

ORIGINAL ARTICLE

Coping strategies used by people with spinal cord injury: a qualitative study

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Study design: Qualitative.

Objectives: Although using coping strategies have an important role in the adaptation process and quality of life following spinal cord injury (SCI), there is still trivial information about this issue in the world and especially in Iran. The purpose of this study was to explore coping strategies used by Iranian patients with spinal cord injuries.

Setting: The Brain and Spinal injury Repair Research Center of Tehran University of Medical Sciences and the Protection Center of spinal cord disables, Iran.

Method: Eighteen patients with SCI were interviewed deeply. Data were concurrently analyzed, using the content analysis method.

Results: During the data analysis, three coping strategies, including seeking help from religious beliefs (understanding the disease as a divine fate and as a spiritual combat), hope and making efforts towards independence/self-care appeared.

Conclusion: Understanding strategies that influence the patients' coping with the SCI will contribute to the nursing body of knowledge. It also helps nurses and other health-care professionals as well as the families in reinforcing the most effective coping strategies and promoting the quality of care. Such coping strategies also can help patients to achieve a greater sense of empowerment.

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Introduction

Spinal cord injuries (SCIs) are among the most devastating injuries that one can experience.¹ The annual prevalence of SCI in the USA, besides those who die at the scene of the accident, is about 40 cases per 1 million people, or about 12 000 new cases per year.² Kennedy *et al.*³ found that 56% of injuries occur between the ages 16–30, with the highest prevalence at 19. As the injury occurs at youth and middle age, it creates unique challenges for the person, because it is concurrent with the physical and psychosocial growth and developmental process of the individual.⁴ In Iran, because of the lack of a powerful data registry system, estimation of the number of patients with SCI is very difficult. The data obtained from the authentic resources showed that there are about 70–90 thousands of patients with SCI in Iran.⁵

Background

The occurrence of a SCI is a really challenging and threatening event for individuals. Patients with SCI experience numerous physical, psychological and social function problems,⁶ which often lead to sensory-motor defects and intestinal and urinary bladder incontinence. All of these limit the ability of the individual to carry out common self-care activities, as well as individual and occupational responsibilities. In addition to the physical limitations caused by SCI, the individuals experience various emotional, psychological, economic and environmental stressors.^{7–9} Complex interactions between these stressors affect individual and family coping following an SCI. Transition from an independent life to a dependent state entails redefinition and reassessment of individual, social and occupational aspects of life,^{7,10} objectives and meanings.^{11,12} Clearly, living with SCI is a complex process, needing adaptation with changes in the physical, mental and social functions for those affected and their families.

Coping is defined as constantly changing behavioral and cognitive efforts made by the individual to cope with stressful events.¹³ Coping has an important role in the

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adaptation process following SCI.⁶ Strategies used by the people in coping with stressful events affect their life outcomes^{13–15} and is associated with the emotional well-being of those with SCI.¹⁶ In the current study, coping was defined as the strategies that the Iranian patients were reported to use for managing the challenges of the SCI.

A review of the literature identified that patients with SCI cope in diverse ways with their situation.^{4,17} The most common coping strategies that were reported in the literature included an acceptance of the situation,^{17–19} seeking information,²⁰ positive reframing,^{6,17} minimization,^{19,21} self-trust and social trust,^{19,21} and optimism and positive thinking.^{4,22} Some studies indicated that spirituality and religiousness facilitated patients' ability to cope with disability.^{17,18,23,24} Others reported that social support predict survival and a higher quality of life and decreases the rate of depression, susceptibility to illness and emotional distress.²⁵ Although numerous quantitative studies focused on this subject matter, none of them point out to the patients' experiences in coping with the disease and, hence, there are still many ambiguities about the coping strategies following SCI. Moreover, the total sum of coping strategies does not constitute a global definition of the concept.²³ Patients' coping strategies vary according to contextual factors.¹⁵ Thus, more studies are needed with various groups of patients with SCI in different countries. Iran is an Islamic country in which religious culture is dominant. Therefore, the coping strategies of patients in Iran could differ from those identified in other cultures.

