During this course I had the opportunity to use a wheelchair in different situations, like using an escalator or going by the metro, and also learn how to adapt wheelchairs. Throughout the research process, this pre-understanding was an advantage when meeting with persons in interview situations or talking with them when conducting the phone survey. At the same time, I have tried to keep an open mind and be aware of my pre-understanding, reflecting upon it when, for example, doing data analysis. In my effort to work with my pre-understanding, it has been of great value that my supervisors and research colleagues in the studies for this thesis have had a great variety of experience regarding SCI, and that we also have different health care and rehabilitation professions. These diversities have been a strength because it have contributed to our discussions about, for example, the data analysis and the findings from different angles, thus enhancing the trustworthiness of the studies.

SUMMARY IN SWEDISH – SVENSK SAMMANFATTNING

Att drabbas av en ryggmärgsskada innebär en dramatisk förändring i livet och även till synes enkla vardagliga aktiviteter kan bli en utmaning. Det initiala omhändertagandet efter en ryggmärgsskada fokuserar på att ge vård för att förebygga medicinska komplikationer men också på rehabilitering, det vill säga att ge dessa personer möjlighet att leva ett aktivt liv utifrån de nya förutsättningarna de har beroende på ryggmärgsskadans nivå och omfattning. Under en lång tid ansågs personer med ryggmärgsskador kunna bibehålla sin uppnådda funktionsnivå efter den initiala rehabiliteringen resten av livet. Allt eftersom personer i allt större utsträckning både överlever och åldras med en ryggmärgsskada, har senare forskning belyst ett för tidigt åldrande hos denna grupp. Detta innebär en tidigare debut av sjukdomar som exempelvis diabetes och hjärt-kärlsjukdomar men även en ökad svårighetsgrad och/eller frekvens av vissa sjukdomar i motsats till jämnåriga individer utan funktionshinder. Även andra sekundära medicinska komplikationer såsom exempelvis smärta, nytillkommen muskelsvaghet och fatigue har beskrivits för personer som åldras med en ryggmärgsskada. Däremot är kunskapen begränsad om hur personerna själva beskriver deras möjlighet att vara delaktiga i vardagslivet över tid samt hur sekundära medicinska komplikationer påverkar möjligheter att delta i aktiviteter. Vidare saknas studier kring och hur behovet av rehabilitering och/eller stöd från samhället förändras över tid. Kunskap som är viktig att utveckla utifrån ett rehabiliterings- och tillika ett arbetsterapeutiskt perspektiv för att kunna förbättra rehabiliteringsinsatserna för att personer med ryggmärgsskada ska kunna vara delaktiga i aktiviteter genom hela livet. Det övergripande syftet med denna avhandling var därför att utveckla kunskap om delaktighet i vardagslivet hos personer som åldras med en traumatisk ryggmärgsskada.

Avhandlingen har en mixad metod design med en explorativ ansats och består av fyra studier, två utförda med kvantitativ metod och två utförda med kvalitativ metod. I studie I, II och III rekryterades deltagarna från RG Aktiv Rehabilitering som är en intresseorganisation med särskilt intresse för aktiv rehabilitering för personer med ryggmärgsskada. Genom att vända sig till denna organisation så var det möjligt att erhålla en nationell spridning av deltagare i Sverige. Deltagarna i studie IV rekryterades via ett samarbete med Rehab Station Stockholm och Spinalis.

Nedanstående tabell visar information om deltagarna i de olika studierna.

	Studie I	**Studie II**	**Studie III**	**Studie IV**		
				RD⋆ Total population	RD AH†	RD AH TE‡
Deltagare	97	8	1	121	102	73
Män n (%)	55 (56.7)	4		94 (77.7)	80 (78.4)	55 (75.3)
Kvinnor	42 (43.3)	4		27 (22.3)	22 (21.6)	18 (24.7)
Ålder $\bar{x}$±SD	43.5±12.0 19 – 69	57.6±9.0 48 – 74	52	62.2±9.2 50 – 87	62.7±9.5	63.7±9.4
TSS″ $\bar{x}$±SD	7.3±5.6 2 – 31	27.1±10.4 13 – 41	35	35.5±8.8	35.9±8.7	36.3±9.2

⋆RD = Register Data. †AH = Allmän Hälsa. ‡TE = Telefon Enkät.

″TSS = Tid Sedan Skada

Till tabellen bör tilläggas att deltagarnas nivå och omfattning på ryggmärgsskadan varierade mellan studierna. I studie I och IV deltog personer med para- eller tetraplegi. I studie IV fanns följande specifika inklusionskriterier för deltagande, skadenivå: halskotsnivå C5[3]- ländkotsnivå L2, och AIS A-D[4]. I studie II och III deltog personer med komplett eller inkomplett tetraplegi.

En kvantitativ metod användes i studie I, för att utforska och få en beskrivning av fritidsrepertoaren bland personer med en traumatisk ryggmärgsskada. Deltagarna besvarade en enkät baserad på NPS-Intressechecklista. För att utvidga förståelsen

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[3] C5, C= Cervical, dvs indikerar 5:e halskotan.

[4] Ryggmärgsskadans omfattning i enlighet med ASIA Impairment Scale (Marino et al., 2003).

och kunna beskriva hur möjligheten att delta i aktiviteter förändrades över tid användes en kvalitativ metod med en narrativ ansats i studie II och III. I studie II genomfördes intervjuer med de åtta deltagarna och i studie III genomfördes fyra intervjuer med en man mellan 2010-2014. Baserat på resultaten i studie II och III, valdes återigen en kvantitativ metod i studie IV för att utforska och beskriva delaktighet i aktiviteter och frekvensen av sekundära medicinska komplikationer i ett större stickprov. För detta ändamål användes en enkät baserad på instrumentet PARTS/Mv-3.

En sekundär analys av resultaten från de fyra studierna genomfördes för att kunna belysa och ge en mer heltäckande bild av resultaten. Kawa modellen valdes som kategoriseringsmatrix till analysen för att modellen beskriver livet som en komplex resa som flyter genom tid och rymd på ett liknande sätt som en flod. En metafor som passar med det övergripande syftet med denna avhandling. I modellen beskrivs hur vissa strukturer som stenar (livssituationer/problem), väggar och botten (miljön) samt drivved (tillgångar och ansvar) är alla olika delar av en flod som kommer att påverka dess gränser, form, flöde och kvalitet, och tillika möjligheten att delta i aktiviteter och uppleva välbefinnande. Att använda Kawa modellen visade på den komplexitet som det innebär att åldras med en ryggmärgsskada.

Resultaten visade hur deltagarnas möjligheter att delta i aktiviteter och därmed uppleva välbefinnande förändrades dramatiskt i samband med att de drabbades av en ryggmärgsskada. Den långa initiala rehabiliteringen tillsammans med att möta välmatchade förebilder inspirerade deltagarna att prova nya och gamla aktiviteter samt att inte låta sig begränsas av ryggmärgsskadan. Detta bidrog till att deltagarna utvecklade en förmåga att agera. En förmåga som bland annat visade sig i hur de själva var aktiva och gjorde medvetna val för att kunna återgå till arbete eller för att välja personlig assistans. Under en förhållandevis lång period, cirka 10 till 20 år så visade resultatet hur deltagarna hade nått en trygghetszon där de visste hur de skulle kompensera för ryggmärgsskadan i vardagslivet. Deltagarnas förmåga att agera var en tillgång som hjälpte dem vid eventuella problem eller när det exempelvis handlade om att kämpa för att få ett visst hjälpmedel. Allt verkade möjligt och deltagarna tvekade inte att delta i olika aktiviteter oavsett om det handlade om aktiviteter på hemmaplan eller att resa utomlands. Samtidigt så gjorde deltagarna medvetna val om vilka aktiviteter de skulle delta i och utmanade sig inte på samma sätt som tidigare. Deltagarna upplevde framtiden som positiv och de hade en känsla av att det skulle finnas möjligheter för dem att fortsätta utvecklas.

Resultatet visade att när cirka 20 till 55 år hade gått sedan ryggmärgsskadan så började deras möjlighet till delaktighet i vardagslivet att förändras. Deltagarna beskrev hur sekundära medicinska komplikationer såsom exempelvis tilltagande smärta i exempelvis axlar, progressiv muskelsvaghet, spasticitet och trötthet påverkade deras möjlighet att delta i aktiviteter. De försökte agera och göra olika aktiva val för att bland annat kunna fortsätta arbeta. Deras aktiva val baserades på vilka aktiviteter de själva och/eller sina närstående upplevde som meningsfulla. De saknade kunskap och stöd från hälso- och sjukvården. Deltagarna upplevde ett vardagsliv i obalans till följd av förändringar i den egna hälsan men även av att det inte fanns tillräckligt med stöd i samhället för att de skulle kunna fortsätta delta i aktiviteter. Det fanns till exempelvis ingen möjligt att utöka personlig assistans eller att få en anpassad bil efter att man fyllt 65 år.

Resultaten från avhandlingen ger implikationer för praxis och rehabilitering för att främja att personer som åldras med en ryggmärgsskada ska kunna fortsätta delta i aktiviteter och återfå balans i vardagslivet. Det kan vara värdefullt att använda Kawa modellen som grund för mötena i samband med regelbundna uppföljningar. Det finns behov av att se över rehabiliteringen så att det finns ett multi-professionellt team som samarbetar och har god kunskap om vilka behov som kan uppstå hos dessa personer genom livet. Det är viktigt att varje profession ser över vilka åtgärder som kan vara effektiva och skapa lämpliga åtgärdsprogram. För arbetsterapeuters del handlar det exempelvis om att undersöka hur exempelvis hjälpmedel och energibesparande arbetssätt kan minska smärta och fatigue samt främja möjligheten att delta i aktiviteter. Baserat på hur utformningen av samhällets lagar och riktlinjer i dagsläget inte stödjer dessa personers möjlighet att delta i aktiviteter efter att de exempelvis fyller 65 år så finns det ett behov av att undersöka detta vidare för att ge alla samma rättigheter till delaktighet i sitt vardagsliv.

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REFERENCES

Adkins, R. H. (2001). Research issues in aging studies associated with SCI. *Topics in Spinal Cord Injury Rehabilitation, 6*(3), 128-135.

American Occupational Therapy Association. (2008). Occupational therapy practice framework: Domain and process. *American Journal of Occupational Therapy*, 62, 625-683. doi:10.5014/ajot.62.6.625

Amsters, D. I., Pershouse, K. J., Price, G. L., & Kendall, M. B. (2005). Long duration spinal cord injury: Perceptions of functional change over time. *Disability and Rehabilitation, 27*(9), 489-497. doi:10.1080/09638280400018478

Angel, S., Kirkevold, M., & Pedersen, B. D. (2009). Getting on with life following a spinal cord injury: Regaining meaning through six phases. *International Journal of Qualitative Studies on Health and Well-Being, 4*(1), 39-50. doi:10.1080/17482620802393492

Barker, R. N., Kendall, M., Amsters, D., Pershouse, K. J., Haines, T. P., & Kuipers, P. (2009). The relationship between quality of life and disability across the lifespan for people with spinal cord injury. *Spinal Cord, 47*(2), 149-155. doi:10.1038/sc.2008.82

Bauman, W. A., & Spungen, A. M. (2001). Carbohydrate and lipid metabolism in chronic spinal cord injury. *The Journal of Spinal Cord Medicine, 24*(4), 266-277.

Bergstrom, A., Eriksson, G., Asaba, E., Erikson, A., & Tham, K. (2014). The lived experience of enacting agency in everyday life after a stroke. *Brain Injury, 28*(5-6), 674-.

Biering-Sørensen, F., Jennum, P., & Laub, M. (2009). Sleep disordered breathing following spinal cord injury. *Respiratory Physiology & Neurobiology, 169*(2), 165-170. doi:10.1016/j.resp.2009.08.014

Bond, T. G., & Fox, C. M. (2007). *Applying the Rasch model: Fundamental measurement in the human sciences*. Mahwah, NJ: Lawrence Erlbaum.

Borell, L., Asaba, E., Rosenberg, L., Schult, M., & Townsend, E. (2006). Exploring experiences of "participation" among individuals living with chronic pain. *Scandinavian Journal of Occupational Therapy, 13*(2), 76-85. doi:10.1080/11038120600673023

Boyce, K. O., & Fleming-Castaldy, R. P. (2012). Active recreation and well-being: The reconstruction of the self-identity of women with spinal cord injury. *Occupational Therapy in Mental Health, 28*(4), 356-378. doi:10.1080/0164212X.2012.708603

Brah, A. (1996). *Cartographies of diaspora: Contesting identities.* London: Routledge Press.

Brose, S. W., Boninger, M. L., Fullerton, B., McCann, T., Collinger, J. L., Impink, B. G., & Dyson-Hudson, T. A. (2008). Shoulder ultrasound abnormalities, physical examination findings, and pain in manual wheelchair users with spinal cord injury. *Archives of Physical Medicine and Rehabilitation, 89*(11), 2086-2093. doi:10.1016/j.apmr.2008.05.015

Brougham, R., David, D. S., Adornato, V., Gordan, W., Dale, B., Georgeadis, A. C., & Gassaway, J. (2011). Speech-language pathology treatment time during inpatient spinal cord injury rehabilitation: The SCIRehab project. *The Journal of Spinal Cord Medicine, 34*(2), 186-195. doi: http://dx.doi.org/10.1179/107902611X12971826988174

Buchholz, A. C., Martin Ginis, K. A., Bray, S. R., Craven, B. C., Hicks, A. L., Hayes, K. C., Latimer, A. E., McColl, M. A., Potter, P. J., & Wolfe, D. L. (2009). Greater daily leisure time physical activity is associated with lower chronic disease risk in adults with spinal cord injury. *Applied Physiology, Nutrition, and Metabolism, 34*(4), 640-647. doi: 10.1139/H09-050

Caldwell, L., Adolph, S., & Gilbert, A. (1989). Caution! Leisure counselors at work: Long term effects of leisure counseling. *Therapeutic Recreation Journal, 23*(3), 41-49.

