

*Original Article***The process of confrontation with disability in patients with spinal cord injury**

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**Abstract**

**BACKGROUND:** Spinal injury can establish severe psychological outcomes for the patient and his/her family which requires high adjustment. Health system staff would be able to play their roles well in caring these patients provided with knowing what steps spinal injured people should pass to handle their disability and also what assistance they need in what stages from what sources. This study aimed to explain the process of confrontation with disability in spinal cord injured patients.

**METHODS:** This was a qualitative study with grounded theory approach which was performed in Strauss and Corbin proposed method on twenty people with spinal cord injury who had past at least three months from their spinal injury. Sampling was done in purposive and theoretical method, and analysis of the results was also performed during constant comparative process.

**RESULTS:** Central concept in the data was support which was associated with other concepts and affected them. The patients, with the help of internal and external support could overcome their main problem that was disability feeling and dependency on others and find a new definition for the self, and ultimately achieve the sense of independence and autonomy.

**CONCLUSIONS:** Knowing the process of confrontation with disability along with better understanding of spinal cord injured people would help health system staff to actualize and support their potentials much better through strengthening internal resources and providing appropriate supportive services of each individual.

**KEY WORDS:** Spinal cord injuries, people with disabilities, qualitative research.

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Spinal cord injury is a tragic and terrible event for patients who experience this incident. It may have severe psychological consequences for the patient and his/her family. Spinal cord injured individual is exposed to many high risks such as dependency, secondary medical side effects, drug addiction and other outcomes like lack of social, familial and emotional support.<sup>1-3</sup>

The number of disabled (handicapped) people resulted from spinal cord injury in the U.S. estimated almost as 262,000 people in 2009 and it is estimated that annually, 12,000 new spinal injured people are diagnosed in differ-

ent survivors' incidents, which more than 41 percent of these cases are related to road accidents.<sup>4</sup>

In Iran, although no accurate statistics are available from the number of handicapped people with spinal cord injury, the words of welfare organization authorities and Association for Defense of Handicapped Rights indicated that it is approximately 120,000 people which this number is increasing everyday due to various incidents. For example in Bam's earthquake, 320 people suffered from spinal cord injury, and every year two thousand people are added to them due to road acci-

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dents.<sup>5</sup> According to Road Traffic Officials, the rate of mortality caused by traffic accidents on Iran's roads (to the ratio of population and number of vehicles) is higher than the world's average number. In Iran in 2009, more than 23,000 people were killed in road accidents and 280,000 people also were injured. Statistical reviews illustrated that in the mentioned year, totally 800,000 accidents happened in Iran's roads (i.e., 90 accidents per hour) in which some of those accidents led to injury or death of the vehicle's passengers. Many of these wounded people suffered from spinal cord injury.<sup>6,7</sup>

The occurrence of spinal cord injury would create a situation for everybody which requires a high adaptation. With increasing the survival rate and life expectancy after the spinal accidents, the patients with spinal cord injury sometimes would live with this injury and disability for long years. This injury would establish a situation in the life so that individual has to acquire new capabilities to overcome his/her stress and adapt the current conditions.<sup>2</sup> Meanwhile, many factors can be effective to help individual to pass acute stages and to move on from acute tension conditions and after the crisis, to have a good life. Health system staff would be able to play their roles well in caring these patients provided with knowing what steps spinal injured people should pass to overcome their disability and also what type of helps they need in what stages from what sources.<sup>3,8-11</sup>

Therefore, considering the frequency of accidents and increase in the number of this type of handicapped people in the society, the present study aimed to explain the process of confrontation with disability in patients with spinal cord injury. Considering the nature of this objective, which requires studying deep experiences of the study subjects, qualitative approach seemed appropriate, and among different methods of qualitative study, grounded theory method was chosen which is suitable to review social interactions of people in dealing with their problems and detecting hidden process lies in these interactions.<sup>12</sup>

## Methods

This was a qualitative research with grounded theory method. Study population included the patients who had been suffered from spinal cord injury due to an incident. Sampling was done in purposive method and the participants of the study selected from those with spinal cord injury who were the member of the Spinal Cord Injury Support Association and well were able to express their experiences orally. They were selected after they were explained about the method and study objectives and also obtaining informed consent. Considering that in qualitative studies the experiences of participants are reviewed about the studied concept or phenomenon, the people were selected as the participants from the study population who had past at least three months from their spinal injury. With research progression and analysis of the obtained data, theoretical sampling was performed to find the manner of association between the concepts and obtained completion of the theoretical structure. Finally, 28 participants entered the study.

