"Hope is definitely not the same thing as optimism. It is not the conviction that something will turn out well, but the certainty that something makes sense, regardless of how it turns out. It is also this hope, above all, which gives us the strength to live and continually try new things".


Abstract

This paper presents narratives that focus on experiences of hope, told by 10 participants three to four years after suffering spinal cord injury. Experiences of hope are understood as vital, essential and dynamic aspects of human life and human health. This is the first study addressing patients’ experiences of hope three to four years following spinal cord injury. This study has a descriptive, longitudinal design, and is part of a larger study on patients’ experiences of hope three to four years following spinal cord injury (Lohne, 2001, 2006, 2008a, 2008b; Lohne & Severinsson, 2004a, 2004b, 2005, 2006). Data were collected at three points in time by personal interviews. A phenomenological approach inspired by Ricoeur (1976) was used to extract the meaningful content of the patients’ experiences. Findings revealed three main themes: Life-related hopes (I), Body-related hopes (II), and Creative and expanding hopes (III). Results indicated that three to four years following injury, participants were focusing on life more than on hope due to improvements and adaptation to a new life.

Introduction

This paper will present narratives focusing on experiences of hope, told by 10 participants three to four years after suffering from a spinal cord injury. Most of us pay little attention to our bodies, as long as they function automatically (Cole, 2004) and, according to Merleau-Ponty (1962), the body is our expression of the world. But after a spinal cord injury, parts of the body become insensitive and unable to move. The body seems almost silent or absent. For a person suffering from a spinal cord injury, the body becomes an irritating stranger that only can be observed from the outside (Cole). Since we experience the world through our body, when parts of our body suddenly become absent, we can no longer experience the world as before.

According to several nursing studies, patients’ hope seems to be regarded as a universal experience and it is also contextual, general and unified (Farran, Herth, & Popovich, 1995). Hope may be a challenging phenomenon that influences the emotions and thought processes, as well as behaviour and actions (Dufault & Martocchio, 1985). Experiences of hope are understood as vital, essential and dynamic aspects of human life and human health (Farran, Herth, & Popovich). Marcel (1951) differentiated desire for hope, in which he viewed wishes as more specific ‘wants’ or premature hopes, while the experience of hope holds a deeper, more basic and personally important essence of expectations and future possibilities. Yet, hope is regarded as an important nursing concept (Farran, Herth & Popovich). Few studies have addressed the phenomenon of hope in the rehabilitation context. However, no studies were found addressing the experiences of hope over time among patients suffering from spinal cord injury.

Literature review

Patients suffering from a spinal cord injury may experience a wide range of activity limitations due to impairment or loss of motor and sensory functions below the level of the neurological lesion (Biering-Sørensen et al, 2006). A spinal cord injury may, therefore, lead to health problems, such as pain, loss of strength and lack of control, boredom and loneliness, stress, anxiety and depression (McColl et al, 2001; Crews et al., 1998), which, however, usually tend to improve over time according to Dorsett and Geraghty (2004). The longer the individuals live with the injury the fewer problems they experience—probably due to adaptation and/or developing coping strategies over...
time (McCull et al., 2001). Kennedy et al. (1995) found that after four to seven years following the injury, patients used fewer, though more emotional strategies, compared to newly injured patients. According to the researchers, the most useful strategy for preventing emotional suffering was acceptance. The focus on hope, however, sometimes may be in conflict with acceptance, even though the substance of hope may be related to acceptance.

The totally unexpected and critical nature of the event and its consequences probably gives rise to the clinical anxiety and depressive reactions frequently noted among patients suffering from a spinal cord injury (Crews et al., 1998). Physical pain is more dramatic than mental pain (Lewis, 1940). Pain and lack of sensitivity are common and can easily be recognized. A short attack of severe physical pain is overwhelming while if it lasts, the suffering person will beg for relief. When short, severe physical pain passes, however, it leaves no obvious alteration in behaviour. On the other hand, long-term pain has more noticeable effects and is, therefore, accepted with little or no complaint, developing great strength and providing an opportunity for heroism (Lewis, 1940).

