The Effect of Knowledge & Learning on Perception and Experience of Independence among Patients with Spinal Cord Injury

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ABSTRACT

Purpose: Individuals' personal awareness and learning after spinal cord injury is one of the most important factors in patients' confrontation with subsequent disabilities and new life style which affects their ultimate independence. This article is an abstracted result of a qualitative study on effective factors of independence among patients with spinal cord injury.

Methods: This study adopts a phenomenological qualitative approach and chooses its research samples from individuals with spinal cord injury including four women and seven men with paraplegic and tetraplegic SCI who live in Tehran. The data gathered trough In-depth semi-structural interviews and interpreted using Coliazzi's method.

Results: The data divided into 10 categories and 38 subcategories arranging in three general domains: the individual, familial and social. Knowledge and learning are important categories in the individual domain which includes five subcategories: Initial knowledge level, searching for information, learning from similar pattern, needs based learning, learning from experience and repetition.

Conclusion: The research shows that the amount of information about the spinal cord injury before and learning more information after the injury influences on the sense of independence, and individuals who trying more to learn about their subsequent difficulties and needs are more successful in their future life.

1. Introduction

Spinal cord injury is one of the most dangerous traumas which may cause disorders in different organs and even threaten individual's life. Spinal cord injury can lead to sensory and motor disorders and some limitations in disturbances daily activities like walking, self-care and so on. It can also cause emotional, social, psychological and economic consequences on patients, their families and society [1].

Unfortunately, spinal cord injury is most often among the youth, so that more than half issues (53%) usually occur among 16–30 years old adolescents [2]. The number of spinal cord injured patients is about 120000 in Iran and this trend is increasing based on several reasons. Regarding to high rate of car accidents and other unexpected events in the country, a huge number of people getting involved in spinal cord injury annually, who face serious limitations based on inappropriate urban planning. This situation isolates them

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from social sphere which can endanger their health and eventually impose heavy costs on the society. [3, 4]

Following the injury, the rehabilitation team starts their activities through informing the patient and his family about the disorder, although it seems that in this stage helpful activities were not usually executed. This deficiency in turn reduces patient's participation in treatment process and his willingness to the final cure. Depression, delayed seeking for rehabilitation services, and some side effects like bed sore, are other problems in this stage. [5]

In 2011, BabaMohamadi et al, seeking for the limitation and facilitation factors in adaptation among Iranian spinal cord injured patients, reported that lack of information is one of the basic limitations in adaptation of patients to their problem, which includes lack of enough training about spinal cord injury and rehabilitation resources in Iran [6].

Kehn and collogues in 2009 explained two different types of motivational and inhibiting factors in spinal cord injured patients' activeness. In this study, lack of information and knowledge resources declared as a basic barrier in the patient's activeness after disorder [7].

The patient and his family's awareness about spinal cord injury and subsequent difficulties, in addition to the patient attempts to learning about the new situation are essential factors in patient's final independence. In this study, most of the patients declare that having sufficient knowledge before the injury and getting adequate information after the injury is a fundamental key to individual's independence and adaption to the new situation. They even mentioned "knowledge" as the start point of their efforts. Learning various activities following the injury is also an important issue in their independence which this article has focused on.

2. Methods

This study adopts a phenomenological qualitative approach and the samples were chosen using a judgmental sampling method among patients with more than two years of experiencing spinal cord injury. All the samples have the ability to talk about their experience and all of them settled in their homes with their families. Age, gender and the level of injury were not among inclusion criteria.

