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Living with Disability after Spinal Cord Injury: A Grounded Theory Methodology

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ORIGINAL ARTICLE

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Abstract

Study design: **A Grounded Theory Methodology is employed to investigate the study phenomenon. The entire study started from Jan. 15th. 2021 to March, 1st. 2022.**

Aim: **The study is conducted to explore the concepts that shape the experience of living with disability among patients with spinal cord injury, and to formulating a grounded theory regarding nursing care for patients with spinal cord injuries.**

Setting: **The study is conducted in Ibn Alkuf Hospital for Spinal Cord Injuries, Baghdad, Iraq.**

Methods: **A non-probability purposive sampling technique was used to select (12) patients with chronic (more than 5 years) spinal cord injury. The purposive sampling is used to reach data. Additionally, the sample size is justified after the full saturation of data is achieved. All patients are continuing with a rehabilitation program in the hospital. The researcher uses an open-ended question to explore how the patients are lived with their disability.**

Results: **The study results show that the patients had to live with their disability with some limitations to recover. There are four major categories explaining the way by which the patients lived with their disability, these categories are as follows: A devastating life-altering situation, standing up to difficulties, passing forward in the Society, and social withdrawing.**

Conclusions: **The study concludes that the devastating life-altering situation, standing up to difficulties, and passing forward in the society, and social withdrawing and its related sub-categories are major concepts describing patients' living with their disability after spinal cord injury.**

Keywords: Spinal cord injuries, Grounded theory, Nursing, Nurse, Qualitative methodology

1. Introduction

A Spinal Cord Injury (SCI) is a devastating occurrence in life. It's affected all the human dimensions; it has bio-psycho-social and spiritual effects (Alizadeh et al., 2019; Moghimian et al., 2015). SCI is dissociation in the function of the spinal cord, it's responsible for socio-economic consequences. The Spinal Cord Injury Statistical Center mentioned that more than 12 thousand new cases of spinal cord injury in North America (Hachem et al., 2017). Some people have identified it as a life-changing disability, necessitating significant adjustments in the way of life for those affected (Lynch & Cahalan, 2017). Adapting to significant alterations in bodily functions, lifestyle, personal identity, family dynamics, and social connections is a personalized journey that persists throughout one's life (Kalpakjian et al., 2015). LaVela et al. (2016) mentioned that SCI can cause physical, psychological, and social challenges. Moreover, it causes a variety of health problems that affect patients' quality of life and self-care behaviors.

Regarding the clinical problems associated with spinal cord injury, Wilson et al. (2012) stated that the severity of the clinical problems depends on the severity and the location of the injury. When the lesion affects the cervical level it causes quadriplegia, while the injury of the lower thoracic levels can cause paraplegia. Moreover, the survival rate among 40 years spinal cord injured persons is less than 50 % for tetraplegic persons, and less than 63 % for paraplegic persons

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(Middleton et al., 2007). The coping process is an important process that helps the patients to pass over the tragedy of spinal cord injury. Otherwise, when it fails, the patients may withdraw from society. The patients need to adapt and cope with their new status, and these mechanisms should involve all the challenges (in the physiological, social, environmental, and psychological domains), (Lude et al., 2014). The patient's quality of life is also affected due to SCI. All the physiological, psychological, and social factors together figure shape the patients' quality of life (Lidl et al., 2008; Middleton et al., 2007).

Methods and materials

This study is part of a qualitative research effort aimed at formulating a grounded theory regarding nursing care for patients with spinal cord injuries. It aims to explore the concepts that shape the experience of living with disability among patients with spinal cord injury, and to formulating a grounded theory regarding nursing care for patients with spinal cord injuries.

Sample

The study sample involved 12 participants selected purposefully. The following criteria used in the study participant's selection:

1. Currently inpatient in a rehabilitation unit.
2. Age: >14 years.
3. Admitted to rehabilitation unit frequently.
4. Discharge home many times.

Data collection method and measurement

Semi-structured interviews and observation were used. The responses of the participants were measured through tap recorded.

