THE BATTLE BETWEEN HOPING AND SUFFERING

A Conceptual Model of Hope within a Context of Spinal Cord Injury

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Abstract

The aim of this longitudinal study was to explore ten patients' experiences of the meaning they attribute to the substance of hope and the process of hoping during the first three to four years following a spinal cord injury. This qualitative study is a synthesis of three empirical studies of hope and the overall aim was to deepen the understanding of the phenomenon of hope, based on the text representing the main contextual findings, to develop a theoretical framework on hope within a context of spinal cord injury, illustrated in the conceptual model (fig 1 & 2). In correspondence with Ricoeur, this conceptual model, which was developed from a new understanding, based on a new text of the phenomenon of hope, develops a new and deeper understanding of the meaning of hope. Findings revealed nine themes; universal hope, uncertain hope, hope as a turning point, the power of hope, boundless-creative and flexible hope, enduring hope, despairing hope, body-related hope and existential hope. The conceptual model was derived from these themes, illustrated as The Battle between Hoping and Suffering and The Road of Hope. The interpretations also revealed a distinction between being in hope and having hope, and having a hope of improvements was the main focus at the early stage of rehabilitation, while being in hope as being just fine was the main focus after three to four years of rehabilitation.

Key words: *Conceptual model on hope, Despair, Longing, Suffering, Vicious cycle.*

INTRODUCTION

The aim of nursing is to alleviate suffering as well as to promote health, courage and hope in individuals when they potentially or actually are suffering from illness or disease. [1-3] Many patients are enduring sudden and unexpectedly, seriously and often aggravating symptoms that cannot be cured nor healed. According to research, however, hope relieves suffering and influencing the process of rehabilitation and recovery by stimulating the will to fight and to survive. [4] Patients' suffering from injuries and illnesses need both courage and endurance. Without the hope of future possibilities the vital power of life will sooner or later diminish or fade away. [5]

Experiences of hope has been regarded as a central nursing concern, and according to nursing research, there seems to be an important relationship between experiences of critical injury and experiences of hope. [1,2, 6-8] A spinal cord injury is a sudden, incomprehensible, serious and dramatic incident with long-term consequences such as isolation, profound despair and extreme dependency. [5] The spinal cord is like a cable, connecting the communication between sensory and muscle functions in the body with the brain. The individual experiences his or her body being affected by impaired mobility and sensory ability depending on the level of injury and distal. [9-11]

Experiences of suffering are some of the most profound conditions of human life and the destiny to suffer is unique and lonely. The phenomenon of suffering is difficult to define, since suffering constitutes a sum of every painful (physical or mental) or vicious experience that we must meet. The suffering as such has no meaning, however, the process of reconciliation may transform experiences of suffering into creative and meaningful aspects of life, over time.[2] Patients suffering from a spinal cord injury have to face a future of probable complications requiring a lengthy period of relearning skills.[12] A spinal cord injury is therefore a comprehensive and stressful event, where sensory and mobility impairments lead

to physiological dependence, pain problems, depression and anxiety. Even though the situation tends to improve over time [5,12-16] a traumatically injured individual is in great need of endurance and hope. [5,6,8] Every positive future perspective will be of vital importance to these struggling and suffering individuals. [17]

LITERATURE REVIEW

Hope is a multidimensional and holistic patient phenomenon. Nursing literature highlights the importance of maintaining, sustaining and restoring hope in patients. [4,18] According to Nowotny [19], hope usually arises from experiences of injuries and suffering. At the same time, patients suffering from injuries are in great need of hope. According to Eriksson, [20] experiences of suffering are described as a movement between experiences of hope and hopelessness. The term hope is both used as a substantive (the substance of hope) and as a verb (to hope) or as an adjective (to be hopeful).[4,9] The substance of hope, or the individual and specific hope, appears through wishes or expectations, whereas the process of hoping represents experiences of having a hope or being in hope over time.[5] Hoping or having a hope is understood as a way of feeling, thinking, behaving or relating. Hope expresses itself as an active process in which the individual seeks possible and appropriate solutions and goals.[4,18] Still, hope as an abstract and general expression, has been difficult to explore and comprehend as a patient phenomenon. Based on a meta-analysis of 46 empirical studies of hope (published between 1975 and 1993), Kylmä and Vehviläinene-Julkunen maintained that so far, nursing research into hope has mainly been grounded in a positivistic paradigm.[21]

Hope is directed towards salvation form the darkness of the illness and the ability to survive the almost total destruction of the organism. Hope holds a passion for the possible, as hope transmutes inner workings of the minds into creative processes. [22-4] But, according to Lynch,[23]

the possibilities involved presuppose freedom from the situation in the light of escape and to find a way out.