The phenomenon of hope is related to time and oriented towards the future. The past, which is history, points to our experiences while the future is still a mystery. Hope itself is created in the present, pointing to the future and holds a positive substance. Depending on the present condition, the hopeful patient will focus on improvements when experiencing illness or suffering. However, when experiencing moments of wellness, the main focus will be general, like “hoping to continue to stay just fine” (Lohne, 2006). According to Marcel (1951), we may refuse to hope or deny hoping, but “to live in hope is to remain faithful in the darkness” (p. 63). Being in hope is, therefore, living in hope instead of concentrating on fears. “Having” hope or “hoping for” may be limited to an activity outside of us while “being in” hope may be understood as an internal activity. The word “being” is derived from existence. Therefore, being in hope can be linked to “existing” or “living” in hope (Marcel, 2001). Having hope may be understood as a more particular hope, such as, hoping for improvements, while being in hope is pointing towards a more generalized hope, like “being just fine” (Lohne, 2006).

Hope is regarded as having dynamic patterns since it is in dialectical interaction with cognitive and affective dimensions (Kylmä & Vehviläinen-Julkunen, 1997). Hoping has a therapeutic potential and importance because hope provides one with a sense that there is a future. Hope is an individual project beyond our physical existence and, therefore, beyond death. Hope, therefore, is also understood as transcendental and magical (Cutcliff & Herth, 2002a; Kim, Kim, Schwartz Barcott & Zucker, 2006). Hope is perceived as a force of will and power and may also represent encouragement or comfort (Lohne, 2006). Hoping processes may vary, especially in patients following different injuries and illnesses (Kim, Kim, Schwartz Barcott & Zucker). The substance of hope was found to be related to receiving help (from relatives or nurses), to caring (being understood) and to inner or external resources among injured individuals. Therefore, inspiring or maintaining hope in patients should be highlighted, even if such approaches may be dependent on personal attitudes or connections (Cutcliff & Herth, 2002b). According to Morse and Doberneck (1995), hope was understood as ‘incremental’ among individuals with spinal cord injury during their long process of hoping to walk again. Uncertainty and fear for the future may cast hope in shadow. On the other hand, according to narrated experiences of patients suffering from a spinal cord injury, experiences of hope may relieve anxiety (Lohne, 2008b).

This longitudinal study contributes new knowledge on patient experiences of the process of hope, as well as the substance of hope, three to four years after spinal cord injury, not available in literature. As clinical nurses are involved in the care of patients suffering from acute and dramatic incidents, such as spinal cord injury, the knowledge of long-term patient experiences will be useful to both patients and their families in providing the necessary support in the rehabilitation process.

Methodological framework

This qualitative study has a descriptive, explorative and longitudinal design. A phenomenological-hermeneutic approach, inspired by Ricoeur (1976), was used to extract the meaningful content of the patients’ experiences. This theory of interpretation is a spiral process that includes gaining a sense of the whole, followed by the identification of meaningful parts, and an interpretation of potential horizons of meaning in the text as a whole.

The following research questions were investigated:
• How are experiences of hope being described from the perspective of patients following three to four years of suffering from spinal cord injury?
• What is the expressed meaning of their experiences of hope after the first three to four years following spinal cord injury?

Ethical considerations

This study has been approved by the Norwegian Ethical Committee and the Norwegian Social Science Data Services. On the basis of inclusion criteria, two ward nurses asked recently admitted patients to voluntarily participate in this longitudinal study (a total of 14 patients). Four patients declined to take part in the investigation; three men and one woman. The patients were guaranteed anonymity and integrity. All patients received both oral and written information about the purpose, content and extent of the study, and their informed consent was obtained.