Semi-structured and in-depth interview was applied as the main data collection method. Interviews were conducted according to previous agreement with the participants in the forum or their workplace or home. The participants were asked to describe their experiences at the time of accident so far. Related to each statement, they were asked some questions about the problems they were faced with and the way they confronted with and also how they used the current supportive facilities. Probing method was applied during the interview in order to encourage participants to keep on conversation and express all their experiences. Other data collection methods also were used such as filed notes and memoing which helped enrich the data.<sup>13</sup> Observation method also was used to confirm and complete the data about the interaction of people at the workplace or their life, and were recorded and analyzed as field notes form. Furthermore, behavior and reactions of the participants were noted during the interview. The researcher also recorded his/her analysis and assumptions

as memo towards reactions of the individuals as well as complementary ideas to guide sampling process and used them in data analysis process.

Data analysis was performed based on Strauss and Corbin method (1998) simultaneous with data collection progression.<sup>13</sup> Open coding was conducted after writing down the text of the first interview. In this stage, data were furcated to meaningful components and each component was identified with a label from the text's words or concept of that component in the text. The codes were compared with other codes and interviews in terms of similarities and differences so that similar codes were placed alongside each other and formed categories. To ensure the reliability of results, the interpretations of the researcher (from the interviews' text) were shown to the participants and were approved by them. With research progression and more data collection and continuing constant process of comparing the codes, categories and texts, acts, incidents, and similar topics were gathered together to emerge more abstract concepts. With creating the classes and categories and discovering their characteristics and dimensions, the researcher continued axial coding during which main classes and subclasses were identified. Continuing constant comparison process of the association between main classes and subclasses, to some extent, determined their characteristics and dimensions. In this stage, the classes which were similar in terms of characteristics and dimensions were merged together and central class, main psychosocial problem and used strategy of the participants to cope with these problems were obtained. Using theoretical sampling and completing the association between the obtained concepts, researcher found the theoretical expression of the studied phenomenon.<sup>14,15</sup> Theoretical sampling was performed in the third stage of data analysis to clarify the association between interrelated concepts and the central class. In this stage, some individuals were selected who could help this issue using their information and experiences. Three patients, who had

pointed out to the type of relation the researcher had been asked in the previous interviews, were re-interviewed and two wives and three family members of the participants also were interviewed. Ultimately, the time no new data was appeared in relation between the concepts as well as about the study question, the researchers were convinced to find theoretical saturation and therefore, sampling was discontinued.

## Results

The participants of study consisted of 28 people (20 from the spinal cord injured, 5 from the families and 3 from Spinal Cord Injury Support Association).

As it was explained in the methods, data analysis began with the first interview and appeared after passing the initial coding and axial coding according to Strauss and Corbin proposed method (1998), and finally 5 main classes including grief reaction, disability, support, new self and independence along with subclasses were recognized. Among these, disability was diagnosed as the main psychosocial problem of these patients. Participants defined disability as dependency to others to perform everyday tasks and activities.

**1. Grief:** what these people expressed from their memories in early incidents indicated grief reaction which its stages already had been clarified by Kübler-Ross. The statements of some of the patients about the first experience after the incident were as:

*"... I was shocked after I was told about it. I couldn't believe it at first; I used to say they were wrong and there have been some mistakes."*

*"... I was so angry and upset why this happened to me? I always used to tell God, why me? Me, I always tried to be a good person, I helped every one...why me?"*

**2. Disability:** After the grief reaction, the participants accepted that they have been disabled. Some of the statements are as the following:

*"In that accident, only I seriously got injured; others, they only had a broken head. I was disabled from neck"*.