Capoor, J., & Stein, A. B. (2005). Aging with spinal cord injury. *Physical Medicine and Rehabilitation Clinics of North America, 16*(1), 129-161. doi:10.1016/j.pmr.2004.06.016

Carmody, S., Nolan, R., Ni Chonchuir, N., Curry, M., Halligan, C., & Robinson, K. (2007). The guiding nature of the kawa (river) model in Ireland: Creating both opportunities and challenges for occupational therapists. *Occupational Therapy International, 14*(4), 221-236. doi: 10.1002/oti.235

Charlifue, S. W., Weitzenkamp, D. A., & Whiteneck, G. G. (1999). Longitudinal outcomes in spinal cord injury: Aging, secondary conditions, and well-being. *Archives of Physical Medicine and Rehabilitation, 80*(11), 1429-1434. doi:10.1016/S0003-9993(99)90254-X

Clayton, K. S., & Chubon, R. A. (1994). Factors associated with the quality of life of long-term spinal cord injured persons. *Archives of Physical Medicine and Rehabilitation, 75*(6), 633-638.

Cook, K. F., Molton, I. R., & Jensen, M. P. (2011). Fatigue and aging with a disability. *Archives of Physical Medicine and Rehabilitation, 92*(7), 1126-1133. doi:10.1016/j.apmr.2011.02.017

Coyle, C. P., & Kinney, W. B. (1990). Leisure characteristics of adults with physical disabilities. *Therapeutic Recreation Journal, 24*(4), 64-73.

Creswell, J. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches* (3rd ed.). Thousand Oaks, CA: Sage Publications, Inc.

Creswell, J., & Plano, C. (2010). *Designing and conducting mixed methods research* (2nd ed.). Thousand Oaks, CA: SAGE Publications , Inc.

Crewe, N., & Krause, J. (1990). An eleven-year follow-up of adjustment to spinal cord injury. *Rehabilitation Psychology, 35*(4), 205-210. doi: http://dx.doi.org/10.1037/h0079064

Cushman, L., & Hassett, J. (1992). Spinal cord injury: 10 and 15 years after. *Spinal Cord, 30*(10), 690-696. doi:10.1038/sc.1992.135

Daniel, A., & Manigandan, C. (2005). Efficacy of leisure intervention groups and their impact on quality of life among people with spinal cord injury. *International Journal of Rehabilitation Research, 28*(1), 43-48.

Dawson, B., & Trapp, R. G. (2004). *Basic & Clinical Biostatistics* (4th ed.). New York, Lange Medical Books/McGraw-Hill Companies, Inc.

Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing, 62*(1), 107-115. doi: 10.1111/j.1365-2648.2007.04569.x

Erlandsson, L. (2013). The redesigning daily occupations (ReDO)-program: Supporting women with stress-related disorders to return to Work—Knowledge base, structure, and content. *Occupational Therapy in Mental Health, 29*(1), 85-101. doi:10.1080/0164212X.2013.761451

Faaborg, P. M., Christensen, P., Finnerup, N., Laurberg, S., & Krogh, K. (2008). The pattern of colorectal dysfunction changes with time since spinal cord injury. *Spinal Cord, 46*(3), 234-238. doi:10.1038/sj.sc.3102121

Fadyl, J. K., & McPherson, K. M. (2010). Understanding decisions about work after spinal cord injury. *Journal of Occupational Rehabilitation, 20*(1), 69-80. doi: 10.1007/s10926-009-9204-1

Fallahpour, M., Jonsson, H., Taghi Joghataei, M., Nikbakht Nasrabadi, A., & Tham, K. (2013). "I am not living my life": Lived experience of participation in everyday occupations after stroke in Tehran. *Journal of Rehabilitation Medicine, 45*(6), 528-534. doi: http://dx.doi.org/10.2340/16501977-1143

Foy, T., Perritt, G., Thimmaiah, D., Heisler, L., Offutt, J. L., Cantoni, K., Hsei, C. H., Gassaway, J., Ozelie, R., & Backus, D. (2011). Occupational therapy treatment time during inpatient spinal cord injury rehabilitation. *The Journal of Spinal Cord Medicine, 34*(2), 162-175. doi: http://dx.doi.org/10.1179/107902611X12971826988093

Franits, L. E. (2005). Nothing about us without us: Searching for the narrative of disability. *American Journal of Occupational Therapy, 59*(5), 577-579. doi:10.5014/ajot.59.5.577

Fuhrer, M., Rintala, D., Hart KA, Clearman, R., & Young, M. (1992). Relationship of life satisfaction to impairment, disability, and handicap among persons with spinal cord injury living in the community. *Archives of Physical Medicine and Rehabilitation, 73*(6), 552-557.

Fuhrer, M. (2000). Subjectifying quality of life as a medical rehabilitation outcome. *Disability & Rehabilitation, 22*(11), 481-489. doi:10.1080/096382800413961

Garland, D. E., Adkins, R. H., Rah, A., & Stewart, C. A. (2001). Bone loss with aging and the impact of SCI. *Topics in Spinal Cord Injury Rehabilitation, 6*(3), 47-60.

Gassaway, J., Dijkers, M., Riders, C., Edens, K., Cahow, C., & Joyce, J. (2010). The SCIRehab project: Treatment time spent in SCI rehabilitation. Therapeutic recreation treatment time during inpatient rehabilitation. *The Journal of Spinal Cord Medicine, 34*(2), 176-185. doi: 10.1179/107902611X12971826988138

Ginis, K. M., Jetha, A., Mack, D., & Hetz, S. (2010). Physical activity and subjective well-being among people with spinal cord injury: A meta-analysis. *Spinal Cord, 48*(1), 65-72. doi:10.1038/sc.2009.87

Goodman, S. (1986). *Spirit of Stoke Mandeville: The story of sir Ludwig Guttmann*. London: Collins.

Gray, D. B., Hollingsworth, H. H., Stark, S. L., & Morgan, K. A. (2006). Participation survey/mobility: Psychometric properties of a measure of participation for people with mobility impairments and limitations. *Archives of Physical Medicine and Rehabilitation, 87*(2), 189-197. doi:10.1016/j.apmr.2005.09.014

Groah, S. L., & Kehn, M. (2010). The state of aging and public health for people with spinal cord injury: Lost in transition? *Topics in Spinal Cord Injury Rehabilitation, 15*(3), 1-10. doi: http://dx.doi.org/10.1310/sci1503-1

Groah, S. L., Charlifue, S., Tate, D., Jensen, M. P., Molton, I. R., Forchheimer, M. M., Krause, J. S., Lammertse, D. P., & Campbell, M. (2012). Spinal cord injury and aging: Challenges and recommendations for future research. *American Journal of Physical Medicine & Rehabilitation, 91*(1), 80-93. doi: 10.1097/PHM.0b013e31821f70bc

Hagglund, K. J., Clark, M. J., Mokelke, E. K., & Stout, B. J. (2004). The current state of personal assistance services: Implications for policy and future research. *NeuroRehabilitation, 19*(2), 115-120.

Hammel, J., Magasi, S., Heinemann, A., Whiteneck, G., Bogner, J., & Rodriguez, E. (2008). What does participation mean? An insider perspective from people with disabilities. *Disability & Rehabilitation, 30*(19), 1445-1460. doi: 10.1080/09638280701625534

Hammell, K. W. (2004). Dimensions of meaning in the occupations of daily life. *Canadian Journal of Occupational Therapy, 71*(5), 296-305. doi: 10.1177/000841740407100509

Hammell, K. W. (2009). Self-care, productivity, and leisure, or dimensions of occupational experience? Rethinking occupational "categories". *Canadian Journal of Occupational Therapy, 76*(2), 107-114. doi: 10.1177/000841740907600208

Hammond, F. M., Gassaway, J., Abeyta, N., Freeman, E. S., & Primack, D. (2010). The SCIRehab project: Social work and case management. Social work and case management treatment time during inpatient spinal cord injury rehabilitation. *The Journal of Spinal Cord Medicine, 34*(2), 216-226. doi: 10.1179/107902611X12971826988291

Harper, S. (2000). Ageing 2000 - Questions for the 21st century. *Ageing and Society, 20*(01), 111-122.

Hay-Smith, E. J. C., Dickson, B., Nunnerley, J., & Anne Sinnott, K. (2013). "The final piece of the puzzle to fit in": An interpretative phenomenological analysis of the return to employment in New Zealand after spinal cord injury. *Disability and Rehabilitation, 35*(17), 1436-1446. doi: 10.3109/09638288.2012.737079

Hemmingsson, H., & Jonsson, H. (2005). An occupational perspective on the concept of participation in the International Classification of Functioning, disability and health - some critical remarks. *American Journal of Occupational Therapy, 59*(5), 569-576. doi:10.5014/ajot.59.5.569

Henderson, K. A., & Bedini, L. A. (1995). "I have a soul that dances like Tina Turner, but my body can't": Physical activity and women with mobility impairments. *Research Quarterly for Exercise and Sport, 66*(2), 151-161. doi: 10.1080/02701367.1995.10762222

Hicks, A. L., Ginis Martin, K.A., Pelletier, C. A., Ditor, D. S., Foulon, B., & Wolfe, D. L. (2011). The effects of exercise training on physical capacity, strength, body composition and functional performance among adults with spinal cord injury: A systematic review. *Spinal Cord, 49*(11), 1103-1127. doi:10.1038/sc.2011.62

Hill, M. R., Noonan, V. K., Sakakibara, B. M., & Miller, W. C. (2010). Quality of life instruments and definitions in individuals with spinal cord injury: A systematic review. *Spinal Cord, 48*(6), 438-450. doi:10.1038/sc.2009.164

Hitch, D., Pépin, G., & Stagnitti, K. (2014a). In the footsteps of Wilcock, part one: The evolution of doing, being, becoming, and belonging. *Occupational Therapy in Health Care, 28*(3), 231-246. doi: 10.3109/07380577.2014.898114

Hitch, D., Pépin, G., & Stagnitti, K. (2014b). In the footsteps of Wilcock, part two: The interdependent nature of doing, being, becoming, and belonging. *Occupational Therapy in Health Care, 28*(3), 247-263. doi: 10.3109/07380577.2014.898115

Hitzig, S., Tonack, M., Campbell, K., McGillivray, C., Boschen, K., Richards, K., & Craven, B. (2008). Secondary health complications in an aging Canadian spinal cord injury sample. *American Journal of Physical Medicine & Rehabilitation, 87*(7), 545-555. doi: 10.1097/PHM.0b013e31817c16d6

Hitzig, S. L., Eng, J. J., Miller, W. C., & Sakakibara, B. M. (2011). An evidence-based review of aging of the body systems following spinal cord injury. *Spinal Cord, 49*(6), 684-701. doi:10.1038/sc.2010.178

Hockey, J. L., & James, A. (2003). *Social identities across the life course*. New York: Palgrave Macmillan Basingstoke.

Holtz, A., & Levi, R. (2006). *Ryggmärgsskador: Behandling och rehabilitering*. Lund: Studentlitteratur.

Huston, T., Gassaway, J., Wilson, C., Gordon, S., Koval, J., & Schwebel, A. (2011). Psychology treatment time during inpatient spinal cord injury rehabilitation. *The Journal of Spinal Cord Medicine, 34*(2), 196-204. doi: http://dx.doi.org/10.1179/107902611X12971826988219

Håkansson, C., Dahlin-Ivanoff, S., & Sonn, U. (2006). Achieving balance in everyday life. *Journal of Occupational Science, 13*(1), 74-82. doi: 10.1080/14427591.2006.9686572

Isaksson, G., Lexell, J., & Skär, L. (2007). Social support provides motivation and ability to participate in occupation. *OTJR: Occupation, Participation and Health, 27*(1), 23-30. doi: 10.1177/153944920702700104

Isaksson, G., & Prellwitz, M. (2010). One woman's story about her everyday life after a spinal cord injury. *Disability and Rehabilitation, 32*(16), 1376-1386. doi:10.3109/09638280903514762

Iwama, M. (2005). Situated meaning: An issue of culture, inclusion and occupational therapy. In F. Kronenberg, S. S. Algado, N. Pollard, D. Werner & K. Sinclair (Eds.), *Occupational therapy without borders: Learning from the spirit of survivors*. Edinburgh: Elsevier – Churchill Livingstone.

Iwama, M., Thomson, N., Macdonald, R., Iwama, M., Thomson, N., & Macdonald, R. (2009). The Kawa model: The power of culturally responsive occupational therapy. *Disability & Rehabilitation, 31*(14), 1125-1135. doi: 10.1080/09638280902773711

Iwama, M. (2012). *Kawa modellen: Kulturrelevant arbetsterapi* (A. Schaerström, Trans.). Lund: Studentlitteratur. (Original work published 2006).

Jensen, M. P., Truitt, A. R., Schomer, K. G., Yorkston, K. M., Baylor, C., & Molton, I. R. (2013). Frequency and age effects of secondary health conditions in individuals with spinal cord injury: A scoping review. *Spinal Cord, 51*, 882-892. doi:10.1038/sc.2013.112

Johnson Burke, R., & Onwuegbuzie, A. J. (2004). Mixed methods research: A research paradigm whose time has come. *Educational Researcher, 33*(7), 14-26. doi: 10.3102/0013189X033007014

Kelly, J. R., & Kelly, J. R. (1994). Multiple dimensions of meaning in the domains of work, family, and leisure. *Journal of Leisure Research, 26*(3), 250-274.

Kennedy, P., Taylor, N., & Hindson, L. (2006). A pilot investigation of a psychosocial activity course for people with spinal cord injuries. *Psychology, Health & Medicine, 11*(1), 91-99. doi: 10.1080/13548500500330494

Kennedy, P., Sherlock, O., McClelland, M., Short, D., Royle, J., & Wilson, C. (2010). A multi-centre study of the community needs of people with spinal cord injuries: The first 18 months. *Spinal Cord, 48*(1), 15-20. doi:10.1038/sc.2009.65

Kielhofner, G. (2008). *Model of human occupation: Theory and application.* (4th ed.). Baltimore, PA: Lippincott Williams & Wilkins.