Subjects

This study was carried out in Norway. One participant died during the investigation. Nine participants were included according to the following criteria: Over 20 years of age, diagnosis of spinal cord injury, newly admitted to the rehabilitation institution, cognitively intact, and able to speak a Scandinavian language. The participants were between 22 and 68 years of age, five men and four women. Two of the patients suffered from inner vascular damage and seven suffered from external injuries as a result of car accidents or falls (one had tried to commit suicide). All injuries had occurred suddenly and unexpectedly. Four patients had symptoms of complete spinal cord damage, and five were not completely injured. The lesion levels were from C5 to L4 (fifth cervical to fourth lumbar level).
Data collection
This study is part of a larger study (Lohne, 2001, 2006, 2008a, 2008b; Lohne & Severinson 2004a, 2004b, 2005, 2006). Data were collected three times by personal interviews. The first interview was collected at the rehabilitation institution during autumn, 2001. The next two interviews for some were conducted at the participants’ homes. During autumn 2002 and spring 2005, only two interviews were conducted at the investigator’s office because this was most suitable for the participants. All interviews were conducted by the investigator lasting on average 60 to 90 minutes. The interviews were tape-recorded and transcribed. The interviews followed a semi-structured guide based on a theoretical analysis of the phenomenon of hope (Lohne, 2001). The participants were asked open-ended questions concerning the past event (the accident or vascular damage), the present (at the rehabilitation centre, or at home) and the future (expectations or future orientation). The following are examples of interview questions: “How do you feel when you look at your future?” “What kind of changes do you hope for?” “What does hope mean to you, personally?” The participants described their feelings and experiences of hope, their hoping process since the accident, the meaning of hope, and their short-term, long-term and future perspectives. Additional clarifying questions were asked by the interviewer, depending on what the participants had expressed.

Data analysis
The purpose of the data analysis was to extract meaningful content from the participants’ experiences. The analysis was performed in several steps. In the first step, the researcher attempted to understand the meaning of the whole text. “Understanding a text is only a particular case in the dialogical situation in which someone responds to someone else” (Ricoeur, 1976, p.22). The second step involved a number of structural analyses to grasp the most probable interpretation and explanation of parts of the text. The structural analysis was performed inductively. The final step was to make a comprehensive and understandable interpretation of the whole text, taking into account the structural analysis (Ricoeur).

Findings and interpretations
In this longitudinal study of hope, the findings revealed three main themes: Life-related hopes (I), Body-related hopes (II), and Creative and expanding hopes (III). The interpretations of hope described by the participants were narrated in different ways, as well as in different perspectives, depending on the degree of wellness and bodily improvements each of the participants had gained emotionally, mentally and physically following their injuries. Since the last interview, when every participants’ experiences of hope still fluctuated between suffering from the injury and their individual struggle to become reconciled with reality, their individual lives had brought them even further in terms of their life-related hopes, as well as their body-related hopes through creative and expanding hopes.

Theme I: Life-related hopes
The concerns of life-related hopes were narrated as moving rather to a new and different life or “back to life again”—but not to life as it was before. According to the participants, hope seemed to be most important shortly after the injury. However, three to four years following their injury, they were now more or less living in hope. Life-related hopes were comprehended as “being” in hope—and sometimes also “existing” in the future, “longing back”, originating from the still-missing past. From moving along the road of hope, they were now moving along the road of life, meaning that their illness and suffering were comprehended as being in the “background”.

This study on hope following a spinal cord injury has confirmed that human nature has a remarkable ability to adapt to totally new contexts—usually through dramatic turning-points, from one context (wellness and contentment/happiness), and then suddenly to another (slowness and mobility impairments/wheelchair) and gradually back again. For the participants, this created dramatic and painful, but also surprising and pleasant experiences. Every participant’s life had undergone major changes during these three to four years. At the time of the third interview, they were living with new partners, new stepchildren and grandchildren, having moved into new houses or flats, sometimes to new parts of the country or even abroad. For some, a wheelchair had become a natural part of their daily lives. Some had started new studies, new jobs or new hobbies, and they had adapted to new outdoor activities (boating, camping, etc.). One participant had died from natural causes and several had considered committing suicide when living through painful experiences, but nobody did. The idea of death had therefore, at times, also brought hope to some, and life had won in the end.