As there is no sufficient and deep information on the coping strategies used by patients with SCI in the world, and especially in Iran, the present study aimed to explore the approach used by Iranians chronically affected by SCI to cope with their chronic illness complications in its cultural context using a qualitative approach and to provide some culturally based foundations for their care.

Methods

The present study was a part of a grounded theory PhD dissertation investigating coping process of people with SCI. In this research, a qualitative design on the basis of content analysis approach was used for data collection and analysis of the perspectives and experiences of SCI patients in Iran. As coping is a process that occurs during a time period and through a complex individual–social context relation,^{7,18} this approach was chosen for the study.

Participants

The sample consisted of 18 patients with SCI referring to the Brain and Spinal injury Repair Research Center of Imam Khomeini hospital and the Protection Center of Spinal Cord Disabilities of Iran in Tehran, Iran.

A purposive sampling method with maximum variation (regarding age, duration of living with the injury, the injury level and its cause) was used. Inclusion criteria were having SCI, willingness to participate in the study, having the ability to share their experiences, being Iranian and Persian speak-

ing, diagnosed as paraplegia or quadriplegia, living with SCI for at least one year and aged more than 18 years.

Sampling continued up to the saturation of the categories. The age range of participants was from 19 to 63 years (with a mean of 37.2 years). Totally, 18 patients were interviewed from whom, 10 were females, 11 married, one divorced and the remaining were singles; 10 of the participants suffered from SCI due to road accidents, 5 due to fall and the rest of them due to swimming and spinal tumors. The minimum and maximum time duration of living with the disability was 2.5 and 26 years, respectively. Of the participants, 83.3% suffered from paraplegia and 16.7% suffered from quadriplegia.

Data collection

The research was conducted during the period August 2009–September 2010. The main method for data collection in this study was the interview method. The first author (HB) described the purpose of the study and the research questions for each potential participant. In case of agreement for participation in the study and signing the informed consent, an appointment was made on the basis of the participant's convenience. The interviews were performed at the participants' preferred time, when they had sufficient time for an interview.

Interviews were performed in a private room. Each interview began with a general question such as, 'could you explain your experience when you encountered the injury?' The participants were asked to express their experiences and understandings of the coping strategies used for overcoming the challenges following the injury. Interviews were continued for acquiring a deep understanding of the phenomenon under study. The interviews were recorded using a digital sound recorder. They were transcribed verbatim and were analyzed at the end of each interview.

The time period of interview sessions was from 40 to 90 min, with a mean of 1 h, depending on the tolerance of participants and their interest in explaining their experience. When necessary, a second session was arranged for interview.

Data analysis

Interviews were analyzed concurrently using the content analysis method.²⁶ The transcripts of each interview were reviewed several times and data were broken down into meaningful segments and assigned a conceptual name (codes). Then, through constant comparative method, the codes that were conceptually similar were grouped into categories. Categories and codes of each interview were constantly compared with other interviews. Interviewing stopped when data saturation occurred. Saturation refers to the repetition of discovered information and confirmation of previously collected data. Data were considered saturated when no more codes emerged and the category was coherent or made sense. The analysis was finalized by identifying a number of themes that emerged to describe the participants' experiences and viewpoints regarding strategies used to cope with SCI.

Data trustworthiness

Credibility was established through prolonged engagement, validation of emerging codes and categories in subsequent interviews (member checking), and debriefing with two faculty supervisors (peer check). Prolonged engagement with the participants within the research field helped the researchers to gain the participants' trust and a better understanding of the research fields. Sampling with maximum variation increased the confirmability and credibility of the data. This sampling strategy enables the investigator to capture a wide range of views and experiences.²⁷

The authors ensured the depth of the content and its authenticity by thoroughly identifying diverse and novel data. Moreover, the findings were checked with some of the SCI patients, who were not the study participants.