The concept of hope has been explored and explained from a philosophical, theological, psychological as well as a sociological perspective, which has influenced all nursing literature and research on hope. Consequently, the comprehension of hope has evolved epistemologically from existential philosophy, developmental psychology and social learning theories. Based on world-wide studies on hope, and illuminated by the central nursing hope-researchers Farran, Herth & Popovich [4] hope may ontologically be summed up as having four attributes: an experiential process, a spiritual or transcendent process, a rational thought process and a relational process. Hoping involves a creative and imaginative process. A hopeful person will experience wider boundaries giving possibilities that are not bound to absolutes. In a spiritual perspective, hope is inseparable from faith. At the same time hope is based in reality, and may be 'goal-oriented' in an objectively possible way, even though the future is always uncertain. [25-6] Nurses may influence patient's hope for a period of time, either by being a supportive, positive listener or by tearing it away . However, basic and fundamental hope is understood as having deeper qualities when tied to suffering, while an ultimate hope may still be questioned, and more superficial hopes (or wishes) may fluctuate over time.[4,17, 26-8]

Existentialism is related to phenomenology and human existence is grounded in the situation and cannot be understood outside its unique and ever changing context. According to existentialism the individual exists freely in the universe, which is extremely relevant to the phenomenon of hope.[29] Through an existential perspective, nursing researchers and theorists have focused on patient phenomena such as suffering, despair, meaninglessness and death, and existential phenomena such as freedom, and choices, responsibility, possibilities and meaning, illuminating phenomena that are important to hope. The hope for eternal life,

miracles or of receiving help from God belongs to the theological and transcendental perspective of hope. Social learning theories have provided and emphasised the human ability to plan, create, imagine and engage in foresight actions.[4] Furthermore, trusting relationships and cumulative experiences in society, human behaviour and human development and maturity [17,30] have also been found as important aspects in the literature of hope and have evolved from this same perspective. Finally, theories of hope from a psychological perspective view hope as a goal determined and personal motivation factor, contemporarily struggling with experiences of anxiety. [4,25]

Another important study, carried out by Kim *et al.* [31] aimed to discover patterns of hope in hospitalised chronically ill patients in the USA by using Q-Methodology. This study uncovered individual experiences of hope in various ways, when focusing on different dimensions of meaning of hope. Five patterns of subjective experiences of hope emerged: external orientation, pragmatic orientation, realistic orientation, future orientation, and internal orientation. Six of the patients' hope seemed to be based on an external orientation, meaning that the sources of hope were significant others such as God, family or friends, rather than themselves. Four of the participants' sources of hope were the ability to do and enjoy small things. They did not believe in setting big goals, which was understood as a pragmatic orientation Kim *et al*. [31] Only two subjects expressed realistic perceptions about their situation which was comprehended as a reality orientation by the researchers. However, one may raise the question as to whether those two really had hope or not. Among the future orientated patients, five patients experienced having positive possibilities, a hope that was strongly dependent on their belief in God. Even so, they were more focused on their own situation than on their physical environment. Finally, only two patients were mostly self-oriented. Their hope seemed to be expressed through their use of humour or their ability to learn about medical progress. This kind of hope was interpreted as belonging to an internal orientation.

This study, though with a small sample, is worth some consideration. Not only was it carried out by highly regarded nursing researchers, it gives an original perspective of the sources of hope where internal versus external orientation can be related to Jung's two psychological types. [32]

AIMS AND RESEARCH QUESTIONS

The aim of this longitudinal study was to explore ten patients' experiences of the meaning they attribute to the substance of hope and the process of hoping during the first 3-4 years following a spinal cord injury.

The following research questions were investigated:

1. What is the expressed meaning and significance of patients' experiences of the substance of hope and the process of hoping during the first three to four years following a spinal cord injury?
2. What is the essence of patients' experiences of hope within a context of a suddenly suffering from a spinal cord injury and during the first three to four years following this incident?

The overall aim was to deepen the understanding of the phenomenon of hope, based on the text representing the main contextual findings; [17,27-8,33-4] to develop a theoretical framework within a context of spinal cord injury, which is illustrated in the conceptual model (fig 1 & 2).

THE STUDY

This qualitative study has a longitudinal, prospective and descriptive-explorative design and is a synthesis of three empirical studies of hope [17, 27-8,33-5]. The aims of these studies were to describe and interpret individual experiences of the phenomenon over time (3-4 years), to develop a conceptual model based on these experiences. The study of the patient (human)

phenomenon of hope over time is a complex, holistic and context-dependent interpretative phenomenological-hermeneutical approach, in accordance with the philosophy of Ricoeur. [36-7].

The phenomenological hermeneutical interpretations

The purpose of interpretations is to obtain a valid and common understanding of the meaning of the text so that a new and deeper understanding emerges from the text. [36-7] Parts of the text are meaningful signs, endowed with a deeper and richer meaning beyond that immediately grasped by reading. According to Ricoeur, [37] different interpretations of the same text (textual plurality) are not only possible, but rather acknowledged.