Due to depression and vulnerability, participants had hope for further physical improvement in the “background”, and to keep their focus on life in the “foreground”. A 27-year-old woman admitted that she had occasionally experienced depression before the injury. Thus, she sometimes understood her injury as a symbolic “hook” on which to hang her remaining problems. She continued to view her fall from a balcony as a “catharsis, purifying her life through teaching and supervising...” Due to her life experiences, which she described herself as being “lonely”, she had matured from a girl to a young woman in just a few years. She described her rehabilitation period metaphorically, as “hardships create sorrow, but an injury makes you wiser”, and her present hope was wellness “...because to hope for improvements may create dissatisfaction”. Even though the fall had created uncertainty, she continued to feel disappointed about “everything that went wrong” and she still felt like she was living “within a kind of vacuum or stagnation”.

Another woman of about the same age, narrating from her wheelchair, said that she was continually “apprehending life, but never death”, and that her hope was a synthesized experience: “hope is always pointing towards the consequences”. Her comprehension goes beyond meaning, since she experienced that “the evil event brought something good”, and that “without hope one will end up in a vicious circle”. Thus, hope, from her perspective, was an essential factor in the process of improvement.

In spite of suffering and disappointments during four years following injury, a 63-year-old man experienced life as being filled with much joy and peace. However, even though he was
still open to finding a possible meaning for the accident, he no longer pondered it. He chose to live in the now (present)—“being and living in peace and harmony”. “Happiness comes from within, and the more we live in hope, the more we may lose contact with our life (or our living),” “A pleasant life manifests your hope”, according to this man, “because every limitation is seated in your brain. Sometimes one uses the injury to hide oneself.” He concluded his narrative with a more general view: “We fight or we flight (run)—we either struggle or we die”.

Theme II: Body-related hopes

Everyone had fulfilled many hopes and everyone had experienced gradual physical improvements—far beyond what they had expected three to four years earlier. Body-related hopes were comprehended as having a hope concerning physical rehabilitation of mobility or sensitivity. Body-related hopes were experienced or narrated by participants as having hopes for improvements while they continued to experience slowness, stress and fatigue, pain and infections, spasms, as well as incontinence, and sexual problems. Furthermore, continuous incapability, immobility and invisibility (with or without a wheelchair), dependency and patience, as well as vulnerability, were still daily challenges. Several participants described their hopes as “small and incremental” and still, after four years, continued regular experiences of turning points. One woman, nearly 50 years old, described experiences as: “Suddenly my body collapses into crying and despair and out of this my body suddenly repairs into sensitivity, mobility and wellness”. She named her new experiences of sensitivity as “being in new contact with her own body”.

Every participant continued, also, to live in a vicious cycle and was, therefore, still living with experiences of future uncertainty. The vicious cycle had different inner circles: experiences of helplessness, which led to experiences of dependency, which, in turn, led to an almost unbearable impatience when waiting for assistance, which, in turn, led to loneliness, frustrations, vulnerability and despair. Another inner vicious circle came out of experiences of pain, which led to anxiety, depression, restlessness, sadness and, in turn, resulted in disappointment and shame due to lack of understanding or little help from health personnel. A third and last vicious cycle was due to vulnerability coming out of exposure to infections and terrible spasms, which, in turn, led to insomnia and experiences of uncertainty, which sometimes still overshadowed their hope.

Physical pain visited all participants now and then, and had become an inner and angry enemy. “You know, sometimes I am in so much pain that my only thought is to cut my leg off and send it to hell!” explained a 48-year-old man. He described the pain like cramps or drilling – “and you feel that it can’t be more painful… and then the headache comes, the neck pain and finally everything is hurting…” “I would rather have been completely injured and without pain”, was this brave man’s inner hope. In spite of that, his wheelchair finally had become a new, but integrated part of his body, and he proclaimed, “You will never (be) accustomed to the pain…” Other narratives of experienced physical pain were sensations like “needles pricking, or like being stuck by nails”, which kept the participants awake and suffering during days and nights.