Kirshblum, S. C., Priebe, M. M., Ho, C. H., Scelza, W. M., Chiodo, A. E., & Wuermser, L. (2007). Spinal cord injury medicine. 3. Rehabilitation phase after acute spinal cord injury. *Archives of Physical Medicine and Rehabilitation, 88*(3), 62-70. doi:10.1016/j.apmr.2006.12.003

Klassen, A. C., Creswell, J., Clark, V. L. P., Smith, K. C., & Meissner, H. I. (2012). Best practices in mixed methods for quality of life research. *Quality of Life Research, 21*(3), 377-380. doi: 10.1007/s11136-012-0122-x

Kleiber, D. A., Brock, S. C., Lee, Y., Dattilo, J., & Caldwell, L. (1995). The relevance of leisure in an illness experience: Realities of spinal cord injury. *Journal of Leisure Research, 27*(3), 283-299.

Krause, J. S. (1992). Longitudinal changes in adjustment after spinal cord injury: A 15-year study. *Archives of Physical Medicine and Rehabilitation, 73*(6), 564-568.

Krause, J. S. (1998). Changes in adjustment after spinal cord injury: A 20-year longitudinal study. *Rehabilitation Psychology, 43*(1), 41-55. doi: http://dx.doi.org/10.1037/0090-5550.43.1.41

Krause, J. S., & Broderick, L. (2005). A 25-year longitudinal study of the natural course of aging after spinal cord injury. *Spinal Cord, 43*(6), 349-356. doi:10.1038/sj.sc.3101726

Krause, J. S., & Coker, J. (2006). Aging after spinal cord injury: A 30-year longitudinal study. *Journal of Spinal Cord Medicine, 29*(4), 371-376.

Krause, J. S., & Bozard, J. (2012). Natural course of life changes after spinal cord injury: A 35-year longitudinal study. *Spinal Cord, 50*, 227-231. doi:10.1038/sc.2011.106

LaVela, S. L., Weaver, F. M., Goldstein, B., Chen, K., Miskevics, S., Rajan, S., & Gater, D. R.,Jr. (2006). Diabetes mellitus in individuals with spinal cord injury or disorder. *The Journal of Spinal Cord Medicine, 29*(4), 387-395.

Law, M., Steinwender, S., & Leclair, L. (1998). Occupation, health and well-being. *Canadian Journal of Occupational Therapy, 65*(2), 81-91. doi: 10.1177/000841749806500204

Law, M. (2002). Participation in the occupations of everyday life. *The American Journal of Occupational Therapy, 56*(6), 640-649. doi:10.5014/ajot.56.6.640

Lee, B. B., Cripps, R. A., Fitzharris, M., & Wing, P. C., (2014). The global map for traumatic spinal cord injury epidemiology: Update 2011, global incidence rate. *Spinal Cord, 52*(2), 110-116. doi:10.1038/sc.2012.158

Lee, Y., & Mittelstaedt, R. (2004). Impact of injury level and self-monitoring on free time boredom of people with spinal cord injury. *Disability & Rehabilitation, 26*(19), 1143-1149. doi:10.1080/09638280410001724825

Liem, N. R., McColl, M. A., King, W., & Smith, K. M., (2004). Aging with a spinal cord injury: Factors associated with the need for more help with activities of daily living. *Archives of Physical Medicine and Rehabilitation, 85*(10), 1567-1577. doi:10.1016/j.apmr.2003.12.038

Linacre, J. M. (1987-2006). *Facets: Many-facet Rasch measurement program.* Chicago, IL: MESA Press.

Linacre, J. M. (1991-2003). *A user's guide to facets: Rasch-model computer programs.* Chicago, IL: MESA Press.

Magasi, S., & Post, M. W. (2010). A comparative review of contemporary participation measures' psychometric properties and content coverage. *Archives of Physical Medicine and Rehabilitation, 91*(9), 17-28. doi:10.1016/j.apmr.2010.07.011

Majnemer, A. (2010). Balancing the boat: Enabling an ocean of possibilities. *Canadian Journal of Occupational Therapy,* 77(4), 198-205. doi: 10.2182/cjot.2010.77.4.2

Marino, R. J., Barros, T., Biering-Sorensen, F., Burns, S. P., Donovan, W. H., Graves, D. E., Haak, M., Hudson, L. M., & Priebe, M. M. (ASIA Neurological Standards Committee 2002). (2003). International standards for neurological classification of spinal cord injury. *The Journal of Spinal Cord Medicine,* 26(1), 50-56.

Marshall, C., & Rossman, G. B. (2010). Designing qualitative research. (5th ed.). Thousand Oaks, CA: SAGE Publications Inc.

Mathiowetz, V. G., Finlayson, M. L., Matuska, K. M., Chen, H. Y., & Luo, P. (2005). Randomized controlled trial of an energy conservation course for persons with multiple sclerosis. *Multiple Sclerosis, 11*(5), 592-601. doi: 10.1191/1352458505ms1198oa

Mattingly, C. (1998). *Healing dramas and cinical plots. the narrative structure of experience.* Los Angeles, Ca.: University of California Press.

McColl, M. (1999). Expectations of health, independence, and quality of life among aging spinal cord-injured adults. *Assistive Technology, 11*(2), 130-136. doi:10.1080/10400435.1999.10131997

Meadows, K. A. (2003). So you want to do research? 5: Questionnaire design. *British Journal of Community Nursing, 8*(12), 562-570. doi: http://dx.doi.org/10.12968/bjcn.2003.8.12.11854

Mengshoel, A. M. (2012). Mixed methods research–So far easier said than done? *Manual Therapy, 17*(4), 373-375. doi:10.1016/j.math.2012.02.006

Menter, R.R. (1993). Issues of aging with spinal cord injury. In G. Whiteneck, S. Charlifue, K. Gerhart, D. Lammertse, S. Manley, R. R. Menter & K. Seedroff (Eds.), *Aging with spinal cord injury.* New York: Demos Publications.

Moore, E. G., Rosenberg, M. W., & Fitzgibbon, S. H. (1999). Activity limitation and chronic conditions in Canada's elderly, 1986 2011. *Disability & Rehabilitation, 21*(5-6), 196-210.

Myers, J., Lee, M., & Kiratli, J. (2007). Cardiovascular disease in spinal cord injury: An overview of prevalence, risk, evaluation, and management. *American Journal of Physical Medicine & Rehabilitation, 86*(2), 142-152. doi: 10.1097/PHM.0b013e31802f0247

Månsson Lexell, E., Iwarsson, S., & Larsson-Lund, M. (2011). Occupational adaptation in people with multiple sclerosis. *Occupational Therapy Journal of Research: Occupation, Participation and Health., 31*(3), 127-134. doi: 10.3928/15394492-20101025-01

Nilsson, I., & Townsend, E. (2014). Occupational justice-Bridging theory and practice. (Previously published in *Scandinavian journal of occupational therapy*, 2010; 17: 57-63). *Scandinavian Journal of Occupational Therapy, 21*(S1), 64-70. doi:10.3109/11038128.2014.952906

Ozelie, R., Gassaway, J., Buchman, E., Thimmaiah, D., Heisler, L., Cantoni, K., Foy, T., Hsieh, C. H., Smout, R. J., Kreider, S. E., & Whitemeck, G. (2012). Relationship of occupational therapy inpatient rehabilitation interventions and patient characteristics to outcomes following spinal cord injury: The SCIRehab project. *The Journal of Spinal Cord Medicine, 35*(6), 527-546. doi: http://dx.doi.org/10.1179/2045772312Y.0000000062

Patton, M. Q. (2002). *Qualitative research & Evaluation methods* (3rd ed.). London: Sage Publications, Inc.

Paxson, D., Winston, K., Tobey, T., Johnston, S., & Iwama, M. (2012). The Kawa model: Therapists' experiences in mental health practice. *Occupational Therapy in Mental Health, 28*(4), doi: 340-355. 10.1080/0164212X.2012.708586

Pentland, W., Harvey, A. S., Smith, T., & Walker, J. (1999). The impact of spinal cord injury on men's time use. *Spinal Cord, 37*(11), 786-792. doi: 10.1038/sj.sc.3100908

Pettersson, I., & Selander, K. (1996). *Manual till NPS-intressechecklista. (Handbook for the NPS-interest checklist).* Kristianstad: Högskolan i Kristianstad.

Phoenix, C., Smith, B., & Sparkes, A. C. (2010). Narrative analysis in aging studies: A typology for consideration. *Journal of Aging Studies, 24*(1), 1-11. doi:10.1016/j.jaging.2008.06.003

Pierce, D. (2001). Untangling occupation and activity. *American Journal of Occupational Therapy, 55*(2), 138-146. doi:10.5014/ajot.55.2.138

Polkinghorne, E. D. (1995). Narrative configuration in qualitative analysis. *International Journal of Qualitative Studies in Education, 8*(1), 5-23. doi: 10.1080/0951839950080103

Post, M. W., de Witte, L. P., van Asbeck, F. W., van Dijk, A. J., & Schrijvers, A. J. (1998). Predictors of health status and life satisfaction in spinal cord injury. *Archives of Physical Medicine and Rehabilitation, 79*(4), 395-401. doi:10.1016/S0003-9993(98)90139-3

Post, M. W., & Noreau, L. (2005). Quality of life after spinal cord injury. *Journal of Neurologic Physical Therapy, 29*(3), 139-146. doi: 10.1097/01.NPT.0000282246.08288.67

Price, P., Stephenson, S., Krantz, L., & Ward, K. (2011). Beyond my front door: The occupational and social participation of adults with spinal cord injury. *OTJR Occupation Participation and Health, 31*(2), 81-88.

Rajan, S., McNeely, M. J., Hammond, M., Goldstein, B., & Weaver, F. (2010). Association between obesity and diabetes mellitus in veterans with spinal cord injuries and disorders. *American Journal of Physical Medicine & Rehabilitation, 89*(5), 353-361. doi:10.1097/PHM.0b013e3181d896b9

Rebeiro, K. L., Day, D. G., Semeniuk, B., O'Brien, M. C., & Wilson, B. (2001). Northern initiative for social action: An occupation-based mental health program. *American Journal of Occupational Therapy, 55*(5), 493-500. doi:10.5014/ajot.55.5.493

Ricoeur, P. (1991). *From text to action: Eassays in hermeneutics, II.* Evanston, IL: Northwestern University Press.

Riessman, C. (2007). *Narrative methods for the human sciences*. London: Sage Publications, Inc.

Rimmer, J. H., Chen, M. D., & Hsieh, K. (2011). A conceptual model for identifying, preventing, and managing secondary conditions in people with disabilities. *Physical Therapy, 91*(12), 1728-1739. doi:10.2522/ptj.20100410

Rundquist, J., Gassaway, J., Bailey, J., Lingefelt, P., Reyes, I. A., & Thomas, J. (2010). The SCIRehab project: Treatment time spent in SCI rehabilitation. nursing bedside education and care management time during inpatient spinal cord injury rehabilitation. *The Journal of Spinal Cord Medicine, 34*(2), 205-215. doi: 10.1179/107902611X12971826988255

Saikkonen, J., Karppi, P., Huusko, T. M., Dahlberg, A., Mäkinen, J., & Uutela, T. (2004). Life situation of spinal cord-injured persons in Central Finland. *Spinal Cord, 42*, 459-465. doi:10.1038/sj.sc.3101618

Sand, Å, Karlberg, I., & Kreuter, M. (2006). Spinal cord injured persons' conceptions of hospital care, rehabilitation, and a new life situation. *Scandinavian Journal of Occupational Therapy, 13*(3), 183-192. doi:10.1080/11038120500542187

Sauter, C., Zebenholzer, K., Hisakawa, J., Zeitlhofer, J., & Vass, K. (2008). A longitudinal study on effects of a six-week course for energy conservation for multiple sclerosis patients. *Multiple Sclerosis, 14*(4), 500-505. doi: 10.1177/1352458507084649

Savic, G., Charlifue, S., Glass, C., Soni, B. M., Gerhart, K. A., & Ali Jamous, M. (2010). British ageing with SCI study: Changes in physical and psychosocial outcomes over time. *Topics in Spinal Cord Injury Rehabilitation, 15*(3), 41-53.

Schönherr, M. C., Groothoff, J. W., Mulder, G. A., & Eisma, W. H. (2004). Participation and satisfaction after spinal cord injury: Results of a vocational and leisure outcome study. *Spinal Cord, 43*(4), 241-248. doi:10.1038/sj.sc.3101683

SFS 2003:460. *Lag om etikprövning av forskning som avser människor.* Stockholm: Riksdagen. Retrieved 24th April, 2015. http://www.riksdagen.se/sv/Dokument-Lagar/Lagar/Svenskforfattningssamling/Lag-2003460-om-etikprovning_sfs-2003-460/

Smith, B., & Sparkes, A. (2005). Men, sport, spinal cord injury, and narratives of hope. *Social Science & Medicine.,* (61), 1095-1105.

Sohlberg, P., & Sohlberg, B. (2013). *Kunskapens former: Vetenskapsteori och forskningsmetod.* (3rd ed.). Stockholm: Liber.

Spence, D. P. (1986). Narrative smoothing and clinical wisdom. In T. R. Sarbin (Ed.), *Narrative psychology: The storied nature of human conduct.* Westport, CT: Praeger Publishers/Greenwood Publishing Group.

Stucki, G., Ewert, T., & Cieza, A. (2002). Value and application of the ICF in rehabilitation medicine. *Disability & Rehabilitation, 24*(17), 932-938. doi:10.1080/09638280210148594

Taghizadeh Larsson, A. (2009). *Att åldras med funktionshinder : Betydelser av socialt och kronologiskt åldrande för människor som under lång tid levt med fysiska funktionsnedsättningar.*(Doctoral/Monograph). Linköping: Linköpings universitet.

