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Research Article

Living A Good Life Despite Limitations 5 Years Post Spinal Cord Injury

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ABSTRACT

The changed body functions after spinal cord injury challenges all parts of life. The recovery process is supported by many rehabilitation initiatives. This process takes time and it is difficult to pre-tell how life will be. With a Ricoeurian approach, peoples' experiences of life and the difficulties they had to deal with five years after spinal cord injury were explored. Interviews with 11 people were analysed using Ricour's text model. The findings showed that life can be perceived as good despite limitations entailed bodily limitations and strains. The themes were that though bothersome, life was experienced as good and possibilities appreciated. This implied a deliberate choice of not letting limitations take focus. Striving to try out dreams, some found their way though dealing with bodily strain. Furthermore, Negotiation was demanded to be socially included. In overcoming spinal cord injury, the individual dealt with all aspects of life. Coming to terms with the limitations, the decisive factor was that it did not include a loss where value could not be found in something else.

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Introduction

Immediately following a traumatic spinal cord injury, a person can find it hard to imagine a future life [1]. The injured person may not have been confronted with anyone living with a disability before, which may make it even harder to imagine how life can be [2]. A study over a period of two years among 12 people showed that despite differences in locations of the injury and prognosis, the meaning creating process in rehabilitation after spinal cord injury can be described in six phases [3]. The first phase was characterised by the person struggling to survive physically and regain vitality. When the person in phase two improved, also, due to recovering from the spinal shock, the possibilities of a future were slowly disclosed. The initiatives taken by health professionals were the major source, encouraging even the smallest effort and praising every little improvement. However, it was not enough with the physical results of the recovering spine and the exercises in the rehabilitation program. Engaging in rehabilitation could be a challenge if the person was not able to imagine a future life worth living.

When able to imagine this prospect, phase three entailed engagement and eagerness to make the best possible effort and expecting everybody to do the same. The more progress, the more enthusiasm, and expectations to what could be achieved. The injured spine will eventually put an end to the progress. This happened in the fourth phase, and with the fading progress, possibilities narrowed. The expectations to the future life had to be scaled down; the more hope, the more disillusioned. From the disillusion rose recognition of what the person was actually able to and what had value. This may imply that new activities encompassed basic values from life before the accident or finding new values. Thus, the way forward was found by exploiting limited possibilities (phase 5). If this was possible it could result in appreciation of life finding oneself living a good life despite limitations (phase 6). This process could take years and not everyone found peace with the possibilities they had during the first two years [3].

Reintegration in society was a difficult process that entails new ways of being almost in all relations such as loved ones, family, friends, job and society in general according to Suddick & O'Neill [4]. In Bender &

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Burgess' study narratives one, three and six months after spinal cord injury showed different states of mind from being optimistic and confident to being anxious [5]. Noe *et al.* illustrated that the way people deal with the a new and more strained situation implied the ability to come to terms with the situation [6]. The study showed that knowledge about basic life circumstances such as livelihood was not necessarily achieved after one year. This caused insecurity and combined with difficulties in engaging in the mental part of the recovery process; the more issues, the worse. The number of challenging issues increased if core competencies were affected, especially if these were job-related like in craftwork. Despite the level of threats towards a well-functioning life, clarification of functional level, livelihood, social participation and ability to find new ways of performing daily activities and finding comfort in new roles had a positive influence and brought relief, hope and perspective in life [4].

The fact that a spinal cord injury changes life dramatically is well documented and so are many of the negative consequences. When looking at the trajectory of people with spinal cord injury, it is important to remember that being at peace with one's possibilities is a common struggle for many. But when it is related to an injury, the experience of loss added to the burden. Therefore, it is important to obtain a balanced picture of life after spinal cord injury. A study showed that people may, despite the struggle, have positive outcomes due to the process that they appreciated [7]. Furthermore, it may be positive that although people with spinal cord injury score low in all kinds of participation (education, productive activities, social and leisure activities) when defined in relation to the population in general, Suddick & O'Neill [4] found that participation increased if defined by the people with spinal cord injury themselves. Still, it is important to know what it means to get on with life five years after the spinal cord injury. The difficult process after a spinal cord injury may be easier if the person and the professional have knowledge of how life can be. Therefore, the aim of this study was thus to explore people's experience of life five years after spinal cord injury.

