

# The Battle Between Hoping and Suffering

## A Conceptual Model of Hope Within a Context of Spinal Cord Injury

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The aim of this longitudinal study was to explore 10 patients' experiences of the meaning they attribute to the substance of hope and the process of hoping during the first 3 to 4 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. 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 9 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, whereas being in hope as being just fine was the main focus after 3 to 4 years of rehabilitation. **Key words:** *conceptual model on hope, despair, longing, suffering, vicious cycle*

**T**HE 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.<sup>1–3</sup> Many patients are enduring sudden and unexpectedly, seriously and often aggravating symptoms that cannot be cured or healed. According to research, however, hope

relieves suffering and influences the process of rehabilitation and recovery by stimulating the will to fight and to survive.<sup>4</sup> Patients' suffering from injuries and illnesses needs both courage and endurance. Without the hope of future possibilities, the vital power of life will sooner or later diminish or fade away.<sup>5</sup>

Experiences of hope have 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.<sup>1,2,6–8</sup> A spinal cord injury is a sudden, incomprehensible, serious, and dramatic incident with long-term consequences such as isolation, profound despair, and extreme dependency.<sup>5</sup> 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

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ability depending on the level of injury and distal.<sup>9-11</sup>

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 because 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.<sup>2</sup> Patients suffering from a spinal cord injury have to face a future of probable complications requiring a lengthy period of relearning skills.<sup>12</sup> A spinal cord injury is, therefore, a comprehensive and stressful event in which sensory and mobility impairments lead to physiologic dependence, pain problems, depression, and anxiety. Although the situation tends to improve over time,<sup>5,12-16</sup> a traumatically injured individual is in great need of endurance and hope.<sup>5,6,8</sup> Every positive future perspective will be of vital importance to these struggling and suffering individuals.<sup>17</sup>

## LITERATURE REVIEW

Hope is a multidimensional and holistic patient phenomenon. Nursing literature highlights the importance of maintaining, sustaining, and restoring hope in patients.<sup>4,18</sup> According to Nowotny,<sup>19</sup> 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,<sup>20</sup> experiences of suffering are described as a movement between experiences of hope and hopelessness. The term hope is used both as a substantive (the substance of hope) and as a verb (to hope) or as an adjective (to be hopeful).<sup>4,9</sup> 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.<sup>5</sup> 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.<sup>4,18</sup> Still, hope as an abstract and general expression has been difficult to explore and comprehend as a patient phenomenon. On the basis of a meta-analysis of 46 empirical studies of hope (published between 1975 and 1993), Kylmä and Vehviläinen-Julkunen<sup>21</sup> maintained that so far nursing research into hope has mainly been grounded in a positivistic paradigm.

Hope is directed toward salvation from 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.<sup>22-24</sup> But, according to Lynch,<sup>23</sup> 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 philosophic, theologic, psychologic as well as a sociologic 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. On the basis of worldwide studies on hope and illuminated by the central nursing hope-researchers Farran et al,<sup>4</sup> hope may ontologically be summed up as having 4 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 although the future is always uncertain.<sup>25,26</sup> 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, whereas an

ultimate hope may still be questioned and more superficial hopes (or wishes) may fluctuate over time.<sup>4,17,26-28</sup>

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.<sup>29</sup> 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 emphasized the human ability to plan, create, imagine, and engage in foresight actions.<sup>4</sup> Furthermore, trusting relationships and cumulative experiences in society, human behavior, and human development and maturity<sup>17,30</sup> 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 psychologic perspective view hope as a goal determined and personal motivation factor; contemporarily struggling with experiences of anxiety.<sup>4,25</sup>

Another important study, carried out by Kim et al.,<sup>31</sup> aimed to discover patterns of hope in hospitalized 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 abil-

ity to do and enjoy small things. They did not believe in setting big goals, which were understood as a pragmatic orientation Kim et al.<sup>31</sup> Only 2 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 2 really had hope or not. Among the future orientated patients, 5 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 2 patients were mostly self-oriented. Their hope seemed to be expressed through their use of humor 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 in which internal versus external orientation can be related to Jung's<sup>32</sup> 2 psychological types.