“Being or living in uncertainty (because of pain or due to the shame of the pain) casts long shadows on my life, so my life is never black—but rather grey. I still hope to function, but I doubt that improvements will continue as I grow older…” expressed a 27-year-old man who experienced extreme vulnerability because of his pain and the shame of his pain. At the same time, some participants also wondered whether “the spinal cord injury symbolized a peg of painful experiences” at this point in the rehabilitation process, and it was, therefore, understood more like fiction, rather than a real problem. “You cannot live in hopes and dreams, but you may live with hope and willpower”, as stated by a young 28-year-old woman who had jumped from a balcony four years earlier. One could say that they had continuous silent hopes for their silent bodies.

Additionally, several participants frequently experienced being an invisible person, as they moved around in their wheelchairs:

Well, suddenly you are sitting in a wheelchair, and you want to go shopping… but nobody can see you, the tables with the automatic paying machines are placed too high for a wheelchair… and therefore I can no longer use a bank… You feel so lonely, I can tell you… and no one sees your signals… and I remember one night at the concert hall… oh, those huge glass doors, they didn’t open automatically… so I sat there and people crowded out… and I said to myself, I have to be fast… and I rolled a bit further and decided to follow the next group… and so I speeded up, but, no… I couldn’t manage, so I just sat there, waiting while I thought ‘don’t bother, nobody sees me…’ and then I heard a voice behind me, ‘Do you want me to open the door?’

However, even though they had no need for special treatments, they still suffered from an invisible and painful spinal injury. Several felt that they had “an invisible injury”, and this appeared to be impossible for the environment to grasp. This bilateral invisibility increased the burden of being a spinal cord-injured victim, as well as a survivor. Therefore, everybody hoped for being accepted and understood in spite of the spinal cord injury.

Theme III: Creative and expanding hopes

At certain turning points along the road of hope, participants experienced sudden moments of improvement, which gave them the courage to carry on. When expressing their hope, participants used metaphors like “a balloon” or “pushing limits”, highlighting the expanding nature of hope. Other expressions were “springtime” illustrating hope as a source or season of light, with “sprouting leaves” or as “a happy ending”.

According to the participants, hope fostered creativity, and was expressed as “…either you have to live in hope or you will come to a point where you have to live with the pain”. Hope was obviously “an integration of exercise, practice, growth and well-being”, and experiences of hope included vitality and joy of life, when hopes like canoeing or flying with micro planes became actual experiences and challenges. At such instances, the spinal cord injured were being full of hope: “Having hope and being fine is the same to me… and the trick is to integrate hope into the present”, as expressed by a 62-year-old participant.
“Everything starts with hope—and from there, hope ends with several goals”, according to a middle-aged man, meaning that every vision of mobility and sensitivity starts with hope and moves toward more concrete hopes, and towards necessary activities and contacts to fulfill the hope. “Either you continue—or you die, right? ...But I still have some goals—and I will not stop living—rather I will continue having fun... To me, all this is about being fine, but still never losing my hope”. This reflective and creative 63-year-old man suffered from a fall due to a sporting accident four years ago. “Some of the art/creativity of life, is about just being fine, which means that you enjoy life—every day—but without losing your virtue, because you should always hope for improvements and for expanding your limits... which means being comfortable and enjoying life and at the same time maintaining an openness for wishes and ...expansion. Finally, you calm down because you have fulfilled some dreams... and you realize that happiness is relative, though you won't find happiness if not inside yourself. And even when this seems like an empty phrase—it's true, especially with such mobility restrictions... So the creativity in life comes with enjoying the sun and the spring, staying in the now, which has become naturally integrated in my life. And at the same time, I am still in longing, missing people... To me, then, hope is being fine and enjoying life within the limits that we have, because if you just focus on goals, doing physical exercises every day, I think you will lose the sight of life...Well, if the now/present disappears just because you are working on a hope, and maybe you won't reach your goal, and you'll become disillusioned, and disappointed, and you'll have a big relapse... There is a risk in always looking ahead, and life itself is put into the shadow, focusing only on hope and physical training, but physical training should be an integrated part of everybody's life—so we should just enjoy it... Living in richness/wealth and activity, pushing your limits... and fulfilling your hope. At the same time, in the beginning (just after the downfall), hope was extremely important (to me)... I really think that hope is most important when you are newly injured, much more than later on, when you have adjusted yourself to totally new conditions.”

