

ORIGINAL ARTICLE

The trajectory of hope: pathways to find meaning and reconstructing the self after a spinal cord injury

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Study design: This is a qualitative study.

Objectives: To evaluate and track the importance and the continuum of hope, and its trajectory, from the point of view of the individual with a spinal cord injury (SCI) and a rehabilitation psychologist.

Setting: This study was conducted in the Indian Spinal Injuries Centre, New Delhi, India, and in patients' homes in the National Capital Region, India.

Methods: Twenty individuals with an SCI were interviewed for the study at intervals of 2 weeks, 6 months, 1 year and 2 years since the time of the injury. Semi-structured interviews were conducted, in which the following theoretical research questions were investigated: 'What is the meaning, relevance and significance of hope in the individual's life following an SCI? Does the meaning and subject of hope change at different points in time?'

Results: Three distinctive themes markedly emerged in the trajectory of hope: (1) Hope for a complete recovery; (2) hope for self-reliance despite the injury; and (3) hope for an optimum quality of life. The make-up of each theme, its significance and contribution to recovery and/or rehabilitation, while tracking the influence of time since injury, family and friends, as well as other agencies and pathways, are discussed.

Conclusion: After sustaining a life-altering injury, hope becomes the force that spurs individuals. Psychologists and rehabilitation counselors need to focus on instilling realistic hope, goal setting, sustaining motivation, enabling adaptive appraisals and problem-solving. Further recommendations include developing and testing interventions against the context of the continuum of hope.

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INTRODUCTION

Recovery and rehabilitation from a spinal cord injury (SCI) requires continued psychological adjustment, as new challenges emerge over time after the injury.^{1,2} A myriad of factors are relevant in enabling such an adjustment: age, lower levels of anxiety and depression, quality of social support and cognitive appraisals. One factor that has stood out in the researcher's work is the motivating power of hope to overcome the odds against complete recovery. In existing literature, this would be seen as denial. How can a person who participates in rehabilitation and/or is well adjusted to the injury be hoping for something that is intuitively physically impossible?

On the basis of the concepts from grief and loss psychology, older research tended to pathologize the adjustment process rather than identify what promoted positive adjustment.³ The focus was on grief and loss psychology,⁴ through a series of stages that may or may not finally culminate in adjustment. Stage theories seem to imply that depression and grief are, in fact, necessary prerequisites for satisfactory adjustment, and positive adjustment cannot occur without them.⁵ In contrast, the field of positive psychology takes into account patients' strengths, courage and determination, not just barriers and obstacles,⁶ and it sees the emergence of hope as a key component of appraisal and reconstruction of meaning.^{7–13}

Previous studies that were into the role of hope in SCI and its interactions with coping have been from nursing and/or social work

perspectives. Alternatively, they have focused on the pathology of hope and adjustment rather than identifying and affecting its trajectory. From a methodological perspective, some studies have adopted a cross-sectional and phenomenological–hermeneutic approach, whereas others have taken on a purely longitudinal perspective to account for the influence of the time since injury in SCI contexts.

PARTICIPANTS AND METHODS

This study uses a phenomenological–hermeneutic approach through a qualitative study of individuals who had sustained an SCI. The following theoretical research questions were investigated: 'What is the meaning, relevance and significance of hope in an individual's life following an SCI? Does the meaning and subject of hope change at different points in time?' All procedures were approved by the Research Review Committee and the Institutional Ethics Committee of the organization under whose aegis the research study was conducted. The participants were assured of their confidentiality and anonymity. All participants received written and oral information about the purpose, content and format of the study, and an informed consent was obtained. The interviews were recorded by the principal investigator (in this case, also the author).

Participants

Initially, 30 participants with traumatic SCI who were admitted to the Indian Spinal Injuries Centre, New Delhi, India were recruited for the study. The intent was to follow up the participants in their homes post discharge, at 6 months, 1 year and at 2 years after their injury. Ten participants were unable

Table 1 Demographic and injury characteristics

Demographic and injury characteristics	Number
<i>Gender</i>	
Male	13
Female	7
<i>Age at injury (years)</i>	
16–19	9
20–29	9
30–39	2
<i>Level of injury</i>	
Paraplegia	14
Tetraplegia	6
<i>Degree of impairment</i>	
Complete	18
Incomplete	2
<i>Etiology</i>	
Road traffic accidents	14
Fall from height	3
Acts of violence	2
Sports/recreational activities	1

to be contacted at the 6-month follow-up; hence, the final sample comprised 20 adults with traumatic SCI. The demographics and injury characteristics of the participants are presented in Table 1.