Table 1. Demographic and Injury Data. Tehran 2013

Code	Gender	Age (Years)	Injury Level	Injury Type	Injury Cause	Injury Duration (Years)	Marital Status
1.R.M	Female	40	T12-L1	Complete Transection	Car Accident	14	Divorced
2.M.P	Male	28	C6-C7	Crushed	Falling down	3	Single
3.M.A	Male	29	C6-C7	Crushed	Car Accident	7	Single
4.G.B	Male	50	C5	Crushed	Falling down	6	Married
5.M.Kh	Female	29	L3-L4	Crushed	Car Accident	6	Married
6.N.A	Male	47	C5-C6	Crushed	Falling down	6	Married
7.Sh.N	Male	54	T10-T11	Complete transection	Car Accident	42	Married
8.H.S	Male	56	L1	-	Tumor	48	Single
9.H.Ch	Male	40	C4-C5	Complete transection	Falling down	16	Single
10.F.N	Female	58	T3-T4	Complete transection	Car Accident	22	Married
11.F.Q	Female	46 years old	C5	Complete transection	Car Accident	25 years ago	Married

PHYSICAL TREATMENTS

Data was collected through in-depth semi-structured interviews in any places the interviewee feels secure and comfort, in order to create a better communication. All the interviews were recorded via recording machine with the patient's permission. The researcher was writing his observation and important notes during the interview, evaluating the data after the session and setting another appointment in the case of any unan-

swered questions. The interviews were completely open in order to let the patient explain his ideas willingly but there were also some leading questions to prevent misleading.

The researcher applied continuous involvement to increase the validity as she works in a home care group in Tehran and one of its areas – Shahr e Rey- for long time. Therefore, she was in a long relationship with spinal cord injured patients and familiar with their difficulties. The patients were felling free and explaining their experience to her also. After the sessions, the data presented to interviewees to explore their complementary ideas and evaluate whether the gathered data reflect their experience or not. Besides, for the sake of more validity, the data were presented to other researchers who worked more on this field. The researcher also increased the data's accuracy about patient's independence through direct observation.

In all the interviews, patients filled up the written consent. The interviewees were free to leave the session if take any offence or feel uninterested. Names and other personal information classified confidential, so the patients named in some constructed codes and abbreviations.

3. Results

After Data analyzing, we found 10 categories and 38 subcategories in three different domains: individual, familial, and social domains. One of detected categories in individual domain was the role of knowledge and learning in spinal cord injured patients' independence which divided into 5 subcategories like: "patient's initial knowledge level about the injury, patient's effort to learning and getting more information after the injury, learning from observing the similar pattern, learning how to obviate the needs, and learning from repetition and experience".

All the interviewees declare that having basic knowledge and information before and after the injury is an essential issue for individuals who have injured recently. Therefore, they describe "knowledge" as the most important factor in the patient's independence, and lack of knowledge and information related to spinal cord injury as a dependence factor. On the other hand, patient's knowledge about the injury, its related issues, and learning process after the injury (including the sense of willingness, and need to experience and connection with other patients) are among the most effective factors in patient's ultimate independence.

3.1. Initial Awareness Level

This level of awareness is related to both individual's knowledge about spinal cord injury which has attained for any reason before the injury and also the patient's awareness which gained after the injury. The initial awareness can be relevant to people's educational and cultural status or other factors, based on victims report. The data indicates that the initial awareness leads to prompt adjustment and accelerates the independence process. Data also shows that lack of initial awareness in the first stage of or following injury have negative influence of the patient's independence:

R.M says: "in my opinion, people's knowledge is very important in admitting the problem, the more he has the knowledge, the sooner he preserves his new situation. If people know about the injury, then they know it cannot be treated simply. So they have not impossible expectation about their treatment process."

M.A says: "I think the first stage is the patient's understanding about what happened to him. Unfortunately sometimes I meet injured people who think their situation is a temporary one. They think after physiotherapy, the injury, wheelchair, and the whole story will be finished within 2 or 3 years. I think people should percept what is going at first, and they should decide what to do secondly.

F.Q says: "unfortunately we have not enough training about the spinal cord injury and its equipments in Iran. We also have no idea about what to do and where to refer for treatment after the injury."

3.2. Searching for Information

Data shows that while some patients had no information about the spinal cord injury, they gradually percept that their basic need in this stage is knowledge and awareness. Therefore, they try to attain more information in any way. Some say, they would have been more independent if they searched for the information earlier.