The researchers documented the steps followed in the research and the decisions made to provide the auditability for future researchers.

Ethical considerations

The research project was reviewed and approved by the Ethics committee of Tehran University of Medical Sciences. An official permission was obtained for entering the field and carrying out the study. Ethical subjects of interest included protection of the autonomy, confidentiality and anonymity of the participants during the study. All the participants became informed about the objective and the design of the study and they were assured of being able to exit the study unconditionally at every stage of it. In addition, the permission for recording interview was obtained from every participant who agreed to participate. Finally, they were asked to read and sign the informed consent form.

Results

During the data analysis, three coping strategies in patients with SCI, including seeking help from religious beliefs, hope and making efforts towards independence/self-care emerged. These strategies are shown in Table 1.

Seeking help from religious beliefs

People with religious beliefs believe that everything in the universe is subject to the God's will. Therefore, they use this belief to facilitate the acceptance of reality. In this study, most participants believed that their disease was a divine fate/providence, being selected by God for them. In support of that claim, a 50-year-old paraplegic man says,

'This is my fate; God provided it so' (P11).

Table 1 The main coping strategies used by people with SCI

Seeking help from religious beliefs (encountering the disease using a religious approach)
Understanding the disease as a divine fate
Understanding the disease as a divine test (spiritual combat)
Hope
Trying to gain independence/self-care

Abbreviation: SCI, spinal cord injury.

Most of the participants believed that their disease was a form of divine test, and they ought to pass it with pride; for example, one participant said:

'In fact, this disease is a divine test for me. I must pass it successfully' (P2).

This is, in fact, a kind of coping thinking.

Most participants sought help from doing prayers and resorting to innocent Imams as a coping strategy. The following examples reveal the fact:

'I always was doing prayers. I believed that God heals me. Before then, I had no belief in doing prayers, but now I have. Many people did prayers for my healing. My belief in God helped me to accept what happened to me' (P2).

'Resorting to innocent Imams and religious beliefs helped me to persist for eight years' (P7).

Hope

Hope was one of the most common coping strategies used by the participants in the present study. In fact, this strategy was the motive force for other coping strategies and adaptive behaviors reported by participants, including accepting the reality, having a sense of trust and trying for independence.

Hoping for healing, successful surgical operation, divine healing and miracle, progresses in the medicine and, ultimately, hope in the future were among the sources of hope mentioned by participants of this study:

'We are still alive with the hope we have. We hope in God. Maybe He does us a favor. Maybe he blesses us in a moment, and we get healed' (P1).

'Since I hoped to heal, I didn't stop my studies, even for a single semester. I proceeded safely up to now' (P12).

'I hope I can partly heal by this operation that is to be carried out by Dr, and then I will become able to do my activities' (P9).

'I hope a treatment is found for SCI, and we see all patients with SCI leaving their wheelchairs soon, if God wishes so' (P16).

Trying for independence/self-care

A person who had been active before the time of injury, assuming many occupational, familial and social responsibilities, and supporting the family financially and emotionally, turned from an independent person to a dependent one immediately after injury, experiencing many pressures and pains. The person attempts to resume his independence because the dependent state is distressful for him. Annoyance caused by piety expressed by others, dissatisfaction with being a burden for others and being condescended to others cause patients to attempt to reacquire the independent state. Switching from a dependent state to an independent one require re-definition and re-evaluation of individual's social and occupational objectives. The majority of participants in this study used strategies such as trying for movement, receiving education from professional persons and peers,

employment, searching for information, and setting objectives for self-care, to regain independence.

One of the most important aspects of independence is moving and walking again, which is carried out using walker brace or wheelchair. Acceptation of auxiliary devices such as walker and brace is, in fact, an effort towards releasing the burden from others and gaining more independence. The following examples explain the strategy better:

'I accepted walker and brace easily. Perhaps at first my motivation was not to build-up my problems. In addition, I wanted to remain more at home, get more independence and, thereby, could release my old mother a bit from burden' (P5).