Procedure

Semistructured in-depth interviews with participants regarding their rehabilitation journey after SCI were conducted, audio-recorded and transcribed by the principal investigator. A phenomenological–hermeneutic approach, influenced by Ricoeur,¹⁴ was used to extract the meaningful content of the participants' experiences. In the first step, the naive reading, the researcher attempts to understand the meaning of the whole text. The second step involves a number of structural analyses, a process of filtering down the scope, followed by the identification of meaningful parts to grasp the most probable explanation of the text. The final step involves making a comprehensive interpretation of the whole text, taking into account the naive reading and the meaning units, to make a comprehensive interpretation of the whole text to gain potential horizons of meaning. The author carried out the analysis, although additionally the analysis was questioned and refined by an independent consultant qualitative researcher to increase the credibility.

RESULTS

Using the lens of the rehabilitation psychologist, perhaps the specialist most suited to decoding and using the cognitive and emotional ramifications of hope in clinical and theoretical ways, the study's intention was to probe the evolution of hope alongside other influences and outcomes in the post-SCI process. The results bear significance from this differentiated perspective.

A key expected outcome from the research was to frame the evolutionary path of hope. Broadly, three stages were identified in this pathway of hope, with the stages themselves emerging as being more important than the tenure of each stage. Findings also revealed the influencers of hope at each stage and the role they played, as framed against Snyder's Model of Hope. The varying themes in the post-SCI coping process that emerged are detailed here under the broad heads of a continuum of hope, and the influencers of hope.

The continuum of hope

The 'Continuum of Hope' is defined by three sub-themes, marked as stages in the evolutionary path of hope during the coping process. Clear thematic patterns emerged for each of these phases.

Inevitable optimism. Post-SCI, optimism emerged as an important and inherent characteristic. The perceived inevitability of the outcome stemming from this optimism, contrary to the medical implications from the prognosis that the respondent is fully aware of, was quite defining. Optimism spurs the hope of active recovery (being able to walk), enables respondents to use their cognition, emotion, physical, personal and environmental resources to fuel that hope and, in the extreme, spurs them to resort to 'miracle cures.'

One respondent, 6 months after his cervical level complete SCI, said 'hope gives me the motivation, the anger to work more and excel in therapy.' Another respondent, 12 months after her incomplete injury along with a stem cell surgery stated that 'I'm getting some sensation in my legs. There is still no movement yet, but I can only hope and wait.'

Religion and spirituality were other tools resorted to in these initial stages. A respondent stated: 'I used to go to all the temples and prayed to God to make me walk again. I prayed to Jesus that I will light hundred candles, please make me OK. I did this for 2 months, got angry. But never lost hope.'

Tempered optimism. Realization about the implications and permanence of the injury shifted the focus of hope. Respondents talked about being self-reliant, even if it meant in a wheelchair. Time frames were established, with the focus shifting from recovery to rehabilitation. The optimism remained but was now tempered by the implications of the prognosis for daily life.

One respondent said, 'I am setting myself 6 months, and then I will get back to my vocation, and life after.' A male respondent with an incomplete SCI at the 1-year mark stated that 'I still haven't come to terms with what has happened to me. I'm setting myself the 2 year target, by when to accept it.' His progress had reached a plateau and he was about to give up his therapy when there was a return of slight movement in his left foot. With renewed determination, he focused on a new set of goals in physical therapy.

With time, goals shifted focus to an improved quality of life, including return to work, taking care of family responsibilities and social integration. 'Why should I give up living, even if I am in the wheelchair? The injury does not stop me from doing anything.'

Peers made a significant impact on the level of confidence. 'I have the confidence knowing I can make it. So many people can, why can't I? I focused on what I can do, not on what I can't.'

Stem cell therapy offered hope to every participant, but the hope was not always to walk again. Two respondents said that if stem cell therapy ever became successful they would hope that it enables the bladder and bowel to recover. They could manage their mobility limitations with a wheelchair, but the bladder and bowel disruptions were the most significant obstacles in their integration and well-being.

Perhaps nothing exemplifies this hope for self-reliance as this observation from one respondent: 'From lying in bed, being unable to move, someone having to help with bladder and bowel routines, someone needing to turn me every 2 h, to being able to sit in a wheelchair, to eating on my own with an assistive device, I realized I was not going to be a helpless, dependent person. Once I was given options of resuming sexual activity, being able to drive, there was no turning back.'

Inevitable realism. The third stage in the continuum of hope is perhaps the most realistic one, in which respondents have aligned their expectations to the challenges, as well as possibilities of the present. Rehabilitation is an ongoing, current reality, and recovery is now defined from a psychological, rather than a physiological, point of view. There now sets in an inevitability about current reality and its boundaries. However, even within these boundaries, hope exists and continues to remain as a motivating force for coping.