F.Q says: "I was really curious about what happened to me and what to do to prevent other following problems. So, I was searching for more information every day".

H.S says" I was rarely searching for information before, but now I am listening to the radio and watching TV every day based on my recent experiences. Although I have lived most of my life and have just a few, but today I am using my communication devices to gain new medical information every day.

3.3. Learning from Similar Pattern

Most of the patients describe other patients as an influential resource of information and learning. Totally, facing patients who are more independent and successful while suffering from the same injury can crate motivation and positive effects for the others. One of the most important points which patients learn from each other is learning of knowledge and skills they never accept from ordinary people based on their loss of lived experience but when patients encounter each other, they try to act the same way and improve to the stage that their peer have reached.

R.M says:" I think facing other similar patients is really helpful. When I came to Tehran, I saw other guys who are educated and commute on their own and, I asked myself why can't I do the same?"

M.A says: "the matter is to communicate with other patients. When you see how well the others can do some activities and how they have improved after a while, you think I can do the same if I wish, practice, and take my time. I can even do better!"

3.4. Need based Learning

In some cases, the spinal cord injured patient is not trained for the situation but his needs enforce him to try and learn how to obviate the basic needs. In other words, the needs push him forward to independence. People's life can impose new learning which can approach them to self sufficiency.

H.S says: I wanted to cook for myself but the oven was burning my hand all the time. So, I understood that I should decrease its height to cook comfortable."

3.5. Learning from Experience and Repetition

Passing of time, new personal experience, and repetition are other factors teaching the patients how to reach independence. In addition, despite all the trainings, everybody practices his activities in his personal way. In other words, two patients suffering from the same level of injury may perform a single activity in different ways. The interviewees believe that besides proper trainings, repetition leads everyone to find his comfortable way of performing.

S.N says: "look! I never trained how to dismount the wheelchair, but I tried several times in comfort and discomfort ways. Finally I found out how to do this properly."

M.KH says "I tried to realize in which way I can do my works better? I tried many things when I was alone to find the best way."

4. Discussion

Sufficient information is an essential factor for self-care in patients with long term disorder like spinal cord injury [8]. Knowledge, learning and training process needs more consideration. Awareness is the most important factor in patient's independence so that most of problems in spinal cord injured patients refers to the lack of information about the injury and its subsequent problems. In other words, individual's knowledge about spinal cord injury and related issues, learning, training and lived experiences are the resources of their ultimate sense of independence. These findings are comparable with Kehn's research in 2009, in which lack of information and knowledge resources declared as a basic obstacle in the patient's activeness after disorder [7].

Levins and his collogues mentioned the lack of information about benefits of mobility and exercises, is an effective individual factor in patient's immobility after the injury [9]. This content is in agreement to BabaMohamadi's qualitative research which found this phenomenon as one of the basic barriers in patient adjustment [6]. Dalvandi and collogues also detected the lack of information and training about how to adjust to the new situation, and how to use medical equipments as important problems for storke patients, in 2009. [10]

As well, Chappell, Wirz, and others in 2003 found out those patients who trained enough in the rehabilitation to adjust to their new circumstance, have better mental situation after ¬¬discharge from hospital [11]. Godfrey also reported in 2001 that adapting to stressful situations have a significant relationship with patient's accessibility to issues like information and occupation [12]. Therefore, having and getting sufficient information is an essential factor in individual's future life. This research unfortunately indicates that studied patients have a weak side in their independence based on the lack of information.

5. Conclusion

In conclusion, training, learning and acquiring new information can facilitate the ways in which spinal cord injured patients can adapt to their new circumstance and attempt to return to their independent life. Having sufficient information about the spinal cord injury, and its side effects and dangers, is a vital factor in learning new life style and facilities, and preventing from more side effects which can optimize patients about their future. This is to some extent the rehabilitation team's responsibility.

Suggestions

It seems that comprehensive rehabilitation centers which can intervene in the beginning, during and following the treatment, and train patients new skills for their new circumstance are basic requirements that needs an extensive collaboration between the government and the medical system.

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