To understand the meaning constitutes a circular process through objectification of the text based on *distanciation* [36-7] the aim of which is to understand the author (research participant) even better than he understood himself.

The text involved was a result of three recorded, research interviews with each participant, based on their individual experiences of hope and hoping following a spinal cord injury. The interviews were first recorded, and then transcribed into text. According to Ricoeur, [37] when verbalising experience, impressions are transcended and become expressions. At the first level of treating a text, the temporality of speech is exceeded. At the second level, through a dissociation of the mental intentions of the author (research participant), the text gradually develops objectivity. At the third level, the text opens up through transcendence of time and place, and addresses an universal audience. Lastly, through the fourth level of *distanciation,* the written text opens up, becoming a new world.

The conceptual model, which was developed from a new understanding based on a new text in correspondence with Ricoeur, [37] develops a new reference and constitutes a new world of the phenomenon of hope. Through interpretation we comprehend a chain of partial meanings

as a whole in an act of synthesis. Construction of meaning is a process which is moving between guessing and validation. [36 (pp 72-6)] In this study the emerging of interpretations through textual analysis was a process within a hermeneutical circle, moving between whole and parts, between guessing and validation and between appropriation and a new understanding.[38] Appropriation means to "make one's own what was initially alien". [38 (p 185)] Patterns of interpretation were further questioned in an ongoing process of continual dialogue with the text in relation to my pre-understanding. The phenomenological-hermeneutical act of interpreting contextual language to gain a deeper understanding makes unfamiliar, fundamental experiences of human life familiar and comprehensible.[37]

Ethical considerations

The contextual part of this study was conducted through personal interviews. The Norwegian Ethical Committee (S-01093) and the Norwegian Social Science Data Services (No. 8368) approved the study in 2001. The patients were guaranteed anonymity and confidentiality. All patients received both oral and written information of the study, and their written consent to participate was obtained. The participants were free to decide whether to participate as well as to discontinue their participation at any point. Efforts were made to increase sensitivity as well as to avoid exploitation of the participants' vulnerability during the interviews.

Participants

The participants were strategically selected. Ten volunteers were included according to the following criteria: diagnosed spinal cord injury, mentally lucid and speaking a Scandinavian language. One elderly man died from natural causes 3 years after the injury, and therefore did not participate in the last interview. Six men and four female patients, aged between 22 and 76 years at the time of the first interview participated in the study. Two participants suffered

from inner vascular damage and eight from external injuries as a result of traffic accidents or falls. All the injuries had occurred suddenly, dramatically and unexpectedly. Four participants were suffering from a complete spinal cord injury while six appeared to be incomplete. The lesion level of the spine was from C5 to L4 (fifth cervical to fourth lumbar level).

Context of data collection

Data was collected three times from each participant in three separate interviews: the first interview took place about two weeks after admittance to the rehabilitation centre (between six and 19 weeks following the spinal cord injury). Two of the patients had been in deep coma during the first two or three months following the injury, and therefore, all participants had consciously experienced the time lapse as to about six to eight weeks following the injury. The second interview took place about one year and the third about 3, 5 years (between three to four years) following the injury. The first interview took place at the rehabilitation centre, during the autumn of 2001, while the next two (during the autumn of 2002 and during spring 2004) took place in the participants' homes or at my office, depending on the participant's own wish.

Each interview consisted of three sections: the past situation, the present situation and their future expectations and perspectives. Every interview focused on each participant's experience of hope at the different stages of rehabilitation, at the early stage, after one year of rehabilitation and finally after three to four years post injury. The interviews were a process of dialogue, based on a list of open-ended questions, and concerned the accident and the recovery phase, the hospitalisation period, the time at the rehabilitation centre and the time being at home again. The focus was on their continuing expectations and future orientations. I asked clarifying questions depending on what the patients had expressed and described if it did not interrupt the natural flow of the interview. My main concern was sensitivity and

empathy, and several participants experienced that telling the stories of their injury and their struggles had a therapeutic effect on their suffering.

The external context concerning the patients' environment, was primarily represented by the rehabilitation institution, and was, through its rehabilitation programme, an expression of hope in itself. However, when the external context was the participant's private and very different homes, the environment more or less told personal stories through pictures and memories, about their life before the accident. Signs from the accident were present in the form of an electric lift, a wheelchair, or a pair of crutches hidden in the corner.

The phenomenological hermeneutical analysis

Interpretations of texts expressed as the hermeneutic circle, progress from a naïve understanding to deeper understanding in relation to the whole of the text, and the whole in relation to its parts,. To achieve *distanciation*, the interpreter should approach the text without concern for the author (research participant),[37] and focus moves from the research participant's individual intentions and meanings to the meaning of the text. During this process of understanding, the text is freed from its originally context and given a life of its own.