As one respondent stated, 'I was a trained dancer before my injury and my heart wanted to follow that profession. Through the process of hoping for a better future, I moved towards acceptance of the mobility limitations due to my injury. I re-evaluated my priorities. I started setting targets and goals. When those targets kept getting met, I reaffirmed the faith in my abilities.' This individual's perceptions of hope and rebuilding captured the basic theme of the two-sphere model of hope¹¹ where she spoke about the concept of generalized hope initially, which provided a buffer in the early stages of SCI, but was later replaced by particularized hope, which was goal oriented. In addition, her belief reflected the cognitive conceptualization of hope,¹² which is held strongly by defining goals, being motivated and finding ways to attain the goals.

Perhaps this realism is best illustrated by this individual with an incomplete injury: 'Goals keep shifting relating to the mastery over the injury. I know I have to walk, I have to study and I have to work. Sometimes hope starts fading away on its own, and then it builds onto something else.'

Influencers of hope

The study also revealed a set of influencers that played significant roles in the evolution of hope. The first set of influencers includes family and friends. In addition, another set of factors can be seen through Snyder's lenses of agencies and pathways.

Family and friends as hope agents

In India, family members carry the primary responsibility of providing round-the-clock care to an individual with the SCI. The family, as an agent of hope, had two aspects: for the individuals with SCI to avoid being a burden on the family, and the support of the family that enabled the participants to rebuild their lives. As one respondent stated, 'I don't want to be a burden on my family. I have to move forward for them. Hope actually lives when I think of my poor family circumstances.' The individuals from low socioeconomic status had no option but to return to some work to support their family. One individual stated, 'I have no time to grieve, I need to support my family.'

Family functioned as an agent of hope as a support system through each phase. One respondent said, 'My mother made sure I did everything possible on my own. I never felt disabled, because my family focused on my abilities.' One respondent who lost her husband within a year of her injury stated, 'Thanks to the love given by my husband, I never felt helpless. Even now when he's gone, I know I have to live well, because that's what he taught me.'

Agencies and pathways

Snyder (1991)¹² had elucidated that both the will (the agency) and the way (pathway) to attaining goals are key factors in defining hope. Agency can be perceived as willpower, motivation, determination and strength to explore pathways and goals. As one individual summed up, 'I made up my mind that I would drive an adapted car. I went ahead, learnt it, and told my parents I wanted to be independent. Being stubborn helped. Now I am the one who takes my family around.'

The frustration imposed by mobility restrictions acted as a catalyst at times. This 20-year-old individual stated that 'If I want to maneuver a step on my own, I will keep at it. I get angry, and I get more energized. And it happens. I am a high functioning quadriplegic because of this.' The importance of problem-solving coping, instead of feeling overwhelmed with the occurrence of multiple stressors, was underscored.

DISCUSSION

The aim of this study was to explore and elucidate upon the individuals' experiences of, and attributed meanings of, hope, and its role in coping and reconstructing life after sustaining an SCI. The narratives presented above provide preliminary theoretical and research evidence to establish the importance and significance of hope in the adjustment process following an SCI. On the basis of the findings of the study, it was revealed that individuals experienced hope as a continuum. In the initial phase of the injury, hope emerged as the will to walk, despite evidence to the contrary. The participants focused their effort on physical rehabilitation and, in fact, full recovery, often resisting interventions that suggested that the injury was permanent (for example, counseling focusing on adjustment, buying a wheelchair or using assistive devices). This phenomenon has often been labeled as 'denial', and the suggested practice has been to bring down the wall, so that the individual is able to face and accept reality. Often miracle cures are sought with a hope that any alternative treatment will bring some respite. As time progresses, the individuals with SCI acquire more information about the injury, observe peers with similar injuries sustained years ago, benefit from rehabilitation and gain physical competence and mastery of themselves, explore options and focus on community integration. The goals for hope shift from being able to walk to being self-reliant in a wheelchair, being able to return to work, resume family responsibilities and engage in social and recreational opportunities. Although the hope to walk remains, it shifts as a distal goal and the efforts are directed toward accepting the present reality of the permanence of the injury and learning to be functionally independent. Eventually, the goal shifts to a better quality of life, with a focus on enlargement of values. Individuals were pursuing dreams, aspirations and recreational activities, with the wheelchair receding in the background, not perceived as a hindrance anymore. The possibilities were perceived as limitless, with ways to attain goals. The respondents had become proficient in problem-solving; societal attitudes did not faze them, considering the stigma present in India toward people with disabilities. The experience was termed as being liberating and as being masters of their own destiny. Hope was influenced by certain key factors: family, and the need to have a will and a way with a focus on proactive problem solving.