Assumptions

1. Patients who are experiencing spinal cord injury need to figure out their things and learn how to live with their disability.
2. Injury to the spinal cord carries significant biological, psychological, social, and spiritual effects on individuals.
3. Patients who succeed in learning to live with their disability could move forward within their society. Otherwise, they may be frustrated and withdraw from the social context.

Questions

The present study uses the following open questions, to help the patients to organize, explain, and saturate/her ideas.

1. What do you think that spinal cord injury means?
2. Explain your feelings after spinal cord injury.
3. How can you describe your life after spinal cord injury?
4. What are the limitations that you face when you trying to move forward within the social context?
5. Explain how society deals with you after the injury?

Analysis

In grounded theory, data gathering and analysis take place concurrently. Methods of constant comparison, questioning, maintaining notes, diagramming records, and reviewing literature have been intertwined from the outset of data collection. The core category was established based on the participant's responses. The data analysis was performed through the following steps:

1. Open coding (line-by-line analysis).
2. Enumeration.
3. Naming and Defining: naming efforts by investigator to define and create abstract significance for the events or observations noted in their data records by explaining what they believe is happening or being conveyed in those events. Following thorough deliberation, the event is titled and detailed from various angles or viewpoints that can be produced by the researcher, aided by relevant documentation.
4. Comparing entails, the creation of a shared term or classification for several events or observations in the data that result in the establishment of broader categories. Comparison is essential for developing conceptual categories and aids in refining the naming of these categories; this is why it takes place in a way that aligns with the naming process mentioned earlier.
5. Formulating Memorandum (Memoing): Memoing is the process of jotting down notes for expansion. It manifests in two ways: 1) notes that document insights and concepts prompted by a specific event while in the field—offering relevant insight or example, 2) documentation of ideas produced afterward in the research process as category properties are developed and theoretical concepts arise.

6. Abstraction: formulating a general description of the research topic through generating categories.

Results

Patients' general information

The study results show that 58.3 % of the study sample are male and, 41.7 % are female. The mean of the study sample age is 36 years. 66.7 % of patients are diagnosed with paraplegia and, 33.3 % of them are diagnosed with tetraplegia.

Patients' living with disability after SCI

In this study, participants with both tetraplegia and paraplegia shared their experiences of suffering an SCI. They felt the SCI was a disaster; they had to make a lot of changes in lifestyle and face many challenges when they went to move forward in society. Finally, they had to live with their disability with some limitations and return to their life as best they could. Within this context, the present study identified through a line-by line analysis, enumeration, defining the concepts, inductive categories, and creation of hierarchical category systems, four major categories were determined, these categories are as follows: A devastating life-altering situation, standing up to difficulties, and passing forward in the society, and social withdrawing. These major categories that emerged from the data were supported by several subcategories.

1. A Devastating Life-Altering Situation

The individual experience, physical problems, cloudy future, and financial issues were identified by the participants in terms of a devastating life-altering situation. The problems in an individual's experience include infertility, dependency, and lifestyle alteration; physical problems after spinal cord injury including paralysis and urinary incontinence; cloudy future due to the incurability of the spinal cord injury; and financial issues including loss of job and financial problems are the factors making the patients with spinal cord injury living with their disability as a devastating life-altering situation. These experiences are related to and, affect positively the patients living with their disabilities. While it affects negatively the participant's ability to stand up to difficulties and they're passing forward in society as well as affect their exploring the meaning of life with spinal cord injury (Fig. 1).

2. Standing up to Difficulties

During this stage, Patients are usually within hospital care. They expressed that they need to develop strategies to help them successfully reenter the world as people with disability. Three subcategories were generated from the data related to standing up to difficulties. The first one was the reintegration of the body. The other things from the participants' perceptions, were psychological and spiritual well-being and sexual issues.