In addition to improvements, this man has gained a new level of understanding three to four years following the spinal cord injury, due to his sudden and incomprehensible downfall.

During a final interview, a 48-year-old woman explained that she had dreamt that she had been chair-bound just before the car accident, and that she had a warning of the coming accident a few days before.

**Discussion**

The aim of this longitudinal study was to explore and describe patients’ experiences of hope and the meaning and significance of such experiences three to four years following spinal cord injury. The findings revealed three main themes: Life-related hopes (I), Body-related hopes (II), and Creative and expanding hopes (III). According to the findings, everybody’s hope was existing in the shadows as a generalized hope (Dufault & Martocchio, 1985), and the main focus among participants was on life itself, including creativity and life-expansions.

However, there were some methodological issues. Subjects were invited to take part in the study on the basis of their personal appraisal and acceptance to share their personal experiences of hope. Fourteen subjects were invited to participate, and four subjects declined to participate due to personal reasons, and they could have made an important difference in the findings. All participants were willing and eager to take part in the interviews, and many of them stated that they wanted to help other spinal cord-injured individuals by sharing their personal experiences.

Some study participants had experienced the future as frightening and painful for weeks and months. They had been temporarily without hope and had considered ending their lives because of their immobility and pain. Additionally, periodic experiences of invisibility, vulnerability, dependency, loneliness and despair were extremely difficult for participants to bear. However, nobody committed suicide, not even one 24-year-old woman whose injury had been caused when she had jumped from a balcony. Somehow, after the fall, she found the meaning and courage to go on living in her wheelchair. To many participants, the future sometimes seemed overwhelming. Such contextual experiences may not require hope, but rather staying in the present and having a focus on pleasant experiences in the present. Paterson (2001), with reference to a meta-analysis, emphasized that patients suffering from chronic illness tend to alternate over time between focusing on wellness in the foreground and illness in the background or the opposite. Sometimes living in “the now” brings wellness to the foreground. But other times, when illness is in the foreground, future hopes might be a better place on which to focus. The focus on hope is not always hope for a treatment or elimination of a disease, or that something is going to go well, but rather a trust that whatever happens will make sense or meaning (Parker-Oliver, 2002).

The overall findings of the study, indicated that the experience of health is a dialectic movement, which indicates awareness and strength, and that experiences of health and suffering are integrated into each other in a dialectic movement, in which suffering can create the prerequisites for health (Lindholm & Eriksson, 1998). In this study, the researchers explored the importance of strength, such as willpower, courage and loyalty for health, while the suffering that has been endured provides strength. With this perspective, health and suffering are understood as a dialectical alteration between good and evil or death. Likewise, according to participants in this longitudinal study, experiences of hope were comprehended as a dialectic movement between helplessness and courage, vulnerability and improvements, dependency and creativity, painfulness and comfort, and uncertainty and strength. Participants in this study demonstrated the following accommodation, called response shift, from suffering and immobility to increased mobility and changes in values, and a redefinition of targets (goals and hopes).

**Implications for practice**

According to the participants in this study, hope is essential to recovering from trauma. Whenever a painful event
suddenly occurs in our lives, the mind becomes polluted with negative and fearful thoughts. Hope, however, made the injured individuals believe that sooner or later the bad times would improve, and experiences of hope would strengthen the ability to fight through periods of discouragement or despair. Individuals, three to four years following spinal injury, were focusing on life more than on hope, due to improvements and adaptation to a new life. This study emphasizes the importance of neuroscience nurses to promote hope in individuals following a spinal cord injury, and to help them, in a long-term perspective, focus on life and living. According to this empirical study, nurses should stimulate patients to hope for improvements, as well as adaptation to a new life, even three to four years following a spinal cord injury.

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