Design

This study is based on interviews five years after spinal cord injury. The participants were interviewed to understand what characterises life five years after the injury and makes it work. I wanted to find out "how do people experience life 5 years after a spinal cord injury".

I Theoretical Perspective

Developing knowledge about peoples' everyday life experiences is possible with a hermeneutic phenomenology approach. Paul Ricoeur's philosophy explains how peoples' narratives allow access to their

participants' perspectives on their life [8]. In the narratives, new happenings are related to the past till they outline a meaningful configuration and the person's story serves to understand themselves and life [8]. From their stories, people gain meaning and their narratives allow others to get insight. The personal narratives express peoples' interpretation of what has happened in their lives more than facts about how events, in fact, took place. This understanding is the starting point for action and thereby future life [8, 9].

II Setting and Participants

Eleven participants from a study three years earlier were interviewed in their homes five years after they sustained a traumatic spinal cord injury (Table 1) [3]. Eight had incomplete and three had complete paraplegia, and all were able to breathe without aid and had some functions of their hands. After three-five months they had been discharged from the rehabilitation unit to continue rehabilitation and recovery in their homes. Initially, one participant lived alone and had a little limited professional help to manage cleaning and gardening, but not cooking; she got by with takeout food. One needed professional support day and night for personal hygiene the first couple of years; later aid was only needed in the day time. Nine were assisted by family members to tasks of daily living like cooking, laundering, cleaning, organising the home, shopping and thus managed more or less on their own. The job was managed with reduced hours and less demanding tasks. One managed working seven days a week with a personal assistant 20 hours a week. One gave up having a job.

III Data Collection

The participants' stories about life five years after spinal cord injury were elicited by open questions about their life. This openness was in line with a phenomenological approach and allowed the participants to talk freely given time to configure their story [8]. According to Ricoeur, the participant "draws a meaningful story from a diversity of events and incidents" [10]. Furthermore, it is part of the phenomenological approach that the interviewer must be willing to follow the participant's telling [10]. However, this "followability" as Ricoeur name it, implies simultaneously that the listener can follow what is told [10]. There is no possibility of accessing the other's lifeworld without personal commitment. Thus, the interviewer's preunderstanding was used when asking follow-up questions, probing, revealing details of how life was when spinal cord injured. Thereby, the interviewer supported the participants' configuration of their narratives. Finally, in an attempt to ensure that significant issues had been covered, the participant was asked "is there more you think needs to be added to cover life five years after the spinal cord injury?"

Table 1: Demographic description and functional abilities.

Name ¹	Age ²	Civil status ³	Employment ⁴	Accident ⁵	Spinal Cord Injury	Bowel/bladder function ⁶	Dysfunction of hands ⁶	Mobility ⁶
Adrian	30-40/ 30-40	married to Ann	academic	road trauma	incomplete C4	+/ ⁶ + ⁷	-/ ⁷	wheelchair/ ⁶ walk
Belinda	60-70/ 60-70	married to Ben	middle-range training	fall	incomplete C5	-/-	+/+	wheelchair/ walk with sticks, wheelchair
Cindy	60-70/	married to	pensioner	road	incomplete C5	-/+	+/+	walk with rollator/

	60-70	Charles		trauma				walk, wheelchair
Debbie	25-30	single	academic	road trauma	incomplete C5	-/+	+/+	walk with rollator/ walk
Edward	15-20/ 15-20	has a girlfriend	theoretical highschool	road trauma	severe incomplete Th1	-/-	+/-	wheelchair/ wheelchair, walk with rollator
Frank	30-40/ 30-40	married to Frida	skilled worker	industrial accident	severe incomplete L1	-/-	-/-	wheelchair/ wheelchair, walk with sticks
Georg	30-40/ 30-40	married to Geogina	skilled worker	industrial accident	complete Th4+Th5	-/-	+/+	wheelchair/ wheelchair
Hank	40-50/ 40-50	married to Henny	unskilled worker	industrial accident	complete Th11	-/-	-/-	wheelchair/ wheelchair
Isabel	40-50/ 60-70	married to Ib	middle-range training	fall	incomplete C7+Th1	-/+	+/+	wheelchair/ walk, walk with sticks, wheelchair
Kate	40-50/ 40-50	married to Kent	middle-range training	road trauma	severe incomplete C7+Th1	-/-	+/+	wheelchair/ wheelchair
Larry	30-40/ 30-40	married to Laura	skilled worker	road trauma	complete Th4	-/-	-/-	wheelchair/ wheelchair

¹Fictitious name ²Age at the time of the accident ³Civil status at the time of the accident

⁴Employment at the time of the accident ⁵Type of accident ⁶4 weeks versus 2 years after the accident

⁷+ means normal function ⁷- means reduced function.