Tasiemski, T., Kennedy, P., Gardener, B., & Taylor, N. (2005). The association of sports and physical recreation with life satisfaction in a community sample of people of with spinal cord injuries. *Neurorehabilitation, 20*(4), 253-265.

Taylor-Schroeder, S., LaBarbera, J., McDowell, S., Zanca, J. M., Natale, A., Mumma, S., Gassaway, J., & Backus, D. (2010). The SCIRehab project: Treatment time spent in SCI rehabilitation. Physical therapy treatment time during inpatient spinal cord injury rehabilitation. *The Journal of Spinal Cord Medicine, 34*(2), 149-161. doi: 10.1179/107902611X12971826988057

Tesio, L. (2003). Measuring behaviours and perceptions: Rasch analysis as a tool for rehabilitation research. *Journal of Rehabilitation Medicine, 35*(3), 105-115.

Thompson, L. (1999). Functional changes in persons aging with spinal cord injury. *Assistive Technology, 11*(2), 123-129. doi: 10.1080/10400435.1999.10131996

Townsend, E. A., & Polatajko, H. J. (2013). *Enabling occupaion II: Advancing an occupational therapy vision for health, well-being and justice through occuaption* (2nd ed.). Ottawa: CAOT Publications ACE.

Trieschmann, R. B. (1987). *Aging with a disability*. New York: Demos Publications.

van den Berg, M., Castellote, J., Mahillo-Fernandez, I., & de Pedro-Cuesta, J. (2010). Incidence of spinal cord injury worldwide: A systematic review. *Neuroepidemiology, 34*(3), 184-192. doi: 10.1159/000279335

van der Woude, L., de Groot, S., Postema, K., Bussmann, J. B., Janssen, T., & Post, M.W. (2013). Active LifestyLe Rehabilitation Interventions in aging Spinal Cord injury (ALLRISC): A multicentre research program. *Disability and Rehabilitation, 35*(13), 1097-1103. doi:10.3109/09638288.2012.718407

Ville, I. (2005). Biographical work and returning to employment following a spinal cord injury. *Sociology of Health & Illness, 27*(3), 324-350. doi: 10.1111/j.1467-9566.2005.00445.x

von Heideken Wågert, P., Gustavsson, J. M., Lundin-Olsson, L., Kallin, K., Nygren, B., Lundman, B., Norberg, A., & Gustafson, Y. (2006). Health status in the oldest old. age and sex differences in the umeå 85 study. *Aging Clinical and Experimental Research, 18*(2), 116-126. doi: 10.1007/BF03327426

Wahman, K., Nash, M. S., Lewis, J. E., Seiger, Å, & Levi, R. (2010). Increased cardiovascular disease risk in swedish persons with paraplegia: The Stockholm spinal cord injury study. *Journal of Rehabilitation Medicine, 42*(5), 489-492.

Wahman, K., Biguet, G., & Levi, R. (2006). What promotes physical activity after spinal cord injury? an interview study from a patient perspective. *Disability and Rehabilitation, 28*(8), 481-488. doi: http://dx.doi.org/10.2340/16501977-0541

Waters, R. L., & Sie, l. H. (2001). Upper extremity changes with SCI contrasted to common aging in the musculoskeletal system. *Topics in Spinal Cord Injury Rehabilitation, 6*(3), 61-68.

Whiteford, G. (2010). Occupational deprivation: Understanding limitied participation. In C. Christiansen, & E. Townsend (Eds.), *An introduction to occupation: The art and science of living.* (2nd ed.). Upple Saddle River, NJ: Prentice Hall.

Whiteneck, G. G., Charlifue, S. W., Frankel, H. L., Fraser, M. H., Gardner, B. P., Gerhart, K. A., Krishnan, K. R., Menter, R. R., Nuseibeh, I., Short, D., & Silver, J. R. (1992). Mortality, morbidity, and psychosocial outcomes of persons spinal cord injured more than 20 years ago. *Spinal Cord, 30*(9), 617-630. doi:10.1038/sc.1992.124

Whiteneck, G. G., Meade, M. A., Dijkers, M., Tate, D. G., Bushnik, T., & Forchheimer, M. B. (2004). Environmental factors and their role in participation and life satisfaction after spinal cord injury. *Archives of Physical Medicine and Rehabilitation, 85*(11), 1793-1803. doi:10.1016/j.apmr.2004.04.024

Whiteneck, G. G., Gassaway, J., Dijkers, M., Backus, D., Charlifue, S. W., Chen, D., Hammond, F., Hsieh, C. H., & Smout, R. J. (2011). Inpatient treatment time across disciplines in spinal cord injury rehabilitation. *The Journal of Spinal Cord Medicine, 34*(2), 133-148. doi: http://dx.doi.org/10.1179/107902611X12971826988011

Wilcock, A. A. (1999). Reflections on doing, being and becoming*. *Australian Occupational Therapy Journal, 46*(1), 1-11. doi: 10.1046/j.1440-1630.1999.00174.x

Wilcock, A. A. (2006). *An Occupational Perspective of Health*. Thorofare, NJ: SLACK Incorporated.

Wilcock, A. A. (2007). Occupation and health: Are they one and the same? *Journal of Occupational Science, 14*(1), 3-8. doi: 10.1080/14427591.2007.9686577

World Health Organization. (2002). *Toward a common language for functioning, disability and health: ICF, the International cCassification of Functioning, disability and health*. Geneva: World Health Organization.

World Medical Association. (2008). WMA Declaration of Helsinki - Ethical principles for medical research involving human subjects. Retrieved 15th April, 2015. http://www.wma.net/en/30publications/10policies/b3/17c.pdf

Wray, S. (2004). What constitutes agency and empowerment for women in later life? *The Sociological Review, 52*(1), 22-38.

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Paper I

Research article

Leisure repertoire among persons with a spinal cord injury: Interests, performance, and well-being

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Objective: To explore and describe the leisure repertoire of persons with traumatic spinal cord injury (SCI) and how the repertoire is related to interest, performance, and well-being.
Design: Cross-sectional study.
Setting: A total of 97 persons with traumatic SCI were recruited from the non-profit national organization, RG Active Rehabilitation in Sweden.
Outcome measure: Data were collected through a two-part postal survey. The first comprised of questions investigating socio-demographic variables and injury characteristics; the second part included an interest checklist with 20 areas of leisure activities.
Results: The participants were mostly interested in, performed, and experienced well-being from social and culture activities and TV/DVD/movies. The areas of leisure activities in which they had most likely experienced changes after the SCI were outdoor activities, exercise, and gardening. Sex, age, and to some extent, time since injury were related to interest, performance, well-being, and changed performance.
Conclusions: The results provided an explanation and limited description of a changed leisure repertoire among persons after a traumatic SCI. The study showed that sex, age, and time since injury were more closely related to the choice of leisure activities to include in the leisure repertoire than the level of injury. This knowledge can be of importance when professionals in the field of rehabilitation are planning and implementing interventions concerning leisure activities for persons with SCI.

Keywords: Leisure activities, Rehabilitation, Spinal cord injuries, Well-being, Disability, Quality of life

Introduction

Leisure activities can be described as activities in which people participate, in order to socialize, relax, or to pursue interest and hobbies. Therefore, these activities can be considered enjoyable and freely chosen rather than chosen by necessity. Each person has a unique leisure repertoire of leisure activities that he or she finds meaningful and practices regularly.[1] After a traumatic spinal cord injury (SCI), persons might experience disrupted living patterns including a changed leisure repertoire, regardless of the localization of the injury and the time since the injury.[2] This can mean changes in hours spent on various leisure activities and changes in leisure activities that are accessible to these individuals, which can affect their well-being.

Earlier research about persons with SCI has focused mainly on the reasons why they experienced difficulties performing leisure activities. To a great extent, this research has described personal and/or environmental factors associated with the difficulties performing leisure activities and implied that the absence or lack of skills required for performing leisure activities can result in negative attitudes toward life after the injury

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and to a lowered sense of self-esteem.[3,4] In addition, the consequences of the SCI can result in personal feelings of a reduced freedom to choose appealing leisure activities and an altered perception of the meaning of performing leisure activities.[5,6] The changes that occur in leisure activities after an SCI may also be affected by the reduced time and energy available to perform desired leisure activities, since self-care activities can take considerably longer to perform for persons with SCI[7]. Earlier research has also described how persons with SCI reduced or even completely ceased, engaging in desired leisure activities because of barriers in the physical environment, including in-accessible buildings, long distances,[3] and lack of suitable transportation[8] or weather conditions.[9] Feelings of being dependent on others, the absence of social support, a lack of appropriate assistance, and negative attitudes in society toward people with disabilities have also been reported as hindrances to performing leisure activities.[4,10,11] However, persons with SCI spend significantly more time every day on leisure activities than persons without disabilities,[12–14] and these leisure activities contain an over-representation of sedentary activities, such as listening to music, watching TV, reading,[6,7,13,14] and engaging in computer-based activities.[7] Reports have also indicated that persons with SCI can experience dissatisfaction and boredom in everyday life when they are unable to achieve an optimal level of well-being because they are not satisfied with their leisure activities.[15]

On the other hand, research has shown that persons with SCI who frequently participate in sports have greater life satisfaction and self-esteem than persons with SCI who do not participate in sports.[4,6,16] Researchers have explored how persons with SCI could overcome barriers to participation in an active leisure life by pursuing pre-injury leisure activities with appropriate adaptations and/or by exploring new interests.[17–19] Martin Ginis *et al.*[20] have investigated the physical activities in which persons with SCI choose to engage in their free time based on a definition for leisure time physical activity (LTPA);[21] they found that some persons with SCI chose, for example walking/wheeling, playing sports, or exercising at a gym.

To summarize, several studies have described different reasons why persons with SCI can experience difficulties performing leisure activities and why they often spend much time engaging in mainly sedentary leisure activities. However, research has also revealed that persons with SCI can be interested in and perform physical activities, and that engaging in such activities can positively affect their feelings of life satisfaction and self-esteem. Yet, these studies did not explore the types of leisure activities chosen by persons after an SCI. Therefore, in an effort to respond to this gap in knowledge, the purpose of this study was to explore and describe the leisure repertoire of persons with traumatic SCI and how the repertoire is related to interest, performance, and well-being.

Materials and methods

Study population

Participants in this cross-sectional study were recruited through the non-profit national organization, RG Active Rehabilitation in Sweden, which has approximately 800 members. The constitution of the membership list included members with an SCI and supporting members and it was not possible to discern them from each other. A simple random sampling method[22] was used to select 200 participants from the membership list; this method was used with the intention of ensuring that all members had an equal probability of being selected to participate. A postal survey was sent to the 200 selected members. Ten surveys were returned due to incorrect address information, and 90 of the selected members did not respond. Therefore, 100 members in total returned the survey. The inclusion criteria were as follows: (i) males and females with a traumatic SCI, (ii) at least 2 years post-injury, and (iii) 18 years of age or older. Three respondents were excluded: two declared that they were supportive members and one had spina bifida. Thus, a total of 97 participants who corresponded with the inclusion criteria's were included. No reminders were sent.

Survey

The survey consisted of two parts. The first part was developed by the authors for this study and consisted of questions related to socio-demographic variables and injury characteristics (e.g. sex, age, level of injury, the time since the injury, type of mobility device used, marital status, residential location, level of education, and employment status).

The second part of the survey consisted of the NPS-interest checklist,[23] which is an extension of the original interest checklist devised by Norling and Jägnert.[24] NPS stands for the initials of Norling, the constructor of the original interest checklist and Pettersson and Selander, the ones extending the original version by adding two areas of leisure activities (cooking and house work) and additional information. The NPS-interest checklist (Table 1) was developed in Sweden for persons with disabilities caused by disease or injury. It consists of 20 areas of leisure activities for which participants

Table 1 Leisure activities on NPS-interest checklist

1. Outdoor activities, e.g. walking/wheeling, camping, being in the nature
2. Gardening, e.g. cultivate
3. Animals, e.g. taking care of animals
4. Culture activities, e g. reading, listening to radio, theater, concerts
5. TV, DVD, movies
6. Music, e.g. listening, playing, singing
7. Physical exercise, e g. workout, swimming, jogging/wheeling
8. Equipment sports, e g. ice hockey, athletics
9. Ball sports, e.g. football, handball, table tennis
10. Bath, boating
11. Sport observation
12. Fishing, hunting, shooting
13. Hobby, e.g. mechanical work, knitting, needlework, stamps
14. Associations, e.g. club activities, politics, union work, voluntary work
15. Religious activities
16. Pleasure, e.g. restaurants, dancing
17. Social activities, e.g. being with friends, family, relatives
18. Gambling, e.g. bingo, poker, lottery
19. Cooking, e.g. prepare food, baking
20. House work, e.g. cleaning, doing laundry
21. Additional information

Questions for each area of leisure activities 1-20: (a) are you interested in the activity, (b) do you perform the activity, (c) is the activity of importance for your well-being, and (d) has your performance of the activity changed since injury?
Note: The translation of the NPS-interest checklist from Swedish to English was made by the first author.

provide self-reported answers to the following questions: (a) are you interested in the activity, (b) do you perform the activity, (c) is the activity of importance for your well-being, and (d) has your performance of the activity changed since injury? Questions (a) and (d) enabled the respondents to give one of the following three possible answers: yes, very much; somewhat; or not at all. Questions (b) and (c) allowed for two possible answers: yes or no. Participants were also able to add comments, but only the quantitative data were used for this study.

The validity of the original interest checklist has been supported.[24] However, since the NPS-interest checklist has not been used to survey persons with SCI, information regarding the validity of the instrument among this group of persons was lacking. Therefore, the four questions in the NPS-interest checklist were investigated via a series of Rasch analyses,[25] using the software FACETS.[26] This method has been increasingly used in rehabilitation medicine for testing both new and existing assessments and questionnaires.[27] The person response validity indicated that 95% of the participants demonstrated acceptable goodness-of-fit, which can be judged as sufficient based on the criteria proposed by Linacre,[28] and thus not a threat to validity.[25] Bond and Fox[25] further stated that goodness-of-fit statistics evaluate the degree of fit between the observed responses and the responses expected by the Rasch measurement model. Thus, the analyses provided evidence of the validity of the NPS-interest checklist for measuring interest, performance, experience of well-being, and changed performance of leisure activities for persons with SCI.