The problems with the reintegration of the body including curability of the spinal cord injury and rehabilitation; psychological and spiritual well-

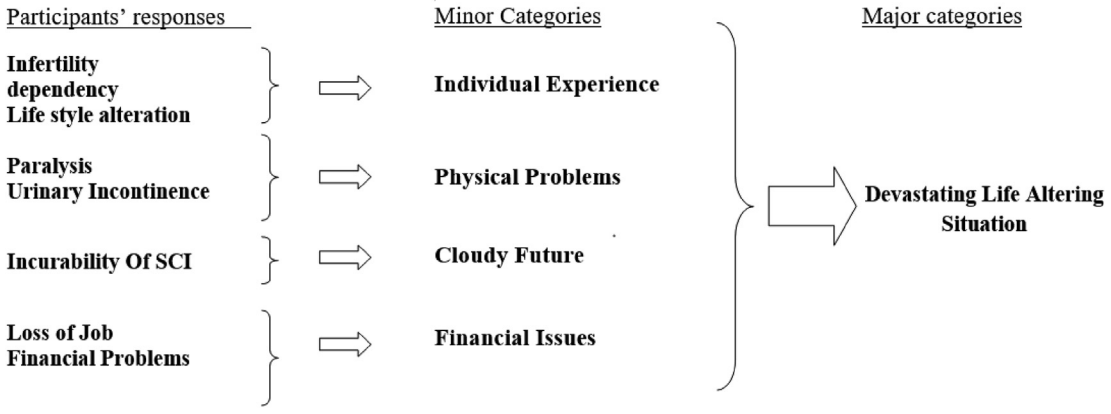

Fig. 1. ***Inductive categorization and Creating Hierarchical Category Systems regarding "Devastating Life-Altering Situation".*** *It illustrates the patients' responses, and minor categories regarding the major category "Devastating Life-Altering Situation", the study results presented in this figure indicate that the patients' responses categorized into four minor categories are individual's experience, physical problems, cloudy future, and financial issues. These minor categories are inductively categorized into the one major category that is devastating life-altering situation. The inductive categorizing is conducted according to the shared meaning between the patients' responses and the minor categories.*

being including faith and adaptation; and sexual issues including fertility and the continuity in the marital status are the factors that help the patient to triumph over tragedy and standup to difficulties and challenges that occur as a result to the injury. These challenges are related and might positively affect each other. Also, its effect positively the patients passing forward in society. While affecting negatively the patients devastating life-altering situation as well as affect the patients living with spinal cord injury. This study also found that study participants have strong beliefs in God, they may commit their souls to God following their injury (Fig. 2).

3. Passing Forward in the Society

Passing forward emphasizes leading a full and independent life as much as possible after injury. This study found that it is much easier for patients with paraplegia to pass forward, in comparison with patients with tetraplegia. Additionally, the study results indicate that the win over misfortune including family coping, social participation, and the ability to perform ADL; and having fortitude including social support, and rehabilitation team encouragement are the factors that enhance patients moving forward with an independent life as possible. These issues are related and, affect negatively the individual's devastating life-altering situation. While affecting positively the patients standing up to difficulties as well as the living with spinal cord injury (Fig. 3).

4. Social Withdrawing

Additionally, the study results indicate that social withdrawal occurs as the patient impaired coping mechanisms with the injury and loss of social interaction. Social withdrawal affecting negatively the patients standing up to difficulties. While affecting positively the patient's devastating life-altering situation. The impaired coping mechanisms due to unpredictable future and suicidal ideas, and loss of social interaction due to decreased social participation, social isolation, and altered self-esteem. These factors are related to each other and may be affecting positively the devastating life-altering situation. While it may affect negatively the ability to stand up to difficulties and move forward successfully (Fig. 4).