'After 3 months use of medical shoes extending to thighs, I could stand on my feet, of course with pain. Three months later, I used crutch and walker, and, after six months, cane, to walk' (P4).

Receiving education from professional people and especially the peers, concerning the problems and challenges involved, leads to the situation where the person learns how to prevent problems, how to solve them and how to achieve self-control. For example, one participant said:

'With educations presented in this center, I'm now able to do around 90% of the self-care activities independently' (P7).

Employment/job-related activities and work are among the ways used to gain autonomy and independence and are important for enhancing self-esteem and identity. Some participants (paraplegic patients) used this strategy to prove their ability and release the burden of others. For example, one participant said:

'I was an active person before the injury, serving as a nurse. I tried this kind of activity (working at protection centers of spinal cord injury patients), in order to prove my ability and release the burden of others' (P16).

Seeking information is used for maintaining autonomy, preventing further problems and finding solutions to the current problems. For instance, one participant said:

'Generally, I look for further information. The physiotherapist and the nurses were very excellent. I learnt much from what they said' (P9).

In fact, looking for information and gaining knowledge are means for acquiring and maintaining independence and removing dependence on and need for others.

Having an objective in the life is the stimulus for making efforts and creates motivation and hope in the individual. For example, one participant said:

'It is important that we consider a series of partial achievable objectives for ourselves. In my opinion, setting objectives is important. At first, simple, small and easily achievable objectives, then paying attention to greater objectives with a larger scope. My motivators were my objectives' (P7).

'We only must accept that every day is a new day, and we must not set unachievable objectives for ourselves. One must set realistic objectives, try to achieve them and adjust the wishes to the present status of the self' (P7).

Discussion

Although there are around 70 000–90 000 patients and 2100 war disables with SCI in Iran, this is the first qualitative study exploring the coping strategies used by Iranian patients with SCI. According to the findings, one of the most important coping strategies used by the patients with SCI was the religious and spiritual approach. In line with many studies,^{19,23,24,28–31} these strategies, framed by deep religious roots, are considered to be active strategies in helping patients refining their thoughts and focusing on the problems and taking decisions. In this study, the patients had accepted their illness as a spiritual fate, a test bestowed on them by God. As they believed that all of the power in the universe rested with God, they surrendered themselves to their fate. This finding was similar to that of Ebadi *et al.*²³ on Iranian war disables with SCI²³ and Ashing *et al.*³² on patients with breast cancer.³²

This paper focuses on a Muslim society in which the use of social, cultural and/ or spiritual explanations as a way of encountering illness are common. Muslims use their religious beliefs to achieve high levels of spiritual well-being.³³

Muslims learn to pray early in young hood and pray five times a day. In addition, those who seek guidance from the holy Quran and believe that it has power over every aspect of their lives, expect and welcome any eventualities in their lives (Quran, Sura Balad, verse 4). They consider life challenges and hardships as divine will and test and see the future as bright. They feel that some of the difficulties they encounter are the result of their own sins and improve themselves to prevent future problems (Quran, Sura Shuri, verse 30).

Participants in this study believed that when one faces a disease, she/he should not lose her/his faith in God and thus will pass the test successfully. This viewpoint was formed by faith teachings. In this study, the participants used a variety of spiritual/religious coping strategies, including increased worshiping, praying, mosque attendance, Quran reading, resorting to the pure Imams and so on. Several earlier studies in Iran have indicated that praying and spiritual healing were the most commonly used methods of complementary therapies.^{33,34} This study showed that religious aspects of coping with the illness were among the most important coping strategies in taking care of Iranian patients with SCI, and hence, it is crucially important that health professionals understand how religion and spirituality can significantly influence how people cope with life-threatening illnesses. After reviewing all articles on Medline from 1976 to 1999 using the terms 'spirituality,' 'religion,' 'faith,' 'healing' and 'health', Udermann³⁵ concluded that there is strong scientific evidence that individuals who a) regularly participate in spiritual worship services or related activities and/or b) feel