Statistical analysis

The Predictive Analytics Software (PASW Statistics for Windows, Version 18.0. Chicago: SPSS Inc., 2009), previously referred to as SPSS, was used for the descriptive statistical analyses, cross-tabulation, and χ^2 tests. In the first step, descriptive statistical analyses, such as mean, standard deviation (SD), and frequencies, were performed to examine the study population. Second, the results from the testing and analysis of the validity of the NPS-interest check list through Rasch analyses[25] were used to describe the leisure repertoires among the participants with SCI. That is, the participants answers from each of the four questions and every one of the 20 areas of leisure activities were converted through logistic transformation into abstract interval measures in units called log-odds probability units (so-called, logits) by using FACETS.[26] Through the analyses, all participants receive a measure presented in logits on an interval scale representing the extent to which the participants were more or less likely to report that area of leisure activity in relation to interest, performance, well-being, and changed performance. Finally, cross-tabulations and χ^2 tests were used to examine the socio-demographic variables, the injury characteristics, and the questions for the 20 areas of leisure activities in the NPS-interest checklist. A dichotomization of the answer alternatives for the NPS-interest checklist was applied to the questions (a) and (d), in order to ensure that the outcome could take on only one of the following of two values: yes (i.e. yes, very much and somewhat) or no (i.e. not at all). Due to the wide range in age (19–69 years) and time since injury (2–31 years), sub-groups were formed to facilitate the analysis. Age was divided into two groups: age group 1 included persons between 19 and 44 years of age, and age group 2 included those between 45 and 69 years of age. Time since injury was divided into three groups based on the quartiles; group 1: 2–4 years; group 2: 5–8 years; and group 3: 9–31 years. A P value of <0.05 represented statistical significance.[22]

Table 2 Socio-demographic data and injury characteristics for the participants ($n = 97$)

	Mean ± SD
Age (years)	43.5 ± 12.0
Time since injury (years)	7.3 ± 5.6
	n (%)
Participants	
Male	55 (56.7)
Female	42 (43.3)
Injury level	
Tetraplegia	46 (47.4)
Paraplegia	44 (45.4)
Not reported	7 (7.2)
Mobility device	
Wheelchair	77 (79.4)
Walking aid	18 (18.6)
Not reported	2 (2.0)
Marital status	
Single/divorced or widowed	42 (43.3)
Married or common law	55 (56.7)
Residential location	
Rural	36 (37.1)
Urban/suburban	61 (62.9)
Education	
High school or less	60 (61.9)
College/university	37 (38.1)
Employment status	
Full time	10 (10.3)
Part time	52 (53.6)
Not working	34 (35.1)
Not reported	1 (1.0)

Statement of ethics

The principles of the Declaration of Helsinki were followed and the study was approved by the Regional Ethical Review Board in Umeå, Sweden (08–005M).

Results

A summary of the socio-demographic data and injury characteristics of the participants is presented in Table 2. The mean age of the participants was 43.5 years with an SD of 12.0, and at the time of this study, the participants had been injured on average for 7.3 years ±5.6 SD. The sample distribution for males and females and also for tetra- and paraplegia was marginally different but not statistically significant.

In Table 3, the leisure repertoires of the participants showed that they were most interested in, performed, and experienced well-being from both social and cultural activities, and TV/DVD/ movies. The areas of leisure activities in which participants have reported the most changes were outdoor activities, exercise, and gardening. Religious activities and gambling were the leisure activities least reported for interest, performance, well-being, and changed performance.

Table 3 The six most or least likely activities in the participants' leisure repertoire and significant differences related to sex, age, level of injury, and time since injury

	Interest	Performance	Well-being	Changed performance
Most likely	2.57 Social[†]	4.06 Social (A2:44%**)[‡]	4.27 Social	1.44 Outdoor (TI 1:100%**)
	1.08 TV/DVD/movies	2.48 TV/DVD/movies	1.37 Culture (F:91%***)	1.20 Physical exercise
	0.69 Culture	1.90 Culture	1.18 TV/DVD//movies	0.80 Gardening
	0.42 Cooking (F:91%*)	1.20 Music	0.89 Physical exercise	0.73 Housework (F:91%***)
	0.38 Outdoor (TI 1:91%*)	1.08 Cooking (F:86%***; P:82%**)	0.78 Outdoor (TI 1:88%***)	0.60 Pleasure
	0.38 Physical exercise	0.60 Pleasure	0.78 Music	0.56 Bath/boating (M:75%*)
Least likely	−0.49 Ball sports (A1:70%***; M:62%**)	−0.65 Bath/boating (A1:45%**; TI3:58%**)	−1.12 Associations	−0.40 Sport observation
	−0.57 Fish/hunt/shooting (M:67%***)	−0.85 Associations	−1.14 Ball sports (A1:43%***; M:40%***)	−0.44 Animals (F:57%***; A2:55%**)
	−0.73 Equipment sports (A1:55%***; M:53%***)	−1.57 Fish/hunt/shooting (M:29%**)	−1.14 Fish/hunt/shooting (M:42%***)	−0.57 Associations
	−0.89 Associations	−1.65 Ball sports (A1:30%***; M:27%**; TI 3:31%*)	−1.40 Equipment sports (A1:34%**; M:36%***)	−0.66 Music
	−0.98 Gambling (T:57%***)	−2.30 Religious	−2.23 Gambling	−1.56 Gambling
	−2.14 Religious	−2.42 Equipment sports (M:18%***)	−2.58 Religious	−2.20 Religious

[†] All data were Rasch adjusted. Values are given in linear logits (log-odds probability unit, in range between −5 and +5) and indicate the extent to which the participants were most (higher value) or least (lower value) likely to report the area of leisure activity in their leisure repertoire in relation to interest, performance, well-being, and changed performance.

[‡] The percentages of the variable being significant, for example "A2:44%**" communicates that 44% of the participants being between 45 and 69 years of age performed social activities, and this was significantly greater than the proportion of participants being between 19 and 44 years of age.

Sex: F (female), M (male). Age: A1 (19–44 years), A2 (45–69 years) of age. Level of injury: P (paraplegia), T (tetraplegia). Time since injury: TI 1 (2–4 years), TI 2 (5–8 years), TI 3 (9–31 years). Levels of statistical significance: ***$P < 0.001$; **$P < 0.01$; *$P < 0.05$.

Overall, sex and, to some extent, age were the variables that related most to the participants' interest, performance, well-being, and changed performance in some areas of leisure activities. For example, females were most interested in and performed cooking, and experienced changes in leisure activities such as taking care of animals and house work. In contrast, ball and equipment sports, and fishing/hunting/shooting were areas of leisure activities that males reported as most interesting, performed, and frequently endorsed as a source of well-being. Outdoor activities were of interest and a source to well-being for participants who had lived with their SCI for 2–4 years, but it was also the area of leisure activities where they experienced changed performance. Furthermore, the levels of injury among the participants were only related to gambling and cooking, i.e. participants with tetraplegia were more likely to be interested in gambling and participants with paraplegia were more likely to perform cooking.

In addition to the results shown in Table 3, other variables that were related to interest, performance, well-being, and changed performance to a certain extent were residential location, level of education, employment status, and marital status. For example, TV/DVD/movies were reported as interesting (98%, $P < 0.001$), performed (95%, $P < 0.01$), and a source of well-being (84%, $P < 0.001$) from participants living in urban/suburban areas. Participants living in rural areas reported interest in outdoor activities (92%, $P < 0.01$) and fishing/hunting/shooting (57%, $P < 0.01$). Participants with college/university degrees were most interested in areas of leisure activities such as pleasure (87%, $P < 0.001$) and performed bathing/boating (49%, $P < 0.05$) and ball sports (30%, $P < 0.01$). Participants with degrees from high school or less were interested in (58%, $P < 0.01$) and experienced well-being (35%, $P < 0.05$) from fishing/hunting/shooting. Participants working full time reported that they performed bathing/boating (60%, $P < 0.05$) and participants who lived alone experienced well-being from ball sports (38%, $P < 0.05$). Finally, no relationship was observed between the variable mobility device and the leisure repertoire among the participants.

Discussion

The results of this study provide an explanation for and to some extent a description of a changed leisure repertoire among persons following a traumatic SCI. However, the determination of whether this change was positive or negative was not possible, i.e. whether an increase or decrease in performance had occurred. For example, the results suggested that the participants reported that they did not perform outdoor activities and exercise as frequently after their SCI. This is in contrast to a study by Martin Ginis *et al.*,[20] in which persons with SCI reported walking/wheeling, aerobic exercise, and resistance training as the most frequent types of LTPA. Within our study population, the participants were most interested in, performed, and experienced well-being from social and cultural activities as well as TV/DVD/ movies. Their social and cultural activities consisted of a variety of leisure activities, this mean that there were a great variety of leisure activities, e.g. reading, listening to the radio, going to concerts, meeting with friends and family, which could took place either in their homes or in public places. An interesting finding was that even though they engaged mostly in social activities, this area of leisure activity was also one that the participants reported a relatively high degree of changed performance in after the SCI. Earlier research likewise describes a rather complex picture of how the social activities among persons with SCI can be limited in comparison to that of non-disabled persons.[29,30] Furthermore, the importance of social relationships for persons with an SCI increases when they are trying to perform their earlier leisure activities or to find new ones to explore.[9,10,31] Another area of leisure activities among the participants' leisure repertoire that was reported as a source of well-being was watching TV/DVD/movies. This is interesting because earlier research has shown that watching TV can contribute to social isolation and can be a predictor of free-time boredom.[14,32] Our results imply that watching TV/DVD/movies do not necessarily indicate that a person is "killing time": instead, this could depend on how the participants choose to use the time that they spend in front of the TV. Watching TV/DVD/movies can also provide a complement to social and cultural activities that the participants included in their leisure repertoires, thereby creating a balance between both sedentary and more active leisure activities, which can contribute to experiences of well-being. This result indicates that a changed attitude toward sedentary activities after an SCI, such as screen activities, may be needed.

Some areas of leisure activities in this study were significantly related to the socio-demographic variables and injury characteristics of the participants. More specifically, sex, age, and time since injury were significantly associated with different areas of leisure activities in their leisure repertoire. In contrast, level of injury was only significantly associated with two areas of leisure activities. This is somewhat consistent with earlier research that indicated that well-being among persons with SCI is more closely related to community functioning, social interactions, and satisfaction with leisure activities as compared to level of injury and functional independence.[33–37] One fact that may help to explain our results is that the study population was made up entirely of members of a non-profit organization. This organization offers opportunities for persons with SCI to meet role models, persons who have experiences of living with a comparable type of injury, and also chances to try different leisure activities at organized camps. Other studies also showed that participating in camps or leisure intervention groups with the intention to find new leisure activities and meet other persons with SCI increased self-confidence, self-esteem, and the perception of possibilities and capabilities after an SCI.[17,18] Thus, attending such a program may enhance the process of adjusting to life with an SCI, help to redefine identity, and facilitate community re-integration.[37,38]

Participants who were 2–4 years post-injury were interested in and reported well-being from outdoor activities. They also reported the highest changes in performance of outdoor activities. In contrast, participants who were 9–31 years post-injury were interested in observing sports, performing ball sports, and bathing/boating. These results are consistent with earlier research[32,39] that describe how persons who are newly injured and had just finished their rehabilitation after an SCI might be overwhelmed by the many challenges facing them in everyday life and feelings of grief/loss concerning previously performed leisure activities. Meanwhile, persons with long experiences of living with SCI might have more knowledge about the resources available for engaging in leisure activities, since they have had more time to explore and find new leisure activities. The results also showed that the areas of leisure activities reported by males versus that of females were different; moreover, the age-groups (i.e. 19–44 and 45–69 years) were interested in and performed different areas of leisure activities as well. The results probably reflect a more general pattern that is exhibited in samples in the general population within the western culture. Furthermore, our results showed that socio-demographical variables such as residential living, level of education, employment status, and marital status were only related to some extent to the participants' interest, performance, and well-being in a few areas of leisure activities.

Methodological limitations

The study results may have changed if a better response rate had been achieved. Nevertheless, the actual response rate for this study can still be considered as acceptable based on the recommendations for a 50% response rate in the literature.[22] The participants were recruited from a non-profit organization with a special interest in active rehabilitation. Therefore, the participants representing persons with SCI in this study were likely more active and felt more positive about their leisure repertoires, thereby limiting the ability to generalize the results[22] from this study to the whole population with SCI. A specific limitation of the NPS-interest checklist and thus also in our study is that the last question, only provides information about a changed performance. Therefore, determining whether a change is perceived to be positive or negative by the participants is not possible. Nevertheless, the NPS-interest checklist provided a convenient way to capture the participants' experiences of well-being in relation to areas of leisure activities and gave a comprehensive picture of the leisure activities in which they were interested in, performed, and reported changes because of the SCI.

Conclusion

The study provided an explanation and limited description of a changed leisure repertoire among persons after a traumatic SCI. Yet, determining whether the change was positive or negative was impossible, thereby implicating the need for further studies to investigate how persons with SCI experience changes in their leisure repertoires. The participants were most interested in, performed, and reported well-being from social and cultural activities as well as TV/DVD/movies. In addition, the areas of leisure activities in which they had most likely experienced changes after the SCI were outdoor activities, exercise, and gardening. Furthermore, the study showed that sex, age, and time since injury were more closely related to the choice of leisure activities to include in the leisure repertoire by persons with SCI than the level of injury. This knowledge can be of importance to rehabilitation professionals for planning and implementing interventions concerning leisure activities for persons with SCI.