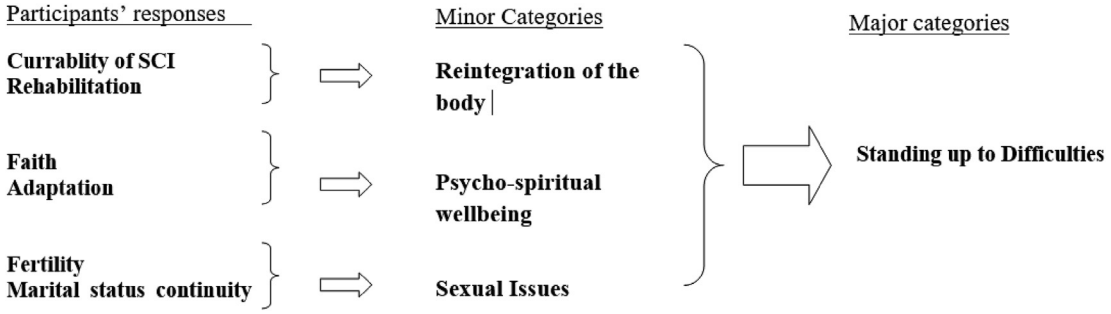

*Fig. 2. **Inductive categorization and Creating Hierarchical Category Systems regarding "Stand up to Difficulties".** Itillustrates the inductive categorizing of the patients' responses, minor categories regarding the major category "Standing up Difficulties". The study results presented in this figure indicate that the curability of the SCI and the rehabilitation are categorized into "reintegration of the body"; faith and adaptation are categorized into "Psycho-spiritual wellbeing"; while the fertility and marital status continuity are categorized into "sexual issues". These minor categories are inductively categorized into the standing up to difficulties. The inductive categorization is conducted according to the shared meaning between the patients' responses and the minor categories.*

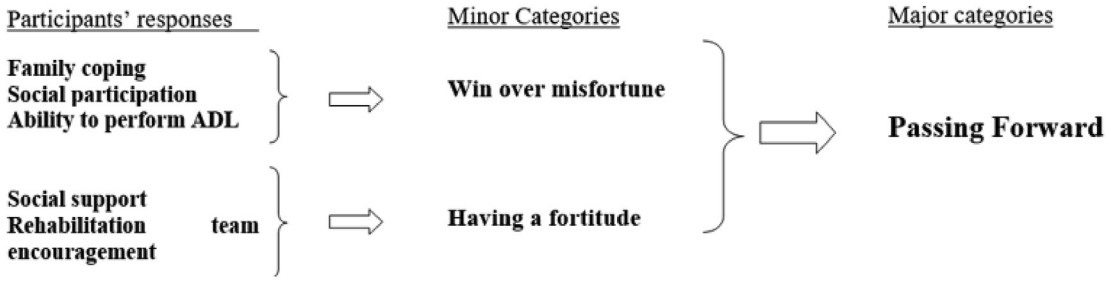

Fig. 3. Inductive categorization and Creating Hierarchical Category Systems regarding "Passing Forward in the Society". Itillustrates the patients' responses, and minor categories regarding "Passing Forward in the society" category, the study results presented in this figure indicate that the patients' responses categorized into two minor categories for the "passing Foreword" are win over misfortune and having a fortitude. The inductive categorizing is conducted according to the shared meaning between the patients' responses and the minor categories.

Fig. 4. Inductive categorization and Creating Hierarchical Category Systems regarding " Social Withdrawing". Itillustrates the patients' responses, and minor categories regarding "Social Withdrawing", the study results presented in this figure indicate that the patients' responses categorized into two minor categories are: impaired coping mechanisms and loss of social interaction. The inductive categorizing is conducted according to the shared meaning between the patients' responses and the minor categories.

Discussion

By comparing the results of the present study with the results of other studies, it found that the factors affecting patients living with disability are mentioned in another manner. The results of the present study indicate that the majority of patients with spinal cord injury experience a devastating life-altering situation because the spinal cord injury has physical, psychological, social, and spiritual implications. These implications affecting negatively on patients' ability to stand up against challenges and difficulties. Therefore, it affects negatively the patients living with their disabilities. Additionally, the study results indicate that the problems in individual's experience, physical problems after spinal cord injury, cloudy future, and financial issues are the factors making the patients with spinal cord injury live with their disability as a devastating life-altering situation. These experiences are related and might be affected positively (direct relationships) each other's, and will negatively affect the participant's ability to stand up to difficulties and they are passing forward in society as well as affect they are exploring the meaning of life with spinal cord injury. Lee et al. (2016) studied the "factors affecting the quality of life among spinal cord injury patients in Korea", they found that there are many physical and psychological problems such as paralysis, bladder and bowel problems, sexual concerns, and patient's satisfaction with their life and the spinal cord injury sequences are affecting the patients' quality of life.