In the beginning of my study, understanding was a guess, since the same sentence could be understood in different ways. According to Ricoeur [37] one-sidedness is always implied in the act of reading. The first step, the naïve reading, involved reading the transcripts as a story, while the second step involved a number of structural analyses, carried out as key statements and themes. Usually, at this stage, interpretative meanings are named by using words that participants had used themselves. Then, every interpretation were checked and compared to the whole text again. At this point, due to textual plurality interpretations only reflected my understanding at that point in time. Now the challenge was to identify central essences and units of meaning, in order to grasp the most probable interpretation from parts of the texts.

Ricoeur describes this as textual plurivocity.[37] At this level, the text opened up to de-contextuality in the analytical-interpretative process and the whole appeared in a hierarchy of topics with different levels of abstractions.

The aim of the third step was to make a comprehensive and understandable interpretation of the whole text, based on the naïve reading and the structural analysis.[36-7] At this level I searched for theoretical and philosophical understanding and reflections as well as my own contextual reflections and pre-understandings.

The conceptual model of hope is a synthesis made at the final and fourth step of interpretation and based on a synthesis of three empirical studies. The main findings from the studies [17, 27-8, 33-4] became a new text and extended the interpretation, resulting in a new conceptual synthesis, deeper and beyond my existing knowledge of experience. At this level, the text opens up through transcendence of time and space to a new world, at a new level of understanding, ready to meet an universal reader.[37] This last phenomenological-hermeneutical interpretation focused on the experiences of the meaning and significances of hope and hoping within a context of spinal cord injury through the 3-4 years following the injury. At this level I constantly asked myself the following question: What are the main concepts in this study and how are they related?

FINDINGS AND INTERPRETATIONS

In this longitudinal Norwegian study, based on a comprehensive understanding from the literature review, hope was defined as follows: the phenomenon of hope is future oriented (though still possessed in the now) and holds a positive substance. [5,9] This perspective has been the foundation of each of the empirical studies that form the basis of this paper.

The following themes are derived from interactive interviews and dialogues with ten (nine at the last interview) participants during the first three to four years following theirs suffering

from a spinal cord injury. Findings revealed the participants' own reflections and experiences concerning the meaning of having hope after their injury. They were interpreted as the following main themes and essences, which forms the basis of the conceptual model of hope within the context of spinal cord injuries: Universal hope, uncertain hope, and hope as a turning point, the power of hope, boundless - creative and flexible hope, despairing hope, body-related hope, enduring hope and existential hope.

Universal hope

Experiences of hope seemed to have some universal dimensions. Universal hope was based on narratives and statements concerning hope as long-term perspective (as opposed to wishes) and that its source came from within. The phenomenon of hope is expressed in future terms; whatever happens, there is always a possible hope. According to the narratives, hoping is a necessity in life, and without hope, humanity would not have existed or survived.

Uncertain hope

At the same time, experiences of hope bring doubt, since hope is future oriented, and the future is always uncertain and holds many "ifs". The future has two dimensions; the apprehension of disappointment or defeat and hope of improvement or of being (or staying) just fine. Therefore, hope was experienced as both seductive and frightening. At the same time it was challenging to balance between hope and reality. The future was experienced as exiting, but the more serious the damage was, the less certain was one's hope. By focusing on the present, the uncertainty was relieved, although this protective approach sometimes overshadowed experiences of hope. At the same time, every improvement stimulated the hope which created emotional dichotomies (ups and downs).

Hope as a turning point

During the rehabilitation process, participants who moved between hope and suffering, experienced sudden changes of improvements, which moved one from suffering and despair,

to experiencing hope. Every turning point occurred unexpectedly and suddenly – usually as an experience of increased mobility or sensitivity and resulted in immediate happiness. Turning points were comprehended at certain points along the rehabilitation process and meant moving from being in despair, to being in hope - like turning from a road of death to a road of life. This battle between hoping and suffering was a main interpretation in this study. The first turning point was the injury itself, including experiences of having survived the accident and the feeling of having been lucky after all, like having lost but at the same time having the understanding of having gained and received.

The power of hope

Every participant's experience of hope was powerful: Without hope one would have given up. Sometimes hope was the only thing left. Hope gave strength and inspiration to carry on and was the flame which managed one to look ahead. Still, experiences of hope were sometimes strong (comprehended as possible or probable hopes), and sometimes faint or weaker. The power of hope was expressed through the physical training and pointed to inner and individually undiscovered endurance and strength, based on the energy from faith and will.

Boundless - flexible and creative hope

The substance of hope was changing according to individual circumstances and events. Hope itself fluctuated between courageous hope and uncertain future expectations. Hope inspired patients to find creative, new solutions, (for example canoeing as an alternative to walking trips). This creativity and longing for regaining mobility created new hopes. Pushing ones limits was also experienced as hope. The flexibility of hope was described in metaphors, like a balloon, that can be stretched, or like having a hope with a parachute, understood as improbable, but still possible hopes. Other hopes were focusing on miracles.