*"I used to be 70 kg, but now I'm 40 kg which is due to muscle loss and muscle weakness. I used to be an athlete and look at my current situation."*

**3. Support:** Reviewing the association between the obtained concepts indicated that the central concept in the findings was "support" which was in relation with all the other concepts and any change in that, can change the whole discovered process. According to the patients' words, "support" would help them achieve the new self and ultimately their sense of independence. They stated support as two main subcategories: internal support and external support. Internal support included spiritual and religious beliefs, self-confidence and self-esteem. External support may be provided by health system staff such as physicians, nurses, social workers, etc., or by the family as the society, governmental agencies. One individual mentioned:

*"... My parents had already died. My mother and father in law also rejected me with a child (lack of family support). However, I was an employee and my husband also used to receive pension and I was trying on myself (internal support). I have very good coworkers who really helped me all the time; they didn't let me be desperate in my affairs (public support). I never had crisis period, because I had a strong relationship with God (strong spiritual belief and God was in my heart (God's love))".*

*"The government should meet our requirements (government support)..."*

**4. New self and 5. Independence:** The main strategy these patients adopted to cope with disability included effort to accept the new self which consisted of identifying the limitations

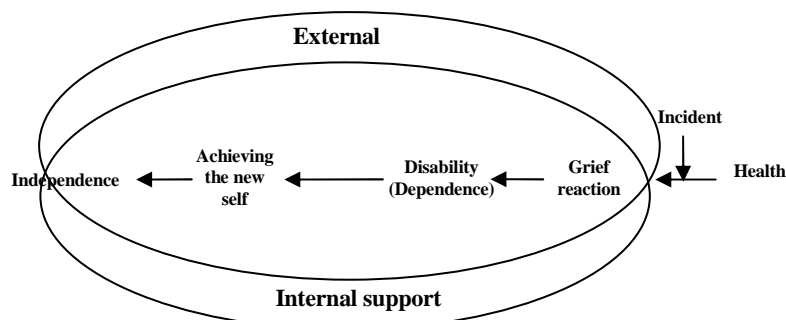
and abilities, and actualizing the potentials that finally guide them towards a new definition from health based on independence in doing the personal activities:

*"My family tells me that my conditions would not be the way I was independent and lived on myself (extra support). I really like to have my own life very much (to want independence)".*

*"I injured by spinal cord through fracture of cervical vertebrae caused by car accident. We were inside the car that this occurred and I was hospitalized in the hospital for more than seven months. I had been watched in the hospital but after I got discharged, my problems just began because we have not been informed enough (inadequate training). As soon as I arrived home, I got bedsore (disability in self-care). My other problem was to provide facilities such as wheelchair or a waterbed mattress because all these stuff cost a lot, besides I was not covered by insurance (lack of social support). Some who has neck problem almost needs more than five people to care of him/her. For instance, I needed at least two people to move me around after a year and four months (dependency)".*

*"I regularly work out in order to get improved sooner (internal support). My hands were pretty weak but now I always work with them (self-care). After my accident, I was fed (food, juice) with syringe (dependency). I try to do some of my personal stuff by my own so that I get more independent (independent); well however, there are many problems (multiple problems) in my life."*

Generally, the statements of the participants indicated that when someone is healthy, the individual feels to have ability; and this ability is manifested in individual's independence to do the personal tasks. After the incident, individual



**Figure 1.** A schema of the confrontation process with disability in spinal cord injury patients



would be disabled and in other words, would lose his/her independence and would require others for small tasks he/she could do them before by him/herself; this will cause dependency feeling and imposing severe mental burden on the patient. In this matter, the individual gradually would deal with his/her new self with the help and support of the internal and external supports. And based on a new definition from the self -appropriate with the information he/she would gain from his/her abilities- the individual would discover the process that is shown in Figure 1.