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References

1 Mobily KE. The idea of leisure repertoire. J Appl Gerontol 1991; 10(2):208–23.

2 Holtz A, Levi R. Epidemiologi. In: Ryggmärgsskador: Behandling och Rehabilitering. Lund, Sweden: Studentlitteratur; 2006. p. 13–5.

3 Caldwell L, Adolph S, Gilbert A. Caution! Leisure counselors at work: long term effects of leisure counseling. Ther Recreation J 1989;23(3):41–9.

4 Kleiber DA, Brock SC, Lee Y, Dattilo J, Caldwell L. The relevance of leisure in an illness experience: realities of spinal cord injury. J Leisure Res 1995;27(3):283–99.

5 O'Brien A, Renwick R, Yoshida K. Leisure participation for individuals living with acquired spinal cord injury. Int J Rehabil Res 2008;31(3):225–30.

6 Tasiemski T, Kennedy P, Gardener B, Taylor N. The association of sports and physical recreation with life satisfaction in a community sample of people of with spinal cord injuries. Neurorehabilitation 2005;20(4):253–65.

7 Schönherr M, Groothoff J, Mulder G, Eisma W. Participation and satisfaction after spinal cord injury: results of a vocational and leisure outcome study. Spinal Cord 2004;43(4):241–8.

8 Coyle CP, Kinney WB. Leisure characteristics of adults with physical disabilities. Ther Recreation J 1990;24(4):64–73.

9 Wahman K, Biguet G, Levi R. What promotes physical activity after spinal cord injury? An interview study from a patient perspective. Disabil Rehabil 2006;28(8):481–8.

10 Isaksson G, Lexell J, Skär L. Social support provides motivation and ability to participate in occupation. OTJR 2007;27(1):23–30.

11 Henderson KA, Bedini LA. I have a soul that dances like tina turner, but my body can't: physical activity and women with mobility impairments. Res Q Exerc Sport 1995;66(2):151–61.

12 Beringer A. Spinal cord injury and outdoor experiences. Int J Rehabil Res 2004;27(1):7–15.

13 Pentland W, Harvey AS, Smith T, Walker J. The impact of spinal cord injury on men's time use. Spinal Cord 1999;37(11):786–92.

14 Yerxa JE, Baum Locker S. Quality of time use by adults with spinal cord injuries. Am J Occup Ther 1989;44(4):318–26.

15 Lee Y, Mittelstaedt R. Impact of injury level and self-monitoring on free time boredom of people with spinal cord injury. Disabil Rehabil 2004;26(19):1143–9.

16 McVeigh SA, Hitzig SL, Craven BC. Influence of sport participation on community integration and quality of life: a comparison between sport participants and non-sport participants with spinal cord injury. J Spinal Cord Med 2009;32(2):115–24.

17 Kennedy P, Taylor N, Hindson L. A pilot investigation of a psychosocial activity course for people with spinal cord injuries. Psychol Health Med 2006;11(1):91–9.

18 Daniel A, Manigandan C. Efficacy of leisure intervention groups and their impact on quality of life among people with spinal cord injury. Int J Rehabil Res 2005;28(1):43–8.

19 Arbour-Nicitopoulos KP, Martin Ginis KA, Latimer A. Planning, leisure-time physical activity, and coping self-efficacy in persons with spinal cord injury: a randomized controlled trial. Arch Phys Med Rehabil 2009;90(12):2003–11.

20 Martin Ginis KA, Arbour-Nicitopoulos KP, Latimer AE, Buchholz AC, Bray SR, Craven C, *et al.* Leisure time physical activity in a population-based sample of people with spinal cord injury part II: activity types, intensities, and durations. Arch Phys Med Rehabil 2010;91(5):729–33.

21 Bouchard CE, Shephard RJ, Stephens TE. Physical activity, fitness, and health: international proceedings and consensus statement. Champaign, IL: Human Kinetics Publishers; 1994. p. 77–88.

22 Dawson B, Trapp RG. Basic & clinical Biostatistics. 4th ed. New York: McGraw-Hill Medical; 2004.

23 Pettersson I, Selander K. Manual till NPS-intressechecklista. (Handbook for the NPS-interest checklist). Kristianstad, Sweden: University of Kristianstad; 1996.

24 Norling I, Jägnert C. Fritiden i din kommun. (Leisure in your municipality). Solna, Sweden: Naturvardsverket; 1986.

25 Bond TG, Fox CM. Applying the Rasch Model: fundamental measurement in the human sciences. Mahwah, NJ: Lawrence Erlbaum; 2007.

26 Linacre JM. FACETS: Many-facet Rasch measurement program. Version 3.61. Chicago, IL: MESA; 1987–2006.

27 Tesio L. Measuring behaviours and perceptions: Rasch analysis as a tool for rehabilitation research. J Rehabil Med 2003;35(3): 105–15.

28 Linacre JM. A user's guide to facets: Rasch-Model Computer Programs. Chicago, IL: MESA Press; 1991–2003.

29 Hammell KRW. Psychosocial outcome following spinal cord injury. Spinal Cord 1994;32(11):771–9.

30 Westgren N, Levi R. Quality of life and traumatic spinal cord injury. Arch Phys Med Rehabil 1998;79(11):1433–9.

31 Isaksson G, Prellwitz M. One woman's story about her everyday life after a spinal cord injury. Disabil Rehabil 2010; 32(16):1376–86.

32 Lee Y, McCormick B. Subjective well-being of persons with spinal cord injury: does leisure contribute?. J Rehabil 2004;70(3): 5–12.

33 Clayton KS, Chubon RA. Factors associated with the quality of life of long-term spinal cord injured persons. Arch Phys Med Rehabil 1994;75(6):633–8.

34 Fuhrer M. The subjective well-being of people with spinal cord injury: relationships to impairment, disability, and handicap. Top Spinal Cord Inj Rehabil 1996;1(4):56–71.

35 Siösteen A, Lundqvist C, Blomstrand C, Sullivan L, Sullivan M. The quality of life of three functional spinal cord injury subgroups in a Swedish community. Spinal Cord 1990;28(8):476–88.

36 Coyle CP, Lesnik-Emas S, Kinney WB. Predicting life satisfaction among adults with spinal cord injuries. Rehabil Psychol 1994; 39(2):95–112.

37 Krause JS. Dimensions of subjective well-being after spinal cord injury: an empirical analysis by gender and race/ethnicity. Arch Phys Med Rehabil 1998;79(8):900–9.

38 Loy DP, Dattilo J, Kleiber DA. Exploring the influence of leisure on adjustment: development of the leisure and spinal cord injury adjustment model. Leisure Sci 2003;25(2–3):231–55.

39 Dattilo J, Caldwell L, Lee Y, Kleiber D. Returning to the community with a spinal cord injury: implications for therapeutic recreation specialists. Ther Recreation J 1998;32(1):13–27.

Paper II

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RESEARCH PAPER

Experiences of participation in everyday occupations among persons aging with a tetraplegia

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Abstract

Purpose: This study aimed to gain understanding of participation in everyday occupations through life stories of persons aging with a traumatic spinal cord injury (SCI). *Method*: A narrative method was used for data collection and a paradigmatic analysis was used to analyze data. *Results*: The analysis resulted in three themes that illustrate how the participants acted to participate in everyday occupations, how that changed over time, and some concerns about their future. The first theme illustrates how participants following SCI acted to become agents of their lives and participate in everyday occupations. The second theme illustrates how participants had to prioritize participation in meaningful occupations due to personal and environmental factors. The third theme shows how they had to try new strategies to continue participation in occupations, due to secondary health complications related to aging. *Conclusions*: This study captures how persons aging with tetraplegia acted to participate in everyday occupations from soon after the injury until several decades later. In addition, their ability to act and participate changed over time. Our findings provide knowledge that can guide clinicians in their work within this complex area of rehabilitation. Besides, it can also guide the work with policy recommendations for healthcare and social service systems.

Keywords

Aging, occupation, participation, rehabilitation, spinal cord injury, tetraplegia

History

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➤ Implications for Rehabilitation

- Aging with a SCI is a complex daily struggle in order to be able to continue acting and participating in everyday occupations, and thereby this gives implications for a lifelong support.
- This study provides knowledge that can guide clinicians in their work within this complex area of rehabilitation.
- Knowledge from this study can guide the work with policy recommendations for healthcare and social service systems.

Introduction

Life expectancy for persons with spinal cord injury (SCI) has improved significantly during the last two decades; several persons living with such injuries are now in their 70s and 80s [1,2]. Nevertheless, life expectancy among persons with SCI varies significantly according to, for example, the level and severity of injury [1]. Over a 35-year interval, research has focused on identifying the natural courses of SCI, life changes, and satisfaction with different aspects of life for persons with SCI. This research identifies both favorable (e.g. increased satisfaction with employment) and unfavorable (decreased satisfaction concerning health, social life and sex life) changes over time [3–8]. Furthermore, research has explored and described secondary health complications (SHC), such as fatigue, pain, new muscle weakness, and greater risks for obesity, cardiovascular diseases, fracture, pressure ulcers, septicemia and obstructive sleep apnea, among persons living and aging with an SCI [1,9,10]. Gender differences have also been found regarding the experiences of aging with an SCI, with men describing aging as complicated and difficult as a result of increasing SHC, and women describing aging as accelerated compared to their peers without an SCI [11]. As a result of declining functioning, individuals who have been injured for more than 20 years experienced an increased need for assistance with personal activities of daily living (P-ADL) [12–14], and this was especially true for individuals with tetraplegia who needed more assistance at a younger age than those with paraplegia [14]. Even though, an extensive body of knowledge exists about SHC that accompany the aging process with an SCI and the increased need for assistance. A gap in knowledge remains regarding persons' own life stories of how participation in daily occupations changes while living and aging with an SCI and, more specifically, for those with tetraplegia.

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Participation has been described in several ways as the opportunity to be involved in diverse life situations [15] and as a multifaceted process resulting from interactions and transactions among persons and occupations within physical, social, cultural, and political environments and communities [16,17]. For this study, we have chosen the description of participation as engagement in occupations that hold personal and social meaning, and are part of the sociocultural context in which the individual lives [18,19]. We knew from several studies that the inability to participate in desired occupations as a result of an SCI can threaten, for example, an individual's identity [20,21]. Whether a person is newly injured or is aging with an SCI, it is important that he or she is given opportunities to act in ways that enable participation in everyday occupations. A person's capacity to act can be defined as agency, which, in turn, is a multifaceted concept defined differently depending on its theoretical foundation. In this study, we use a sociological and gerontological definition of agency according to Wray [22], who describes agency as a creative, generative and relational process in which persons deal with issues in their everyday occupations. Wray's conceptualization emphasizes agency as a dynamic process that is socially and culturally constructed rather than constructed on an individual basis.

Earlier research showed positive changes for an increasing number of persons aging with an SCI today [1,2]. There are also studies that highlight the negative aspects of aging with an SCI, such as the risk for SHC and the loss of physical functioning, which can change participation in everyday occupations for persons with SCI [1,9–14]. Earlier research concerning participation in everyday occupations for persons with SCI focused primarily on the first few years following the injury and the importance of re-integration in the community [23–27]. No studies were found that capture the individuals' personal experiences of how participation in everyday occupation changes throughout the years as they are aging with an SCI, nor are there studies that describe how they act in order to adjust and be able to continue to participate in everyday occupations. It is essential to explore this area to promote lifelong participation across the life span of individuals aging with an SCI. The purpose of this study was, therefore, to gain an understanding of participation in everyday occupations through life stories of persons aging with a traumatic SCI.

Method

Design

To capture life stories about participation in everyday occupations from persons who have lived with an SCI for several years, narrative interviews were used to gather data, and a paradigmatic analysis was used to analyze the data [28,29]. The paradigmatic analysis was chosen since it provides a method where concepts can be inductively derived from the data to uncover commonalities that exist across different stories [29]. The study was approved by the Regional Ethical Review Board in Umeå, Sweden.

Sampling strategy

The participants were selected through criterion sampling, which is one strategy for purposeful sampling [30], based on the following criteria: (1) traumatic SCI; (2) tetraplegia, since persons with tetraplegia need more assistance at a younger age than persons with paraplegia; (3) over 40 years of age; (4) a minimum of 10 years post-injury; (5) place of residence based on geographical location to enable personal encounters for the interviews; and (6) participation in one of the so-called Retro camps, arranged by the national non-profit organization RG Active Rehabilitation[1] in Sweden. These camps lasted for seven days and were designed as a client-centered and goal-oriented program in order to provide information about SHC and how these can be prevented in order to maintain and/or increase quality of life and independence while aging with a SCI.

A total of 47 persons with SCI participated in these camps; 17 had tetraplegia and the remaining 30 had paraplegia. Of the 17 persons with tetraplegia, 10 corresponded to all inclusion criteria. A letter was sent to them with information about the study and a request for their participation. Responses were received from eight persons who returned letters with their written consent and contact information. The first author contacted them by phone to provide more information about the study and answer questions; thereafter, appointments for the interviews were scheduled. All participants were ensured confidentiality and were informed that they could withdraw from the study at any time without giving any explanation, and that their withdrawal would not affect their participation in activities arranged by RG Active Rehabilitation.

Participants

A total of eight persons, four women and four men, aged 48 to 74 years (mean age: 57.63 ± 9.0) with tetraplegia caused by a traumatic SCI (mean years post-injury: 27.13 ± 10.4) participated in this study; a detailed description of the participants is shown in Table 1.

Data collection

The first author conducted all the interviews according to Riessman's [31] description of narrative inquiry using a few broad questions. Initially, the participants were asked one broad question: Tell me your story about how; from soon after the SCI until today, you have participated in different everyday occupations. Follow-up questions were asked about how they had to act in order to continue to participate in, for them, meaningful everyday occupations and about changes over time. They were also asked a broad question regarding their thoughts about possibilities to participate in everyday occupations in the future. Follow-up questions were also asked, according to participants' answers, in order to expand the narratives and to capture their personal stories. The participants chose the setting of the interview; six participants were interviewed in their homes, while two participants were interviewed in their offices. All interviews were recorded digitally using an Mp3 player. The interviews lasted between 1 and 3 h (mean time: 2, 5 h) and were transcribed verbatim.