Enduring hope

Experiences of endurance were related to time and patience, which was continuously tested. Experiences of helplessness, dependency, disappointments and loneliness over time due to the injury mainly resulted in the suffering and despair. Every hope was related to uncertainty – and the knowledge of never knowing the future exactly was exhausting. Therefore, looking forward required patience, strength and faith contemporary with the longing back for their former life before the injury.

Despairing hope

Experiences of hope were also experiences of sadness, which sometimes included the wish of giving up. Longing for encouragement and confirming hopes from one's surroundings (especially from health personnel) was exhausting. The terrifying prospect of becoming a permanent wheelchair user was an ongoing battle between hoping and suffering. At certain times during rehabilitation, especially when improvements were slowing down, patients experienced that hoping was difficult and every wish of giving up was struggling with the hope within a vicious cycle. Despairing hopes were filled with fair and panic and made it sometimes almost impossible to hope which led towards the road of death. The road of death was one alternative out of the vicious cycle and half of the participants had considered suicide on several occasions, though none of them had given up. Another aspect of the road of death was experiences of being trapped in an absent, insentient and unmoving body – like a silent body.

Body-related hope

Their body was injured, but not their minds, according to participants. Body-related hope focused on becoming well again, meaning being independent of assistance from others as well as being self-sufficient as pre-injury. Hope was continually focused on mobility, such as walking, dancing, jumping, running or standing, without using supportive equipment.

Additionally, hope was substantially focused on pain problems, reduced sensibility and slowness following the damage of the spine.

Existential hope

In an existential perspective, experiences of spinal cord injury gave new perspectives on life. Since the injury had totally changed the individually direction in life, it also made them appreciating incremental improvements and small gains. Additionally, some participants hoped to aid or help other individuals suffering from a spinal cord injury in the future. At the same time, participants longed for more peace in life, for becoming more humble, for changing direction in life and to become a better person. Several had experienced that their survival was due to grace from God and several also understood the spinal cord injury as a lesson - giving them new challenges.

The conceptual model of hope within a spinal cord injury context

The conceptual model, derived from an analytical-interpretative process on experiences of hope over time, is illustrated in figure 1 and 2.

Figure 1 about here

Figure 1 illustrates *The Battle between Hoping and Suffering* – encircled by the *vicious cycle*, which is illuminating the context of suffering. The main experience of the ten injured participants during the first three to four years after their spinal cord injury was interpreted as a battle or a struggle. The only two alternatives of escaping the vicious cycle were either by *Road of Death* or by the *Road of Hope* - towards the road to life. Every participant had experienced *The Road of Hope*, while some had been tempted to follow *Road of Death.* Every improvement, however, stimulated their *will* and *faith* and reinforced the will to *struggle* towards the *Road of Hope*. This road was leading towards reconciliation and personally growth. Experiences of *uncertainty* and *suffering* were part of the participant's experiences

when *Being in Despair*. These experiences occurred when participants faced the possibility of death, whether through choice or because of the severity of their injury. The fact that none of the participants had given up was attributed to the *Power of Hope* which both stimulated their energy and strengthened their faith and the will to go on. From this perspective, experiences of hope seemed, after all, to be stronger than experiences of suffering.

Across the Figure runs an axis of *longing*, which illustrates the connection between suffering and hoping – connecting the present with the past and the future. Experiences of hope were inspired from the longing for their former life – and every step of progress was a further step towards future hopes and at the same time 'back' towards their past experiences. Therefore, the individual source of hope was mainly created by experiences of longing back (to one's previous life). In this perspective, hope became a 'memory of the past'.

At the same time, experiences of hope were supported by unexpected and sudden improvements.

Figure 2 about here

In Figure 2, *The Road of Hope* illuminates the process of hoping, starting at *awakenings of hope*, alternating between *emotional dichotomies* (ups and downs) and *uncertainty*, and passing through a *Turning Point*, illustrating certain points where improvements suddenly and unexpectedly turned experiences of *Being in Despair* into experiences of *Being in Hope*. Improvements were mostly related to mobility and sensitivity.

DISCUSSION

The aim of this study was to explore patients' contextual experiences of the meaning they attribute to the substance of hope and the process of hoping during the first three to four years following a spinal cord injury. A phenomenological, hermeneutic approach based on Ricoeur [36-7] was used to extract the meaning content and essences of the participants' experiences.