IV Data Analysis

An understanding of peoples' experiences of everyday life with an injured spinal cord five years after the injury was obtained by analysing the transcribed interviews. According to Ricoeur, the transcription to text is a way of objectification, because it allows transparency in what is said and how it is interpreted [11]. From the immediate understanding of what the text says "with some kind intuitive grasping of the intention underlying the text", the analysis moved towards a deep interpretation [11]. This process contained three levels of interpretation: naïve interpretation, structural analysis, and critical analysis. The naïve interpretation was an immediate understanding of the meaning of the individual interviews and all the interviews as a whole [11]. Thus, the naïve interpretation is a surface interpretation implying intuitive impression, and guesses of the meaning. In this study, the naïve interpretation was that life five years after a spinal cord injury was basically similar to life in general. The difference was numerous time-consuming challenges caused by the lost body functions.

The deeper understanding was sought in the structural analysis by explanations based on the semantics leading to a deeper understanding. Sentence by sentence was read in dialectic with the text as a whole working "from what it says, to what the text talks about" [11]. This was done by explaining what the sentence could mean in a hermeneutical arc reading the parts in the context of the whole and vice versa. Ricoeur explained "the dynamic meaning released by the explanation that is, its power of disclosing a world" [12]. In this process, the researcher "remains in the suspense of the text", meaning that what the participant said was interpreted with the transcribed interview as the reference. This revealed more themes among which strain and mastery were pronounced [13].

To decide the most significant interpretation among possible interpretations, a critical interpretation was made. This was done by relating the explanation of the structural analysis to the surface interpretation of the naïve interpretation, and in the hermeneutic spiral develop the knowledge from the subjective perspectives to a more universal knowledge. In the light of the research question, the most significant interpretation of the narratives of life five years after spinal cord injury was that the damaged spinal cord impacted on all aspects of life; body function, health, and well-being, activities and participation, roles and interactions and way of living. This was dealt with by compensating, awaiting or avoiding activities.

V Ethical Considerations

The study was conducted in line with the Declaration of Helsinki and Danish legislation. The ethical committee in the former County of Aarhus had no objection when starting the study (21.12.2004). The study was registered at the Danish Data Protection Agency in 2010-41-4534 and in 2016-41-4624. Based on the initial written consent, consent was obtained before each interview, where the researcher gave oral information about the study. This implied confidentiality, anonymity and that the consent could be withdrawn at any time.

Findings

Asking participants how things went revealed narratives about how to manage the circumstances of spinal cord injury. Therefore, the narratives were not so focused on the strains of the body. Most strains had become a routine, and the main problem was that more time was needed to perform daily tasks. Many things in life could still be accomplished, though in new ways, especially in everyday life, and those which could not be accomplished were left out or maybe abandoned. Still, the loss of intelligence in bodily ability could not be substituted. The themes were:

- i. Appreciating possibilities
- ii. Non-focusing on limitations
- iii. Trying out dreams
- iv. Finding one's way
- v. Dealing with bodily strain
- vi. Negotiating inclusion

I Appreciating Possibilities

Though everyday life had limitations, there was a solid appreciation of what was possible - praising the luck after all. This was in light of that the situation could have been worse. If young appreciating youth's ability to adapt; if old appreciating having tried many things before. George, married and a father in his thirties that had his own business said:

Now I'm one of the lucky ones who don't take that much time taking a bath and passing stools and all (George). The appreciation was often found in relation to others who might be worse off: If you had no job and wife and kids then it's difficult just to get out of bed and do something. You probably lie down resting a little longer whereas I can't just lie down during the day - I have to move forward (George). And so, he did. However, staying positive seemed to be a task in itself, and this left no room for own or the problematising or negative attitudes of others. This could for example be to engage less in the partner's problems. The strategy was to focus on getting something positive out of the negative and stop the blaming attitude.