Data analysis

To guide the work with the analysis, a paradigmatic analysis of narratives was used in the way that has been described by Polkinghorne [29]. An inductive approach, which has been recommended when there is not enough knowledge in one area or around a phenomena, was used in the analysis [32]. Initially, the transcribed interviews were read several times to obtain a sense of the overall data. Next, the coding process began by identifying significant events for each participant, which could describe changes and/or turning points in the participants' stories about how they participated in everyday occupations immediately after their SCI, how their participation changed over time, and how they acted in order to enable participation. Next, in order to

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[1] This organization has a special interest in active rehabilitation and provides persons with SCI opportunities both to meet role models who have experienced living with a comparable type of injury and to participate in organized camps with different themes.

Table 1. Information about the participants.

Sex	Pseudonyms*	Age	Level of injury/severity	Years post-injury	Social status	Profession
W[a]	Maria	57	C6/C[c]	36	S[e]	Administrator
W	Liza	50	C7/C	15	M/C[f]	Administrator
W	Dana	54	C6-7/C	31	S	Administrator
W	Sarah	74	C5-6/IC[d]	13	M/C	Assistant nurse, retired
M[b]	William	52	C4-5/C	35	M/C	Computer technician
M	Mark	58	C3-5/C	41	M/C	Administrator
M	Steven	68	C3-4/IC	19	S	Engineer, partly retired
M	Jonathan	48	C5/C	27	S	Administrator

*Pseudonyms used in relation to the quotations in the results.
[a]W: woman; [b]M: man; [c]C: complete SCI; [d]IC: incomplete SCI; [e]S: single; [f]M/C: married or cohabitating.

get an overview of the identified significant events, these events were sorted and organized into possible emplotments for each participant. The possible emplotments for each participant were then compared in order to allow for the exploration of commonalities among the different emplotments, which led to the discovery of common themes. Throughout this process, the emplotments for each participant and the exploration of commonalities among them were discussed and tested by the first and last authors; different interpretations were considered by going back and forth to the original transcribed material. The process outlined above was repeated until the emplotments were arranged in the most-appropriate themes to accurately capture how participation in everyday occupations changes over time while aging with an SCI. It is important to remember that the final themes presented in the results are the authors' interpretations and represent just one description of many possible ones. The second and third authors read the drafts for the manuscript and gave constructive feedback regularly throughout the writing process. Pseudonyms are used throughout the results to protect the anonymity and confidentiality of the participants quoted.

Results

Through the analysis of the participants' life stories, three themes emerged that provide a picture of how they acted to participate in everyday occupations, how their actions changed over time, and several concerns about their possibilities to continue to participate in occupations in the future. The first theme illustrates how the participants soon after the injury acted in order to become agents of their own lives to manage the complexity of participation in everyday occupations after the sudden changes they experienced due to the SCI. The second theme describes how they after several years valued and prioritized participation in meaningful occupations due to both personal and environmental factors. The third theme shows how the participants today, tried new strategies in order to continue to participate in occupations in spite of physical deterioration, and how feelings of uncertainty aroused regarding the future as a result of aging.

I could handle my SCI and still participate in everyday occupations

This first theme illustrates how the onset of the SCI initially caused a dramatic change in participation in everyday occupations. Our analysis showed the importance of a rather long period of hospital rehabilitation initially that gave participants, as they said, ''enough time'' to adapt to the consequences of the SCI. During the first two to three years following the SCI, they also learned to perform occupations more efficiently by refining techniques when, for example, dressing or undressing or making different types of transfers. Although we found that participants had chosen to resign from further training when they perceived that training no longer improved their physical functioning, this choice was also connected to frustration. Another choice that participants made and valued in order to challenge themselves to participate in everyday occupations was to meet well-matched role models with an SCI that aligned with their own personality and needs. We interpreted this individualized period of initial rehabilitation and a well-matched role model as a dynamic process that was socially and culturally constructed. Thereby the participants realized that it was possible to act in order to participate in everyday occupations, even though they had to learn that some occupations took longer to perform; some had to be prioritized; and some had to be performed in a different way than prior to the SCI. William, for example, narrated how he handled the difficulties in participating in various occupations after the SCI:

> . . . it is surely a matter of personality and mentality. I've never dug myself into the problems encountered after the injury when it comes to performing activities; I have solved them in some way. If the problems cannot be solved, I can change my aim to avoid fighting with windmills . . . and perform what is simpler . . .

We found that participants valued and expressed the importance of returning to work as soon as possible following the SCI. However, in order to reach this goal, it became clear that they had to act as their own agents, since many professions in the society suggested that they should accept sickness compensation. For example, they expressed that it was up to them to figure out their own needs for education in order to obtain new, more-appropriate employments. Through their own acting, they found employments that was more suitable and possible for them to participate in, mainly conducting administrative duties, and in addition, some engaged themselves as volunteers and gave talks about how they were injured and the experiences of living with an SCI in places like schools. Working part-time was most suitable for the participants because more time was spent on personal care activities and transfers. Even though they were generally satisfied with their work, they experienced an incredible loss in being unable to work manually and use their hands. One example of this is presented in the following citation by Mark:

> . . . I started to study since I lacked grades from high school . . . but also because I could no longer work practically after the injury . . . I'm really a hands-on man . . . being a car mechanic . . . I like working with my hands . . . it's a huge difference to not be able to . . .

Our analysis showed that participants also found it important to participate in leisure activities rather soon after the SCI, even if they had to adapt or change their performance. A common leisure activity following the SCI among participants with earlier experiences in ball and team sports was wheelchair rugby. Others chose leisure activities completely different from what they enjoyed before the SCI, since they experienced a changed meaning when they could no longer participate in the occupations in the same way as a result of the SCI.

The participants realized rather soon following the SCI that they needed help from personal assistants in order to participate in everyday occupations. We found that this insight was associated with complex emotions; in some ways, accepting help was easier than they expected, while at the same time, they could never really accept their need for support. For this reason, some struggled to be independent in occupations like personal care, even if morning routines took longer to perform. Steven shared his complex emotions:

> . . . it is not fun to be dependent on others . . . what if I'm lying there and getting help with my pants, and someone/the personal assistant decides to just leave . . . well, I would have to lie there until someone comes and rescues me . . . you are so vulnerable . . . in order to survive, you have to let go of your integrity without having your dignity violated . . .

The participants had their formal personal assistance arranged in several ways, for example, through the municipality, by different private assistance companies, or by themselves as employers. The analysis showed that they learned that successful participation in everyday occupations with personal assistance depended upon the personal assistant's personality, interest and engagement. Built upon this understanding, they experienced the importance of acting and participating in the process of choosing personal assistants who fit into their everyday lives. We also found that the assistance of informal personal assistants presented both advantages and disadvantages for the participants. In one way, accepting help from relatives was easier, since they did not have to include non-family members in their daily routines. On the other hand, using relatives as personal assistants meant a risk of losing their roles as family members. Based on the participants' experiences, we interpreted that how personal assistance would be arranged after an SCI was not an obvious choice in order for such assistance to work smoothly for both parties. Thereby, participants had to take an active role and act as agents in the arrangements with personal assistance for their possibilities to participate in everyday occupations. Sarah expressed her thoughts regarding the arrangements of her personal assistance:

> . . . for a while I thought that I would employ my own assistants, but then you have no one to complain to . . . it's probably good for the assistants also to have an independent employer to turn to if something does not work, if they are unsatisfied or want to quit. Getting up in the morning, washing me, poking my nose, and everything else that has to be done . . . there is nothing of this that I had to work for in the past, before the injury, so it is just going to work even now . . .

I had to prioritize and value participation in everyday occupations

The second theme illustrates that when several years had passed after their injuries, the participants had to prioritize among their everyday occupations. They resigned from occupations that had been conducted without regularity, for example, camping and spending time outside in nature, because such occupations demanded a lot of planning, and participation in such occupations was still not the same as it had been prior to the SCI. The participants also had resigned from occupations like wheelchair rugby that were associated with big risks, based upon experiences of shoulder and elbow injuries. We interpreted this as the participants having an insight about their vulnerability after several years and how injuries could further complicate their everyday lives. Instead, they came to prioritize participation in occupations that were less demanding, and they altered their participation according to their daily capacities, the meaning of the occupations, and in which context the occupations would be performed.

Over the years, the participants had experienced the complexity of being dependent on personal assistance. Our analysis showed that, after living with an SCI for several years, they often prioritized occupations based on their personal assistants' opinions; additionally, there was little or no room for spontaneous occupations because the personal assistants' schedules were arranged several months in advance. The participants also experienced frustration when occupations of necessity like personal care, cooking and housekeeping were prioritized before more meaningful occupations. Built upon all these experiences of complexity, one way in which they dealt with this was to participate in leisure activities, such as going to the movies or sporting events with friends and/or relatives. We interpreted that a relational process with good communication and clear responsibilities with the personal assistants enabled participants to be agents and participate in everyday occupations. One example of this is presented in the following citation by Jonathan:

> . . . I have found my role and ask the assistants for help with what I can't do . . . because people are amused by and skilled at different things . . . I choose actively which personal assistant is going to help me with what . . . so I think I can increase my participation even though I depend on other people's hands to perform certain activities . . .

We found that several years after the SCI, participants had the insight that their work became too demanding. However, at the same time, they valued their work highly because it fulfilled a social aspect of life that was different from other friendships and social interactions. In order to continue working and still have time and energy to participate in other occupations, they had reduced their working hours and had found employments where they could actively plan, for example, changing their duties according to their abilities and daily capacities. In order to both work and participate in other occupations in the community, they valued their rights to be able to choose between driving their own adapted car or use transportation services according to weather conditions and types of occupations. The value and independence of driving was shared by Liza:

> . . . the feeling of driving can't be described by words . . . freedom . . . while driving you are like anyone else . . . you must follow the same laws/rules . . . no one can see that you're disabled . . . the car means a lot to those of us with impairments . . . I love to drive and intend to do so as long as I can . . .

Through the analysis, we realized how laws and guidelines for obtaining technical aids, such as a wheelchair prescription, depended on which municipality the participants lived in. Over the years, the participants had become creative and generative in order to actively seek out updates, educate themselves, and fight for their rights to obtain a specific technical aid that was well adapted to their individual needs in order to increase participation in everyday occupations.

I experience worries and try new strategies when my conditions change to participate in everyday occupations

The third theme shows that, as a result of living a long life with an SCI, participants had to change their level of participation or resign from everyday occupations due to factors, such as increasing pain in the shoulders and muscles, progressive muscle weakness, fatigue and sleep-disordered breathing/apnea. The participants had concerns about how much longer they would be able to participate in everyday occupations, since their conditions are now constantly changing, and there is an increasing difficulty to compensate for the deterioration of physical functioning. Implicating that participants own attitudes towards themselves, according to a changed body and older age, limited their participation in occupations. Dana shared her thoughts:

> . . . I would like to take more courses . . . such as painting, but they are often held in useless buildings . . . it's hopeless . . . before, I took the courses anyway . . . and I never hesitated to ask (strangers) for help with, for example, a transfer, but it's not as easy anymore. I'm older. There is a difference when you're young and light-weight . . . now I'm more of a hag, and it's not as easy to get help. . .

It became clear that the participants needed more time to recover from occupations as a result of SHC. To manage that, they had introduced daily rests, although this strategy was at the same time a somewhat troublesome solution because of difficulties with independent transfers. They also experienced that occupations conducted outside the home demanded more energy; therefore, a common strategy among them was to participate in one occupation at a time, for example, going to the cinema or a restaurant on different days in order to be able to participate in and appreciate both. Furthermore, the participants hesitated to travel for vacations because of the prolonged recovery time as a result of SHC, something that had never been a problem earlier. The analysis shows that the participants aging with an SCI had to try out new strategies and change their participation in occupations as a result of SHC. The participants also experienced that driving a car was no longer given, and some had to give up driving because of worries regarding safety related to the deterioration of their physical functioning. The following citation is an example of how Maria experienced her worries about the increasing problems of participating in everyday occupations:

> . . . almost every day I have to face the option . . . whether I should choose not to participate in activities and be bored . . . or do what I want and be worn out . . . I do not know how to balance everyday life to be able to handle it . . . but I guess there will be a day when I fall off the line and the problem is solved by itself whether I like it or not . . .

Further, the participants experienced an increased need for technical aids and personal assistance to continue participating in everyday occupations as their physical functioning deteriorated. One strategy they used was to avoid the leadership and stress that personal assistance entailed and to resign from occupations that demanded more personal assistance. Another strategy, in order to continue working, was to reduce their working hours further and introduce rest days between working days. The participants acknowledged the opportunity to be early retirees, but our analysis showed that this was not appealing to them, since they were worried about what they would do when they were no longer able to work. William shared his struggle to cope with his job while taking part in other everyday occupations:

> . . . I begin to glimpse a problem; how will I manage to work in a few more years at this pace, while continuing to be the person William and not the patient William? . . . I want to have energy for work, for myself and for my family, so there are many threads that draw . . . and in the middle of this is the aging tetra body that ultimately decides . . . that doesn't seem to be the least negotiable . . . it is disturbing . . . I got used to the body not cooperating, but now it has started to strive against me . . .

In this theme, it became clear that the participants, despite their concerns about SHC, also had concerns regarding changed and decreased support from society. For example, it is not possible to get an adapted car after the age of 65, and the participants hoped that their current adapted cars would last for many years. Furthermore, it is not possible to extend personal assistance, and they experienced anxiety and concerns about what would happen if their need for help increased in the future. We found that the participants had no clear answers and/or strategies for addressing their increasing problems of participating in everyday occupations, and they did not know where to get suitable support. We realized that both those aging with an SCI and society are facing new and demanding situations to enable the participants to participate in occupations and continue to be agents in their everyday lives. The following citation by Jonathan is an example of this:

> . . . earlier, I always saw a positive development for life with an SCI . . . the situation has improved remarkably as a result of the advancement of technical aids . . . for example light-weight wheelchairs . . . adapted cars and personal assistance . . . these have been exciting developments to see . . . but the future that I see now . . . there is no exciting solution . . . a new approach is probably necessary . . .