Hermeneutics deal with interpretation of the meaning of a text. According to Ricoeur, [37-8, 39] man is language and man exists through a process of interpretation of language and text. Therefore human experiences can be interpreted through language and the process of interpretation may lead to an increased understanding of being, as well as self-understanding. Findings based on prolonged involvements with phenomena are more likely to be credible than those derived from more superficial encounters. [40 (p 121)] In this study, data were derived from the same participants within a time frame of three to four years, which may have increased the representative credibility. Another concern is disciplinary relevance, [40 (p 123)] which is whether the knowledge one seeks is appropriate to the development of the disciplinary science. During the last 30 years nursing literature has focused on hope. [4, 31] and there seems to be little doubt of its relevance to nursing science and to benefit future patients. On the other hand, the concept of hope has been abstract and complex to comprehend, and most nursing studies has been carried out from a quantitative perspective [21] which indicates a need for a more qualitative approach. Finally, contextual awareness has been revealed by qualitative researchers, and implies that the researcher's own perspectives are strongly influenced by their historical context, as well as their professional perspectives or biases. These are often unconscious and tacit assumptions and may also have influenced this study. [40 (p 124)] Every participant in this study experienced hope, which corresponds with the nursing literature and might be a sign of a common appropriation. However, confirmation of findings may point to common biases within a research community. Even so, both the researcher (myself) and several participants questioned their own hope during the interviews. They also became more concerned, and therefore more critical, about their hope, as a result of this longitudinal study. In searching for truths we also accept values as probable truths according to Thorne. [40 (p 125)] The trustworthiness of the analysis is related to the extent to which the

reader finds the interpretation adequate as well as logical. An aim of this study has been to make all the reasoning employed explicit and accessible to the readers.

According to Marcel, hope is an expression of desired expectations, built on past experiences. He described hope as "a memory of the future". [41 (p 53)] The concept of longing, interpreted from participants' statements, was therefore comprehended as a time-related phenomenon, synthesising the memory of the past with future perspectives. Concepts like will, faith and strength (denoted as energy or power) and progress (or improvements) were used to build the conceptual model. The concept of power implies inner strength or energy, vitality or force, [42] but not as a relational concept in this study. Experiences of emotional dichotomies, meaning dualism ("ups and downs" or "back and forth") were a movement between experiences of hoping and experiences of suffering and despair. Experiences of uncertainty, longing and despair, within the vicious cycle, were mainly based on experiences from dependency and disappointments, and has also been found in nursing literature as description of central aspects of hopelessness. [4] The conceptual model included the vicious cycle, corresponding to a circular movement in a spiral, embracing experiences of uncertainty and despair, dependency and disappointments as well as longing, loneliness, restlessness, anxiety and struggling. [33] According to Eriksson, suffering contains aspects of loneliness, despair, hopelessness, shame and fatigue.[43] However, Frankl maintained that every human being has an inner freedom to choose how to face one's suffering.[44] In this study, none of the participants chose *Road of Death* (including "giving up"). However, every participant had the courage to choose to share personal difficult experiences with me, mainly in hopes of helping future injured and suffering individuals. And further, several participants found their own meaning within those experiences, as a result of the injury and sometimes within experiences of suffering. [33-4] Paterson [45] emphasised that living with a chronic illness was found to be an ongoing and shifting process in which an illness-in the-foreground or wellness-in-the-foreground has

specific functions in a person's life perspective. Therefore, patients' perspectives shift in the degree to which the illness is in the foreground or the background of their experience. This shifting process also influenced patients' experiences of hope during the rehabilitation process: Hope-in-the-foreground was a primary focus shortly after the spinal cord injury, while hope-in-the-background was more common three to four years post injury. [34]

The interpretations also revealed a distinction between *being in hope* and *having hope*: *Having hope* may be limited to a concept outside us, [46] like a particular hope – moving between the hoping and the suffering, whereas *being in hope* was associated with dwelling and trusting in the future. According to Marcel,[46] the concept of *being* must be understood as an internal activity and is derived from the act of existence.

CONCLUSIONS

According to this conceptual model, experiences of 'longing', based on the participants' former life before the spinal cord injury, created new hopes. Therefore, patients' longing should be focused as important sources for maintaining and promoting hope when patients are filled with despair and fear: Having a hope of improvements was the main focus at the early stage of rehabilitation, while hoping of being just fine was the main focus after three to four years of rehabilitation.

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REFERENCES

1. Morse, J.M. Towards a praxis theory of suffering. *Adv in Nurs Sci*. 2001; 24,1: 47–59.
2. Eriksson, K. *Lidandets idè. (The idea of suffering)*. In: Möten med lidanden. (Encountering Suffering). (Eriksson, K. ed.) Report from the Department of Caring Science. No. 4, Åbo Akademi. (In Swedish);1993; 1-27.
3. Vaillot, M.C. Hope: the restoration of being. *Am J of Nurs*. 1970;70, 2: 268–273.
4. Farran C.J., Heerth, K.A. & Popovich, J.M. *Hope and Hopelessness: Critical Clinical Constructs*. Sage Publications, London; 1995.
5. Lohne, V. The Power of Hope. Developing a conceptual model based on patients' experiences of hope during the first year following spinal cord injury. *Dissertation.* University of Oslo, Facultyr of Medicine, Oslo; 2006.
6. Morse, J.M. & O'Brien, B. Preserving self: from victim, to patient, to disabled person. *J of Adv Nurs*, 21; 1995: 886-896.
7. Morse, J.M. Responding to threats to integrity of self. *Adv in Nurs Sci*, 1997; 19: 21–36.
8. Granberg, A., Bergbom Engberg, I. & Lundberg, D. Patients' experience of being critically ill or severely injured and cared for in an intensive care unit in relation to the ICU syndrome. Part I. *Int and Crit Care Nurs,* 1998; 6: 261-326.
9. Lohne, V. Hope in patients with spinal cord injury: a literature review related to nursing. *J of Neurosc Nurs*, 2001; 33, 6: 317–326.
10. Lohne, V. The incomprehensible spinal cord injury – interpretations of patients' narratives concerning experiences with an acute and dramatic spinal cord injury. (Accepted for publication In *Scand J of Car Sci* 2007.)
11. Laskiwski, S. & Morse, J.M. The patient with spinal cord injury: the modification of hope and expressions of despair. *Can J of Rehab.* 1993; 6,3: 143–153.