II Non-Focusing on Limitations

The functional impairment was unavoidable due to the bodily limitations. The existence was based on the ability to dealing with bodily limitations and not to let these limitations take focus from life. Instead of letting limitations dominate, the focus was shifted. This deliberate avoidance of letting limitations take the focus was not a neglect, but a positive choice of what was possible. A problem-solving attitude seemed to work for Larry, a craftsman in his forties running his own business:

When there is something you can't do, then you have to do it in another way (Larry).

In this case, the focus was turned away from the limitation by finding another method to handle the task. Still, he mourned the loss of bodily intelligence that had enabled him to know exactly how to perform. If limitations could not be overcome, non-focusing could be a total avoidance. This implied a mental act of restricting oneself and not allowing oneself to be bothered. For example, when not being able to bike, the car was chosen or going on trips was no longer a part of life. The new solution was maybe seen as a temporary solution, expecting to be able to ride a bike again sometime in the future.

III Trying Out Dreams

When recovering after a spinal cord injury and struggling to get on with a life worth living, returning to the previous life with plans and dreams had been the primary goal. Hank, a craftsman in his forties and when he got injured dreaming of establishing his own company, explained:

I remember my wife driving me around in a wheelchair out here and had a blanket over me and I thought shit! Is this the future? Not that it was negative..., but I thought is this the future, really? You can't do anything but this? And I can still remember this coming home and it was spring and I thought, really you should be able to do more. (Hank)

After the injury, he managed to continue with his business among other things. Striving to be able to do as before was particularly pronounced among previous craftsmen, manifested in risky actions such as making a cast floor or replacing roof tiles. The reason behind seemed to be that earlier skills had to be tried out before accepting not to be able to manage these. Another example was related to traveling. However, when meeting one's limits in trying out dreams, sometimes the outcome was not worth the struggle.

IV Finding One's Way

Life had changed and prior possibilities had become limited and it was a struggle to figure out what was possible. Understanding the new situation and getting used to this situation and its consequences took time. Frank, in his thirties, who was no longer able to work as a craftsman found that when you have no control, you can go with the flow:

Of course, you miss the things you could do before and can't do anymore, well you know, all in all, it kind of takes its course. (Frank)

He was surprised to get a job in the production industry again. Taking things as they come may be a personal characteristic, but it could also be the result of lacking the ability and strength to take control. Finding one's way depended on what turned out to be possible and, in this situation support from others and society played an important role. This could e.g. be the offer of a job or even to have a job assigned to you or be engage in any kind of function and could developed to be very stimulating and fascinating.

V Dealing with Bodily Strain

Five years after the spinal cord injury, overcoming bodily limitations was a part of the every day that had to a large extent become a routine. The differences in coping can be seen as a continuum; for some compensations for bodily limitations were incorporated into daily functions as a normal activity that no longer led to reflections. This implied that the bodily changes could be forgotten in short periods or slide into the background. Larry told:

I never go around and think that I actually have a tingling sensation and pain. It's sliding into the background. (Larry)

At the other end of the continuum, there were situations of being too sick to deal with the activity of the day due to the sequelae of the spinal cord injury. Then despair could take over and life seemed to stall.

VI Negotiating Inclusion

The space needed for the time-consuming routines had to be achieved by negotiating flexible solutions with the municipality and/or workplace. Also, the accessibility of the surroundings was critical. This called for

inclusion both environmentally and socially, which did not always happen. Sometimes the needed support was more than the surroundings or municipality could or would provide. This affected the mental drive of the injured person and could cause the person to lose drive. A car was the most important tool to regain freedom and independence. However, if this was not needed to have a job, a car was harder to get. In Isabel's case, economic support for a car was declined:

As they say, you can use the driving services for disabled people and moreover if you have your (own car, you cannot have the) wheelchair in your car without having a lift because they also decline to buy a lift (Isabel).

The municipal authorities had suggested that she should just ask anybody passing by to help her. Isabel thought it was not an option and therefore a ridiculous suggestion. Due to the need for support, the municipality granting the support had a voice in central decisions, which contributed to the experience of lack of control in one's own life.

Discussion

When listening to the narratives of people five years after suffering a spinal cord injury, we are reminded of the existential foundation for being. The narratives were examples of how life can be lived and illustrated how bodily functioning is central to experiencing the world. The sudden loss of a functional body meant that it was not possible to be the person you used to be. Life, as it had been before the injury, was lost due to lost functioning, activity, and participation. When ill and injured, the world changes from "I can" to "I cannot" [14]. Being a body implies also to be limited by the possibilities of the body. The body that had previously been a source of freedom and independence had changed and become an obstacle in the shape of a body that "cannot" thereby causing dependency. In the rehabilitation process it is attempted to change "I cannot" to "I can".