According to the participants' experiences, we found that they would have liked to receive information about aging with an SCI earlier in order to be more attentive to signs of deterioration in physical functioning and to take preventive action. They questioned whether it would have been better to receive more help from personal assistants and use more technical aids at an earlier stage. Built upon the participants' experiences of aging with an SCI, we realized how they struggled with feelings of anxiety and uncertainty but also frustration. We interpreted these struggles as concerns about not knowing how to act in order to continue to be creative, generative and have a relational process in which they could deal with issues in their everyday lives and continue to participate in occupations in the future.

Discussion

The results provide a picture of how persons aging with tetraplegia have acted in order to participate in everyday occupations from soon after their injury until the present time, several decades later. Further, our findings illustrate how that changed over time, some concerns about their own capacity to act in the future, and the possibilities to get appropriate support from healthcare and social services. This study could thereby expand the knowledge from earlier research, which focused mainly on different aspects of rehabilitation and participation in occupations during the first few years after an SCI [20,23–27] or aging with an SCI from a medical perspective [1,3,11,13].

Our findings show that early on after the SCI, the participants started to act in different ways in order to engage and participate in, for them, meaningful occupations. This is in line with earlier research that explored how people whose lives have been disrupted by illness or injury have a need to engage in occupations to take control of their lives [33–35]. The way the participants acted and challenged themselves is in line with earlier research describing that persons' experiences of participation are related to their opportunities to enact agency in challenging situations.

Therefore, this can be understood as a requirement to become agents of their own lives, which implies to act by themselves, through perceiving their capacity and situation, reasoning about it, consciously monitoring their action and forming motives [36–38]. Furthermore, our findings show how the participants as agents could deal with issues in their own everyday lives, for example, through their actions in relation to how they participated in desired and meaningful occupations, such as returning to work and getting the most-appropriate support from personal assistance. It was a constant ongoing process that was associated with different insights and feelings of concerns. Participation changed as a result of personal factors, such as experiences of an altered meaning for occupations, their vulnerability and risk for other injuries, and a variety of SHC. These findings can add to the knowledge of participation explored by Hammel et al. [16], who described participation, based on experiences from persons with disabilities, as a dynamic process that involves a constant negotiation and balancing act of competing needs and values across individual, social and societal levels. Earlier research has also shown that experiences of participation can be viewed as a person's opportunity to choose, access and make decisions about engagement in occupations [16,38,39]. This is in line with our results that show that participants several years after the SCI were active in making choices about occupations they would participate in based on their personal needs and how they valued and experienced meaning in occupations.

Even though our results show how the participants had become agents of their own lives, we also found that this way of acting became more complicated the longer the participants lived with the SCI because of SHC. While aging, they experienced worries, uncertainty and frustration when familiar strategies for participation in occupations were no longer working, and their ability to be agents was threatened by SHC. Further, they experienced that it was difficult to compensate and find new strategies as their conditions were constantly changing, results that align with both Wray's [22] and Brah's [40] descriptions that the ability to act is not fixed and can change continuously due to several different circumstances. Aging with an SCI can be seen as a complex daily struggle in order to know how to act and continue to participate in everyday occupations, an understanding that gives implications for developing well-functioning lifelong support that can enhance participation across the lifespan of individuals' aging with an SCI.

To live an active life and participate in meaningful occupations with well-functioning support as you are aging with an SCI should be a human right. Although, in our results we identified occupational injustices for persons aging with a disability, related to how the laws and guidelines were designed. Occupational injustice is described as an outcome of social policies and governance that structure how power is exerted [41,42]. From earlier research we knew that, for example, persons aging with a tetraplegia need a home that is modified appropriately, to be well equipped with technical aids, and to have sufficient personal assistance [43–45]. We found that it neither was possible to increase the amount of personal assistance and obtain more technical aids in order to prevent SHC, nor was it possible to acquire another adapted car after reaching 65 years of age. Furthermore, the participants realized that laws and guidelines concerning prescriptions of technical aids were different depending upon the region in which they lived. These examples of occupational injustice made participation in occupations uncertain for participants aging with an SCI. Implicating that since life expectancy for persons with SCI has improved, it is important that they receive appropriate support from society in order to enable their participation in everyday occupation throughout the whole life span.

Methodological considerations

To get access to the participant's process of change to participate in occupations in their everyday life, we used a narrative method, since narratives are a person's way of interpreting and making meaning of experiences over time [46]. The strength with this narrative method is that the study does not simply produce a reproduction of data, instead it provides a dynamic framework in which the range of disconnected data elements are made to cohere in an interesting and explanatory way [29]. There is always a possibility that the participants narrate a specific/limited story, although this consideration seems highly unlikely, since all the narratives consisted of joys as well as sorrows and provided a rich variation of narratives. Nevertheless, because of this approach, no attempts were made to analyze differences between genders or those with complete or incomplete SCI. To enhance trustworthiness [47], there is a thick description [48] of the sampling strategy and characteristics of the participants, as well as the process of data collection and analysis. For this study, one inclusion criteria was tetraplegia, which could be a limitation. This decision was based upon earlier research that found that this population first needed more assistance with ADLs compared to persons with paraplegia [14]. To enhance trustworthiness and improve credibility, the first and last authors had a constant dialogue during the analysis process [47]. In addition, the second author asked questions to help the first and last authors to adopt a self-critical stance. Representative quotations from the transcribed text were used to show how the themes cover the data. The knowledge from this study can be relevant to other persons aging with SCI in similar contexts and can be useful in providing knowledge to rehabilitation staff. Therefore, it could be of relevance/interest to perform another study with the same design for persons with paraplegia in order to add to the body of knowledge regarding participation in everyday occupations while aging with an SCI.

Conclusions

To conclude, this study captures how persons aging with tetraplegia acted in order to participate in everyday occupations from soon after their injury until today, several decades later. Further, this ability to act and participate changed over time. In order to promote participation in everyday occupations throughout the life span for individuals with tetraplegia, our findings give knowledge that can guide clinicians in their work within this complex area of rehabilitation. Our findings can also guide the work with policy recommendations for healthcare and social service systems.

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Declaration of interest

The authors report no conflicts of interest with respect to the authorship and/or publication of this article.

References

1. Groah SL, Charlifue S, Tate D, et al. Spinal cord injury and aging: challenges and recommendations for future research. Am J Phys Med Rehabil 2012;91:80–93.
2. Groah SL, Kehn ME. The state of aging and public health for people with spinal cord injury: lost in transition? Top Spinal Cord Inj Rehabil 2010;15:1–10.

3. Krause JS, Bozard JL. Natural course of life changes after spinal cord injury: a 35-year longitudinal study. Spinal Cord 2012;50: 227–31.
4. Krause JS, Coker JL. Aging after spinal cord injury: a 30-year longitudinal study. J Spinal Cord Med 2006;29:371–6.
5. Krause JS, Broderick L. A 25-year longitudinal study of the natural course of aging after spinal cord injury. Spinal Cord 2005;43: 349–56.
6. Krause JS. Changes in adjustment after spinal cord injury: a 20-year longitudinal study. Rehabil Psychol 1998;43:41–55.
7. Krause JS. Longitudinal changes in adjustment after spinal cord injury: a 15-year study. Arch Phys Med Rehabil 1992;73:564–8.
8. Crewe NM, Krause JS. An eleven-year follow-up of adjustment to spinal cord injury. Rehabil Psychol 1990;35:205–10.
9. Savic G, Charlifue S, Glass C, et al. British ageing with SCI study: changes in physical and psychosocial outcomes over time. Top Spinal Cord Inj Rehabil 2010;15:41–53.
10. Hitzig SL, Tonack M, Campbell KA, et al. Secondary health complications in an aging Canadian spinal cord injury sample. Am J Phys Med Rehabil 2008;87:545–55.
11. McColl MA, Charlifue S, Glass C, et al. Aging, gender, and spinal cord injury. Arch Phys Med Rehabil 2004;85:363–7.
12. Thompson L. Functional changes in persons aging with spinal cord injury. Assist Technol 1999;11:123–9.
13. Liem NR, McColl MA, King W, Smith KM. Aging with a spinal cord injury: factors associated with the need for more help with activities of daily living. Arch Phys Med Rehabil 2004;85:1567–77.
14. Gerhart KA, Bergstrom E, Charlifue S, et al. Long-term spinal cord injury: functional changes over time. Arch Phys Med Rehabil 1993; 74:1030–4.
15. World Health Organization [WHO]. Toward a common language for functioning, disability and health: ICF, the international classification of functioning, disability and health. Geneva: WHO; 2002.
16. Hammel J, Magasi S, Heinemann A, et al. What does participation mean? An insider perspective from people with disabilities. Disabil Rehabil 2008;30:1445–60.
17. Mallinson T, Hammel J. Measurement of participation: intersecting person, task, and environment. Arch Phys Med Rehabil 2010;91: 29–33.
18. Kielhofner G. Model of human occupation. Theory and application. 4th ed. Baltimore (MD): Lippincott Williams & Wilkins; 2008.
19. Law M. Participation in the occupations of everyday life. Am J Occup Ther 2002;56:640–9.
20. Isaksson G, Prellwitz M. One woman's story about everday life after a spinal cord injury. Disabil Rehabil 2010;32:1376–86.
21. Magnus E. Everyday occupations and the process of redefinition: a study of how meaning in occupation influences redefinition of identity in women with a disability. Scand J Occup Ther 2001;8: 115–24.
22. Wray S. What constitutes agency and empowerment for women in later life? Sociol Rev 2004;52:22–38.
23. Schönherr MC, Groothoff JW, Mulder GA, Eisma WH. Participation and satisfaction after spinal cord injury: results of a vocational and leisure outcome study. Spinal Cord 2004;43:241–8.
24. Weitzner E, Surca S, Wiese S, et al. Getting on with life positive experiences of living with a spinal cord injury. Qual Health Res 2011;21:1455–68.
25. Isaksson G, Josephsson S, Lexell J, Skär L. To regain participation in occupations through human encounters-narratives from women with spinal cord injury. Disabil Rehabil 2007;29:1679–88.
26. Angel S, Kirkevold M, Pedersen BD. Getting on with life following a spinal cord injury: regaining meaning through six phases. Int J Qual Stud Health Well-Being 2009;4:39–50.
27. Van de Velde D, Bracke P, Van Hove G, et al. The illusion and the paradox of being autonomous, experiences from persons with spinal cord injury in their transition period from hospital to home. Disabil Rehabil 2012;34:491–502.
28. Mattingly C. Healing dramas and clinical plots. The narrative structure of experience. Los Angeles (CA): University of California Press; 1998.
29. Polkinghorne DE. Narrative configuration in qualitative analysis. Int J Qual Stud Educ 1995;8:5–23.
30. Patton MQ. Qualitative research & evaluation methods. 3rd ed. London: Sage Publications Incorporated; 2002.
31. Riessman C. Narrative methods for the human sciences. London: Sage Publications Incorporated; 2007.
32. Elo S, Kyngäs H. The qualitative content analysis process. J Adv Nurs 2008;62:107–15.
33. Yerxa EJ, Clark F, Frank G, et al. An introduction to occupational science: a foundation for occupational therapy in the 21st century. Occup Ther Health Care 1990;4:1–17.
34. Carpenter C. The experience of spinal cord injury: the individual's perspective – implications for rehabilitation practice. Phys Ther 1994;74:614–19.
35. Law M, Cooper B, Strong S, et al. The person-environment-occupation model: a transactive approach to occupational therapy. Can J Occup Ther 1996;63:9–23.
36. Kabeer N. Resources, agency, achievements: reflections on the measurement of women's empowerment. Dev Change 1999;30: 435–64.
37. Wray S. Women growing older: agency, ethnicity and culture. Social 2003;37:511–27.
38. Borell L, Asaba E, Rosenberg L, et al. Exploring experiences of participation among individuals living with chronic pain. Scan J Occup Ther 2006;13:76–85.
39. Fallahpour M, Jonsson H, Joghataei M, et al. ''I am not living my life'': lived experiences of participation in everyday occupations after stroke in Teheran. J Rehabil Med 2013;45:528–34.
40. Brah A. Cartographies of diaspora: contesting identities. London: Routledge Press; 1996.
41. Townsend EA. Muriel driver memorial lecture: occupational therapy's social version. Can J Occup Ther 1993;60:174–8.
42. Whiteford G. Occupational deprivation: understanding limited participation. In: Christiansen CH, Townsend EA, eds. An introduction to occupation: the art and science of living. 2nd ed. Upper Saddle River (NJ): Prentice Hall; 2010:303–28.
43. Dijkers M. Correlates of life satisfaction among persons with spinal cord injury. Arch Phys Med Rehabil 1999;80:867–76.
44. Saikkonen J, Karppi P, Huusko T, et al. Life situation pf spinal cord-injured persons in Central Finland. Spinal Cord 2004;42:459–65.
45. Whiteneck G, Meade MA, Dijkers M, et al. Environmental factors and their role in participation and life satisfaction after spinal cord injury. Arch Phys Med Rehabil 2004;85:1793–803.
46. Josephsson S, Asaba E, Jonsson H, Alsaker S. Creativity and order in communication: implications from philosophy to narrative research concerning human occupation. Scan J Occup Ther 2006; 13:86–93.
47. Lincoln Y, Guba E. Naturalistic inquiry. Newbury Park (CA): Sage Publications Incorporated; 1985.
48. Geertz C. The interpretation of cultures: selected essays. Vol. 5019. New York: Basic books; 1973.

Notice of Correction:
Since the first online publication of this article the Mean values have been updated in the Participants section from 57.3 to 57.63 and 37.25 + 10.5 to 27.13 ± 10.4.