12. Dorsett, P. & Geraghty, T. Depression and Adjustment after Spinal Cord Injury: A Three-Year Longitudinal Study. *Topics in Spin Cord Inj Rehab*. 2004; 9, 4: 43-56.
13. Crews, W.D., Hensley, L.G., Goering, A.M., Barth, J.T. & Rusek, J.T. Spinal cord injury and anxiety: a comprehensive review. *NeuroRehab*, 1998; 11: 155–174.
14. Lucke, K.T., Lucke, J.F. & Martinez, H. Evaluation of a Professional + Peer Telephone intervention with Spinal cord Injured Individuals Following Rehabilitation in south Texas. *The J of Multicult Nurs & Health*. 2004; 10, 2: 68-74.
15. Morse, J.M. & Doberneck, B. Delineating the concept of hope. *IMAGE: J of Nurs Scholars*. 1995; 27**:** 277–285.
16. Dewis, M.E. Spinal cord injured adolescents and young adults: the meaning of body changes. *J of Adv Nurs.* 1989; 14:389-396.
17. Lohne, V. & Severinsson, E. The power of hope: patients' experiences of hope a year after acute spinal cord injury. *J of Clin Nurs*. 2006; 15: 315-323.
18. Dufault, K., & Martocchio, B.C. Hope: its spheres and dimensions. *Nurs Clin of N Am.* 1985; 20, 2:379–391.
19. Nowotny, M.L. Assessment of hope in patients with cancer: development of an instrument. *Oncol Nurs Forum*. 1989; 16,1: 75–79.
20. Eriksson, K. Understanding the world of the patient, the suffering human being: the new clinical paradigm from nursing to caring. *Adv Pract Nurs Quart.*1997; 3:8–13.
21. Kylmä, J., Vehviläinen-Julkunene. Hope in nursing research: A meta-analysis of the ontological and epistemological foundations of research on hope. *J of Adv Nurs*. 1997; 25, 2:364-371.
22. Marcel, G. *The Mystery of Being*. Volume II: *Faith and Reality*. Indiana: St. Augustine's Press; 1951b.

23. Lynch W.F. *Images of Hope: Imagination as the Healer of the Hopeless.* Notre Dame: University of Notre Dame Press; 1974.

24. Travelbee, J. *Interpersonal Aspects of Nursing*. Philadelphia: F.A. Davis; 1971

25. Stotland, E. *The Psychology of Hope*. San Francisco: Jossey-Bass; 1969.

26. Lohne, V. & Severinsson, E. Hope and despair: the awakening of hope following acute spinal cord injury – an interpretative study. *Int J of Nurs Stud.* 2004 b);41, 8: 881–890.

27. Cousins, N. *Head first – the Biology of hope*. New York: E.P Dutton; 1989.

28. Lohne, V. & Severinsson, E. Hope during the first months after acute spinal cord injury. *J of Adv Nurs*. 2004 a); 47,3: 279–286.

29. Kim, H.S. Existential phenomenology as an ontological focus in nursing theories. In: Kim, H.S. & Kollak, I. (eds) *Nursing theories: Conceptual and Philosophical Foundation.*. New York: Springer; 1999:123-135.

30. Erikson, E.H. *The life cycle completed: A review.* New York: Norton; 1982

31. Kim, D.S., Kim, H.S., Schwartz-Barcott, D. & Zucker, D. The Nature of Hope in Hospitalized Chronically Ill Patients. *International Journal of Nursing Studies.* 2006; 43, 5:547-556.

32. Jung, C.G. *Psychological Types*. USA: Princeton University Press; 1974

33. Lohne, V. & Severinsson, E. Patients' experiences of hope and suffering during the first year following acute spinal cord injury. *J of Clinl Nurs*. 2005;14: 285-293.