In this process the bodily limitations are attempted to be overcome by improving bodily functions and if this is not possible, then to try to do things differently ways. When the individual succeed it is a victory leading to a positive self-image. But sometimes it turns out to be too much of a struggle and not worth the effort. Finding a way of being despite the limitations, the individual developed into the person they could become due to the circumstance. Though Kennedy *et al.* [7] found that it is possible to appreciate the gain, this was not the case for all. Being is not only being that person, the person is in the present, but according to the philosophy of Heidegger and Sartre, a person also has the potential to be someone that s/he has not become yet [15, 16]. With the injury, the individual has lost prior direction towards the person, s/he had not yet become. Potentiality in life known from the work of Heidegger and Sartre helps us to understand that life after traumatic spinal cord injury was lived not only in the shadow of who the person used to be and how life was lived before the accident, but the person's potential prior to the accident was also a part of the frame of reference for whether life is good or not. This called for new prospects or future potentials such as meeting a partner, forming a family, finding a new way of being a mother or a father, being able to perform an elite sport, or running your business with success.

The narratives after five years disclosed that getting on with life happened by focusing on what was possible, letting the strain slide into the background. The counter move to the loss could be to downgrade the importance of what was lost. Simultaneously, appreciating what was possible was given a more prominent position. We could question whether this could be characterised as self-deception explored by Sartre in *Being and Nothingness* and Fingarette elaborated on in his book *Self-deception* [16, 17]. In that case, the narrative should serve as a "cover story" allowing a distance to the severe consequences of a spinal cord injury and to continue life without losing oneself in despair. When deceiving oneself, the "cover story" hides the facts that could lead to despair and as the findings disclosed some of these facts, they are not all hidden in the narratives. Somehow, the participants managed to face some severe facts in the interview situation, and they did not seem to let these losses obstruct a well-functioning everyday life.

This study cannot conclude if participants found life overall good due to self-deception. That life was good and that participants managed well were intertwined with narratives of strain. Getting on with life was about keeping a positive attitude to life; Shifting the focus to possibilities and appreciating these possibilities was emphasized instead of being overwhelmed by strain and limitations. It is a happy message that it is possible to lead a good life after spinal cord injury and five years after, life was perceived as good despite limitations. But there is no doubt that it is an extremely demanding struggle with lots of strain as seen in the study by Duggan *et al.* [18]. Furthermore, there are difficult periods. Significant others play an important role in caring and supporting emotionally and practically. Also, societal inclusion was a challenge and could not be managed without support from authorities. This gave people in these positions an overwhelming influence on the lives of people with spinal cord injured [19].

Limitations

The participants in this study more or less succeeded in finding a way of living life that they perceived as good despite limitations. It is possible to imagine some that would not succeed. According to the thorough work of Corbin & Strauss, the process entails many elements not to fail [20]. They emphasised that it was hard work both from a medical, biographical, and rehabilitation perspective; to manage the limitations was the essence of overcoming disability [20]. Furthermore, it takes "knowledge, counselling, money, time and energy" [20]. The present study disclosed themes that together form how it is possible to live a good life, and may address issues if life seems to be stuck.

Conclusions

Life 5 years after spinal cord injury can be perceived as good despite limitations. The lost body functions entailed limitations and caused strains which overall had become a routine. Though bothersome, life was lived and possibilities appreciated. This implied a deliberate choice of not letting limitations take focus. Striving to live out dreams, some found their own way. To be socially included demanded a successful negotiation with authorities. In overcoming spinal cord injury, the individual dealt with all aspects of life. Coming to terms with the limitations set by the body, the decisive factor was that it did not include a loss where the value could not be found in something else.

What This Study Adds

- i. The narratives after five years disclosed that getting on with life happened by focusing on what was possible, letting the strain slide into the background.
- ii. The counter move to the loss could be to downgrade the importance of what was lost.
- iii. Appreciating what was possible was given a more prominent position.
- iv. Societal inclusion was a challenge and could not be managed without support from authorities. This gave people in these positions an overwhelming influence on the lives of people with spinal cord injury.

Author Contributions

Substantial contributions to conception and design, acquisition of data, analysis and interpretation of data and drafting the article.

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Conflicts of Interest

None.

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