## AIMS AND RESEARCH QUESTIONS

The aim of this longitudinal study was to explore 10 patients' experiences of the meaning they attribute to the substance of hope and the process of hoping during the first 3 to 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 3 to 4 years following a spinal cord injury?
2. What is the essence of patients' experiences of hope within a context of a sudden suffering from a spinal cord injury and during the first 3 to 4 years following this incident?

The overall aim was to deepen the understanding of the phenomenon of hope based

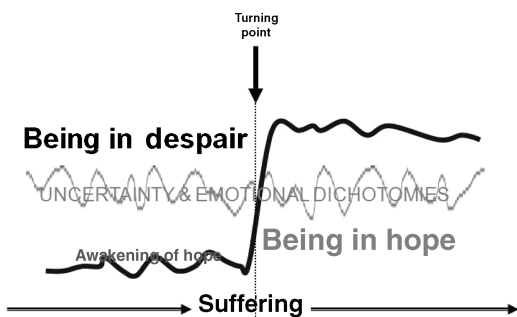


Figure 1. The battle between hope and suffering.

on the text representing the main contextual findings (V. Lohne, unpublished data, 2006)<sup>17,27,28,33</sup> to develop a theoretic framework within a context of spinal cord injury, which is illustrated in the conceptual model (Figs 1 and 2).

## THE STUDY

This qualitative study has a longitudinal, prospective, and descriptive-explorative design and is a synthesis of 3 empirical studies of hope (V. Lohne, unpublished data).<sup>17,27,28,33,34</sup> 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.<sup>35,36</sup>

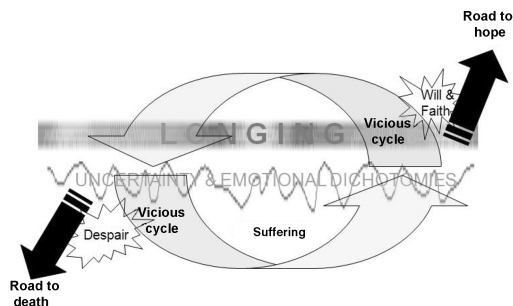


Figure 2. The road to hope.

## 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.<sup>35,36</sup> Parts of the text are meaningful signs endowed with a deeper and richer meaning beyond that immediately grasped by reading. According to Ricoeur,<sup>36</sup> 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*,<sup>35,36</sup> the aim of which is to understand the author (research participant) even better than he understood himself.

The text involved was a result of 3 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,<sup>36</sup> when verbalizing 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 a 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,<sup>36</sup> 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.<sup>35(pp72–76)</sup> In this study, the emerging of interpretations through textual analysis was a process within a hermeneutic

circle, moving between whole and parts, between guessing and validation, and between appropriation and a new understanding.<sup>37</sup> Appropriation means to “make one’s own what was initially alien.”<sup>37(p185)</sup> Patterns of interpretation were further questioned in an ongoing process of continual dialogue with the text in relation to my preunderstanding. The phenomenological-hermeneutical act of interpreting contextual language to gain a deeper understanding makes unfamiliar, fundamental experiences of human life familiar and comprehensible.<sup>36</sup>

### **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 4 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 8 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 whereas 6 injuries 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 were collected 3 times from each participant in 3 separate interviews: the first interview took place about 2 weeks after admittance to the rehabilitation center (between 6 and 19 weeks following the spinal cord injury). Two of the patients had been in deep coma during the first 2 or 3 months following the injury, and, therefore, all participants had consciously experienced the time lapse as to about 6 to 8 weeks following the injury. The second interview took place about 1 year and the third about 3<sup>1</sup>/<sub>2</sub> years (between 3 and 4 years) following the injury. The first interview took place at the rehabilitation center, during the autumn of 2001, whereas the next 2 (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 3 sections: the past situation, the present situation, and their future expectations and perspectives. Every interview focused on each participant’s experience of hope at different stages of rehabilitation, at the early stage, after 1 year of rehabilitation, and finally after 3 to 4 years postinjury. The interviews were a process of dialogue, based on a list of open-ended questions, and concerned the accident and the recovery phase, the hospitalization period, the time at the rehabilitation center, and the time being at home again. The focus was on their continuing expectations and future orientations. I asked clarifying questions depending on what patients had expressed and described whether 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 patients' environment was primarily represented by the rehabilitation institution and was, through its rehabilitation program, 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 and after 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),<sup>36</sup> 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 original context and given a life of its own.