34. Lohne, V. Patients experiences of hope three to four years after a spinal cord injury. (In process)

35. Morse, J.M. & Richards, L. *Readme First*. London: Sage; 2002

36. Ricoeur, P. *Interpretation Theory. Discourse and the Surplus of Meaning.* Fort Worth: Texas Christian University Press; 1976.

37. Ricoeur, P. *Hermeneutics and the Human Sciences.* (J.B. Thompson, ed. and trans.). Cambridge: Cambridge University Press; 1981

38. Ricoeur, P. *The Conflict of Interpretations. Essays in Hermeneutics*. (D. Ihde, ed.) London: Athlone; 1989.

39. Ricoeur, P. *Oneself as Another*. (Blamey, K. trans.). London and Chicago: The University of Chicago Press; 1992.

40. Thorne, S. The art (and science) of critiquing qualitative research. In: *Completing a Qualitative Project: Details and Dialogue.* Morse, J. M. (ed.) Thousand Oaks, CA: Sage; 1997:117–132.

41. Marcel, G. *Homo Viator: Introduction to a Metaphysic of Hope.* Chicago: Gateway Editions;1951a.

42. Eriksson, K. *Vårdtecknologi.* (Caring Technology), Stockholm: Nordstedts Förlag AB. (In Swedish); 1986.

43. Eriksson, K. (ed.), *Det lidende menneske*. (The Suffering Individual). Otta: TANO AS. (In Norwegian); 1994.

44. Frankl, V.E. *Man's Search for Meaning*. New York: Simon and Schuster; 1963.

45. Paterson, B.L. The Shifting Perspectives Model of Chronic Illness, *J of Nurs Scholarsh.* 2001; First Quarter: pp 21-26.

46. Marcel, G. *Being and Having*. London: The Fontana Library: 1965.

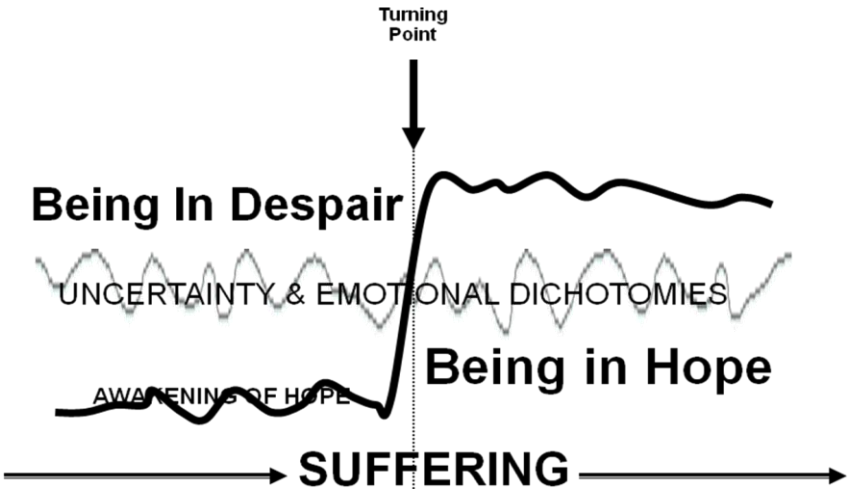

Figure 1: The battle between hope and suffering

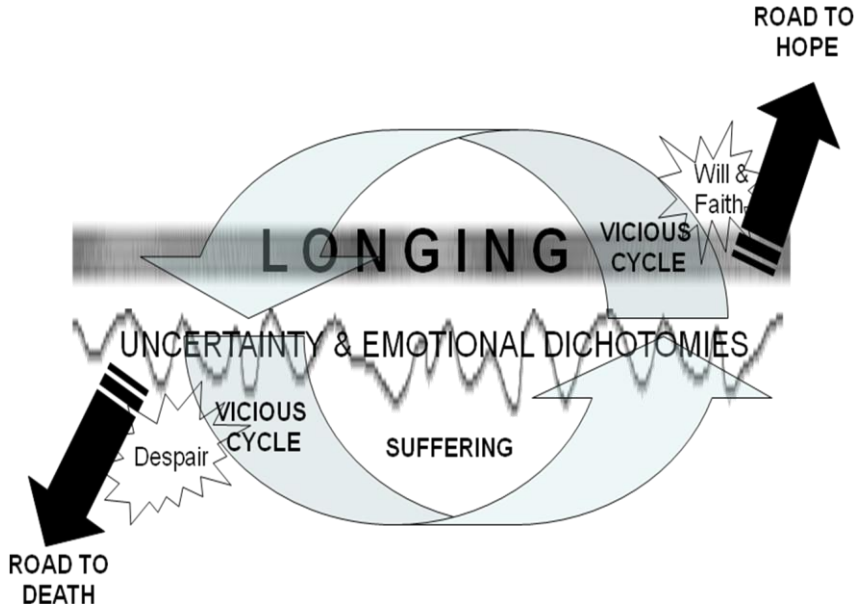

Figure 2: The road to hope