### Discussion

In this study, the process of confrontation with disability in spinal cord injury people has been reviewed which they had been passed their grief process three months after their injury. Grief was the first reaction of all the participants and other concepts were discovered in the content of their statements after accepting the new established conditions due to accident. Grief is considered as an emotional reaction of the survivors to a loss.<sup>16</sup> Here, loss can be defined as losing the health or in other words, as losing the ability to move. Grief reaction stages stated by Kübler-Ross included shock, denial, anger and bargaining, depression and acceptance,<sup>17</sup> which were seen in participants' statements. According to Kübler-Ross, in this process, the last stage is acceptance that the participants of this study also came to accept their disability resulted from spinal injury. But, what distinguished the reaction of this group from what Kübler-Ross stated was that they did not come to peace after acceptance and kept on trying to overcome their disability feeling. The findings of the study showed that the main goal of the patients was to overcome their disability resulted from the incident which was possible through internal and external support. According to the participants' statements, the main function of supporting is that patient can live with the spinal cord injury so that family structure and quality of life be maintained in an optimal level. In other

words, the aim of support is that patients not to face with main problems in playing the individual, familial and social roles and also can reach a better quality of life based on their abilities.<sup>18</sup> Support is known as the major social and familial factors in determining psychological prognosis of the individual with injuries. *Support* is a more general concept than *care* and can be of high importance in different dimensions such as improving physical conditions, increase health care, measures to increase improvement of psychosocial aspects, helping personal promotion and improving family situations.<sup>19</sup> Moreover, support is a profound, emotional and mental process which brings about mental health of the individual and comfort and also helps for better and more complete adaptation of the individual with his/her new conditions. Support is for helping the individual and surrounding him/her in order to increase his/her potential power and also helping his/her progression in different social and personal aspects. Support is happened in different aspects and various conditions as well as in critical conditions which individual has stress and in fact, it is considered as a part of crisis intervention process as well as chronic conditions. Support has various dimensions such as personal support which is formed inside a family.<sup>20</sup>

According to the statements of the present study, family also can be supportive which can be in different forms including emotional, psychological and financial supports. Based on the participants' view, a comprehensive support from the families had higher role in creating recovery feeling. According to findings of Stensman, the individuals, who at least used to live with one of the family members, were more satisfied from the life and doing their daily activities than those who were alone.<sup>21</sup> In a study similar to Anson's study, it was indicated that those with spinal cord injury, who received more support from the families, had a longer life and less suffered from post-traumatic complications.<sup>22</sup> Another study indicated that support of wife and family could have a determining role in

playing the support role and had brought about more healthy feeling and improvement in the injured people.<sup>9</sup>

In this study, many of the participants believed that religious attitudes and beliefs and hope for God's grace would help them in overcoming and release from the disease. The findings of Tam also showed that a group of patients believed that their disease was in the hands of God and for them, religious aspects in releasing from the disease was more important than health care services.<sup>23</sup>

In a studied research in Taiwan it was concluded that spinal cord handicapped people initially would pass a severe crisis and destruction to face with challenges ahead, then they either would go forward in their life or keep away from the society.<sup>24</sup> There are some similarities with the obtained findings in the present study.

In Iran few studies had been done about experiences or problems of spinal cord injured people in which most of the participants were the veterans of the Imposed War. Matini in reviewing the adjustment manner of the veterans' sanatorium showed that the most important problems of the veterans had been interpersonal relations, physical problems and its outcomes particularly lack of

understanding of some of the people from disabled conditions after war and the issues related to occupation and marriage.<sup>25</sup> Similar studies indicated that lack of familial support such as lack of compromise and sympathy, lack of mutual respect of father, mother, wife and children of the war veterans had important role in exacerbating psychiatric and physical symptoms of the veterans.<sup>1</sup>

None of the mentioned reports had provided a complete description of the process that those with spinal cord injury pass to return to a normal life. It is hoped that the present study, with describing the association between the obtained concepts from the description of the participants' experiences, can be helpful for further research in this regard and also helps the health system staff in customizing the care they are providing to this group of clients.

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