In the beginning of my study, understanding was a guess because the same sentence could be understood in different ways. According to Ricoeur,<sup>36</sup> one-sidedness is always implied in the act of reading. The first step, the naïve reading, involved reading the transcripts as a story, whereas 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 was checked and compared with 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 to grasp the most probable interpretation from parts of the texts. Ricoeur describes this as textual plurivocity.<sup>36</sup> 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.<sup>35,36</sup> At this level, I searched for theoretic and philosophical understanding and reflections as well as my own contextual reflections and preunderstandings.

The conceptual model of hope is a synthesis made at the final and fourth step of interpretation and based on a synthesis of 3 empirical studies. The main findings from the studies (V. Lohne, unpublished data)<sup>17,27,28,33</sup> 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 a universal reader.<sup>36</sup> 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 to 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 till now) and holds a positive substance.<sup>5,9</sup> This perspective has been the foundation of each of the empirical studies that form the basis of this article.

The following themes are derived from interactive interviews and dialogues with 10 (9 at the last interview) participants during the first 3 to 4 years following their 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 form 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 because hope is future oriented, and the future is always uncertain and holds many "ifs." The future has 2 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 that created emotional dichotomies (ups and downs).

### **Hope as a turning point**

During the rehabilitation process, participants who moved between hope and suffer-

ing, 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 that 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 one's 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 were continuously tested. Experiences of helplessness, dependency, disappointments, and loneliness over time due to the injury mainly resulted in 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 the 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) were exhausting. The terrifying prospect of becoming a permanent user of wheelchair 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 fear and panic and made it sometimes almost impossible to hope which led toward 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 preinjury. Hope was continually focused on mobility, such as walking, dancing, jumping, running, or standing, without using supportive equipment. In addition, 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. Because the injury had totally changed the individual direction in life, it also made them appreciating incremental improvements and small gains. In addition, 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 Figures 1 and 2.

Figure 2 illustrates *The Road to Hope*—encircled by the *vicious cycle*, which is illuminating the context of suffering. The main experience of the 10 injured participants during the first 3 to 4 years after their spinal cord injury was interpreted as a battle or a struggle. The only 2 alternatives of escaping the vicious cycle were either by *Road of Death* or by the *Road of Hope*—toward the road to life. Every participant had experienced *The Road of Hope*, whereas some had been tempted to follow *Road of Death*. Every improvement, however, stimulated their *will* and *faith* and



reinforced the will to *struggle* toward the *Road of Hope*. This road was leading toward reconciliation and personal 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 toward future hopes and at the same time “back” toward 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.

In Figure 1, *The battle between hope and suffering* 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 in which 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 3 to 4 years following a spinal cord injury. A phenomenological, hermeneutic approach based on Ricoeur<sup>35,36</sup> 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,<sup>36-38</sup> 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.<sup>39(p121)</sup> In this study, data were derived from the same participants within a time frame of 3 to 4 years, which may have increased the representative credibility. Another concern is disciplinary relevance,<sup>39(p123)</sup> 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<sup>4,31</sup> 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 have been carried out from a quantitative perspective<sup>21</sup> 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 his or her historical context, as well as his or her professional perspectives or biases. These are often unconscious and tacit assumptions and may also have influenced this study.<sup>39(p124)</sup> 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.<sup>39(p125)</sup> 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."<sup>40(p53)</sup> The concept of longing, interpreted from participants' statements, was, therefore, comprehended as a time-related phenomenon synthesizing 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<sup>41</sup> 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 have also been found in nursing literature as description of central aspects of hopelessness.<sup>4</sup> 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.<sup>33</sup> According to Eriksson,<sup>42</sup> suffering contains aspects of loneliness, despair, hopelessness, shame, and fatigue. However, Frankl<sup>43</sup> maintained that every human being has an inner freedom to choose how to face one's suffering. 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 (V. Lohne, unpublished data).<sup>33</sup> Paterson<sup>44</sup> emphasized 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, whereas hope-in-the-background was more common 3 to 4 years postinjury (V. Lohne, unpublished data).

The interpretations also revealed a distinction between *being in hope* and *having hope*. *Having hope* may be limited to a concept outside us,<sup>45</sup> 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,<sup>45</sup> 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, whereas hoping of being just fine was the main focus after 3 to 4 years of rehabilitation.

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