strongly that the presence of a higher being or power is a source of strength and comfort to them are healthier and possess greater healing capabilities than people who do not attend worship services and/or have not a strong relationship with a higher being or power.³⁵ Ebadi *et al.*²³ found that effective spiritual coping strategies help individuals to find meaning and purpose in their illnesses.²³ This finding is not congruent with the findings of Pollard and Kennedy,²² who reported that the religious strategy was one of the least used items after suffering 10 years from SCI. This is perhaps due to the different cultural beliefs of the studied communities.²²

The findings showed that hope was one of the most common coping strategies used and the motive force for other adaptive behaviors and coping strategies in patients with SCI in Iran. Hope is a strategy that leads to movement and motivation.

Waiting for new progresses in the medical science, and hope to remain alive and resume normal life are strong motivations for healing, accepting reality, improving self-belief, and trying to achieve independence and adaptation to the disease. This finding is in accordance with the findings of the study, in which hope for healing is an adaptive mechanism in facing with what people experience and could be as a normal response in the early stages of the crisis.¹² Furthermore, it is recognized as a motivator to adopt actions towards healing facilitation.^{36,37} The experience of hope was important for all participants, providing them with the energy and power required for dealing with the challenges of their injury.^{38,39} Contingency of new medical and technological advances is identified as a source of hope and a motivation for healing after the onset of SCI.⁴⁰

We found that making efforts towards independence is also an important coping strategy in Iranian SCI patients, which is proved through being productive, removing pressure from others, removing the distress caused by the dependence on others, the distress due to others' expression of pathos and sympathy, meeting individual needs, and self-care. These findings accords to the findings of Van De Ven.²⁰ Also, one could say that this finding roots in a kind of culture and ideals of traditional Iranian life style, which includes being productive and independent, being able to take care of self and family members, and the concern of Iranian SCI patients for having social roles, such as being a breadwinner, a spouse and a father, which is in accordance with Chan *et al.*⁴¹

The findings showed that engagement in the activities of daily life following trauma is a way to proving productivity, gaining independence and self-care, and coping with challenges caused by injury. This finding accords to the findings of Anderson *et al.*,⁴² in which it is pointed out that there is a positive relationship between employment status and better adaptation, following trauma. Working people enjoy a significantly better adaptation in different aspects of their lives, such as financial satisfaction, social life, and control over life, pain, independence and well-being. Moreover, a positive relationship between being employed and longevity, health status, personal satisfaction, and positive adaptation following SCI has been reported. Working is basically a method for gaining autonomy and independence

and is an important activity that improves self-esteem, sense of independence and identity.⁴²

Most participants used goal setting and information seeking as strategies to gain independence and perform self-care activities. These findings accords with the study conducted by Van De Ven *et al.*,²⁰ in which these strategies are mentioned as strategies for self-determination, by which the individuals will have a stronger position to choose the alternatives and achievable items.²⁰

Finally, the knowledge gained from this study has implications for global healthcare situations among people of different cultural, social and religious background. However, I would caution against using it in a stereotypical manner, that is, using social, cultural and/or spiritual explanations as the only approach to interpreting a patient's way of encountering illness or caring situations. Ahmad⁴³ suggests that, although cultural norms and beliefs give guidelines for understanding people's ways of being, it is important to keep in mind that these are dynamic, situational and changeable over time.⁴³

Conclusion

Understanding the problems of patients with SCI and the strategies being used by them in coping with these problems will contribute to the development of the nursing body of knowledge and the understanding of nurses and other caregivers as well as the families, which finally leads to the development of effective coping strategies and improves the quality of care. The findings of this study provide a framework for the patients who want to learn how to live with SCI. More studies are needed for confirming the effectiveness of these strategies in practice.

Conflict of interest

The authors declare no conflict of interest.

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