Clinical implications and recommendations

This study has highlighted the importance of interventions that could be developed, including those that address psychosocial problems, to sustain and facilitate hope that enables adjustment for individuals with SCI. Recognition of the family as a key enabler, the hope to be able to cope with environmental and attitudinal barriers are also crucial for a well-adjusted quality of life. Given that the nature and focus of hope in the adjustment process following SCI may shift over time, and that hope takes on an affective-emotional and a cognitive response, interventions need to be targeted at these two levels.

In the initial stages, hope is activated by a sense of urgency that they have to get better (that is, have to walk again), with limited pathways that they perceive to be the most important (physical and occupational therapy). As time passes, they gain more knowledge and information about SCI, and contingent pathways are developed. Psychosocial and

vocational goals are established beyond the ones targeting physical recovery. Generalized hope in the initial stages helps deal with the often overwhelming initial emotional distress of shock, sadness and anxiety. The ruminations later transform to goal-directed thinking with a paving of more clear pathways for action. In the initial phase, psychologists can help cope with the emotional distress, enable active goal setting, develop and enhance motivation and empower the individual to develop ways and means to attain those goals.¹⁵

An empathic environment helps in empowering the individual to take charge of their short-term and long-term goals, resume control over key decisions that affect their life, focusing on physical care and mental health, and being knowledgeable about the implications of the injury. Being educated about the long-term care of the injury goes a long way in developing the skills, knowledge and confidence to manage themselves on their own. As they learn to manage their physical routine, the skills and the accompanying sense of independence enable them to formulate realistic goals and the motivation and way to pursue the desired outcomes. Even when the permanence of the injury is realized, the mastery of the environment, return to work and previous social roles enable the restoration of competence, self-esteem and self-efficacy.

In addition to the empathy, interventions that facilitate and sustain hope are crucial. Keeping in mind the trajectory of hope, in the initial stage empowering the patient and the family to be active participants of the rehabilitation process, setting realistic goals, supporting them in their psychosocial rehabilitation and teaching problem solving are important. Addressing biopsychosocial concerns (accessibility, use of assistive devices, sexuality, parenting, return to work, social skills training) becomes the focus of hope. The focus moves away from solely focusing on physical recovery to return to the community. After the individuals have lived in the community for some time, hope shifts to larger goals of a satisfying quality of life, on living life with a purpose, with a sense of well-being. They have accepted the injury to be a part of them, yet they do not let the limitations govern their experience. The focus is on abilities rather than disability. As the individuals learn to successfully problem-solve their way through the rehabilitation phase and beyond, they are better able to address the systemic barriers that may confront them.

The study led to questions that require further investigation: (i) What are the factors that instill hope and positivity in one individual where another responds with despair and despondency? (ii) What is the relationship between spirituality, appraisal and hope and how do they affect anxiety, depression and quality of life? Do people with higher levels of hope achieve more positive long-term adjustment outcomes? (iii) What is the effect of demographic, injury and rehabilitation characteristics on hope and quality of life?

Limitations of the present study

There were a few methodological limitations in this study that need to be addressed: The inclusion criteria were open, only excluding patients less than 15 years of age, and individuals who were willing to share their personal experiences of hope and appraisal were included. The credibility of the study may have been weakened because of the ten people who dropped out of the study because they could not be contacted at the first follow-up. Knowledge produced might not generalize to other people with spinal cord injuries, as the findings may be unique to the people included in the research study. However, the aim of the qualitative study is to make logical generalizations to a

theoretical understanding of a phenomenon such as hope in this case, rather than probabilistic generalizations to a population.

CONCLUSION

In the present study, hope had significant meaning and significance as a coping response through the acute stage, rehabilitation and community integration phases after an individual sustains an SCI. Much of the existing research on adjustment following SCI has focused on the initial crisis period immediately following injury or on identifying factors that are predictive of positive outcomes. The study was formulated to answer the question of how people who were admitted in the hospital and then transitioned to the community were able to successfully cope with the demands placed on them post SCI. Hope emerged as a key construct, with its focus on goals and pathways, and it has significant implications for developing cognitive-behavioral interventions.

When life is threatened by an injury and is accompanied by disruptions, hope becomes the force that makes them go on everyday despite the challenges, giving them a sense of direction. Hope transforms to different goals as time passes and the realization of the permanence of the injury sets in. The team working with individuals with SCI specifically psychologists and counselors need to focus on instilling realistic hope, goal setting, sustaining motivation, enabling adaptive appraisals and problem-solving coping.

DATA ARCHIVING

There were no data to deposit.

CONFLICT OF INTEREST

The author declares no conflict of interest.

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