Standing up to difficulties and triumphing over tragedy is a basic need of patients with spinal cord injury. These needs developed based on many factors some of these factors concerning the patient himself and the other factors developed based on the external environment. The standup difficulties are an important thing making the patients with spinal cord injury passes successfully in the social context and re-enter the world and fulfill their life as possible. Otherwise, patients may withdraw from society.

The study results found that the problems with the reintegration of the body, psychological and spiritual well-being, and sexual issues are the factors that help the patient triumph over tragedy and stand up to difficulties and challenges that occur as a result of the injury. These factors are related and affect the patients living with their disability after spinal cord injury. The standup to difficulties affecting positively the ability of the patients to pass forward in society, at the same time it affecting negatively the patient's withdrawing symptoms and the devastating life-altering situation. Nicholls et al. (2012) studied the" factors influencing acceptance of disability in individuals with spinal cord injury in Neiva, Colombia, and South America", they found that the psychological problems that are related to sexual problems, incurability of the spinal cord injury, and the permanent disability are a factor that affecting the patients' acceptance of their disability and, affecting their living with it after spinal cord injury. Hashemiparast, et al., (2022) studied the experience of living and coping after spinal cord injury. They found that religion is an important factor that affects the patients' living and acceptance of their disability.

Moreover, patients with spinal cord injury need to achieve the highest level of independence. With the incurability of spinal cord injury, the patients need to adapt successfully to their permanent disability. When they succeed in adaptation, they may pass forward in societal activities. Otherwise, they may withdraw from it. The study results indicate that is easy for patients with paraplegia to pass forward compared with tetraplegic patients, and that due to the level of independence that the patients achieved. Additionally, the study results indicate that the win over misfortune and having fortitude are the factors that enhance patients moving forward with an independent life as possible. These factors are related and may be affecting positively the patients' stand

up to difficulties. While it is affecting negatively the patients' devastating life-altering situation and withdrawing symptoms. Nikbakht-Nasrabadi et al. (2019) studied the "toward overcoming physical disability in spinal cord injury: a qualitative inquiry of the experiences of injured individuals and their families", they found that the presence of rehabilitation and social support is a factor that affects positively on the patients' status after spinal cord injury. Khanjani et al. (2019) studied the factors that affect the acceptance and rehabilitation of patients with spinal cord injury. They stated that the "correct support, communication with peers, social participation, spiritual belief, positive attitude, motivators, access to facilities and contextual factors" are the factors that affect the patients' acceptance, and also affect the patients' moving forward in the society.

Although patients with spinal cord injury can forward and pass over tragedy, the study results found that many factors may affect the patients' ability to live an independent life as possible and make them withdraw from society. These factors are impaired coping mechanisms due to unpredictable future and suicidal ideas, loss of social interaction due to decreased social participation, social isolation, and altered self-esteem. These factors are related to each other and may be affecting positively the devastating life-altering situation. While it may affect negatively the ability to stand up to difficulties and move forward successfully. Clayton and Chubon (1994) , studied the factors that affect the quality of life of long-term spinal cord injury. They found that physical problems, permanent disability, and support, are the factors that are associated with quality of life, and may affect the patients moving forward or withdrawing from society.

Conclusion

The study concludes that the devastating life-altering situation, standing up to difficulties, and passing forward in the society, and social withdrawing and its related sub-categories are the major concepts affecting patients' living with their disability after spinal cord injury. Additionally, Spinal cord injury has major bio-psycho-social and spiritual implications for individuals. Patients who succeed in learning to live with their disability could move forward within their society. Otherwise, they may be frustrated and withdraw from the social context.

Conflict of interest

In this study, there is no conflict of interest.

Data availability statement

All data generated or analyzed during this study are included in this article. Additionally, the present study is a part of qualitative − grounded theory methodology, therefore, there are not many datasets used.

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Ethics information

None.

Author contribution

The author is designed the study, collected the data, and analyzed the results, and writing of the entire manuscript.

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