

## Original Article

# Excruciating Care: Experiences of Care Transition from Hospital to Home among the Family Caregivers of Patients with Spinal Cord Injury

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### ABSTRACT

**Background:** Transition of patients with spinal cord injury (SCI) from hospital to home often involves a shift in caregiving responsibility from health-care providers to family caregivers. Poor care transition may lead to poor care-related outcomes. **Objectives:** The aim of this study was to explore experiences of care transition from hospital to home among the family caregivers of patients with SCI. **Methods:** This qualitative study was conducted in 2018–2019. Participants were 17 family caregivers of patients with SCI who were purposively recruited from two specialty SCI care centers in Iran. In-depth semi-structured interviews were held for data collection. Interviews were audio-recorded, transcribed, and analyzed using conventional content analysis. **Results:** The following four main categories were developed during data analysis: lack of knowledge (with two subcategories), excruciating care (with two subcategories), emotional burden of caregiving (with three subcategories), and need for support (with two subcategories). The nine subcategories of these main categories were lack of medical and care-related information, seeking for information, heavy burden of daily caregiving, need for providing professional care at home, feelings of sadness and sorrow, feeling of insufficiency, restriction of life, limited support by family members and relatives, and limited financial support by the government. **Conclusion:** Family caregivers of patients with SCI experience many challenges and problems during care transition from hospital to home, which can affect the quality of their care services for their patients. Therefore, they need ongoing support throughout the process of care.

**KEYWORDS:** Care transition, Family caregivers, Spinal cord injury

## INTRODUCTION

Spinal cord injury (SCI) is a serious health problem which requires hospitalization in trauma care units. After the acute phase of SCI, patients in many countries receive inpatient interdisciplinary rehabilitation care services for 4–8 months. One of the goals of rehabilitation programs for SCI, which start during hospital stay, is to prepare patients for transition from hospital to home.<sup>[1]</sup>

Hospital–home transition is a complex event<sup>[2]</sup> and is associated with a shift in caregiving responsibility from health-care providers to family caregivers. In

Iran, family caregivers are a major source of care and support for people with disabilities.<sup>[3]</sup> However, family caregivers may have limited readiness for caregiving to a patient with SCI, may experience problems and challenges in caregiving, and thus require professional support.<sup>[4]</sup> Home-based professional support in some


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countries, including Iran, is not easily accessible and hence, family caregivers of patients with SCI experience different physical and mental problems<sup>[5]</sup> such as fear and worry,<sup>[1,2,6]</sup> huge caregiving burden,<sup>[1]</sup> and distress.<sup>[7]</sup> Moreover, poor care transition is associated with adverse outcomes such as rehospitalization, prolonged hospital stay, and medication errors.<sup>[8]</sup>

Studies in Western countries reported that during care transition, family caregivers face different challenges and feel various psychological, educational, and supportive needs.<sup>[6,9]</sup> Some studies in Iran also evaluated the burden of caregiving to patients with SCI.<sup>[10,11]</sup> However, limited studies addressed experiences of care transition from hospital to home among the family caregivers of patients with SCI. One of the handful studies in this area was conducted in Italy and found that family caregivers needed to communicate with health-care providers and receive their support.<sup>[1]</sup> Another study in Scotland on patients with SCI showed that they experienced problems such as “loss of camaraderie,” “lack of postdischarge care,” and “other people’s reactions to SCI.”<sup>[12]</sup> The results of studies in Western countries are not easily applicable to people in developing countries.<sup>[13]</sup> Because of the paucity of data about the experiences of care transition from hospital to home among the family caregivers of patients with SCI, the present study was designed and conducted to produce further evidence in this area.

### Objectives

The aim of this study was to explore experiences of care transition from hospital to home among the family caregivers of patients with SCI.

## METHODS

### Design and participants

This qualitative study was conducted from June 2018 to May 2019. Participants were 17 family caregivers of patients with SCI who were selected from Arak SCI Association, Arak, Iran, and a rehabilitation center in Tehran, Iran. These two centers were referral SCI care centers in two populated cities in Iran and provided care services to patients from different cities. Inclusion criteria were caregiving to a patient with SCI as a main family caregiver, caregiving experience of more than 3 months, age over 18 years, no history of mental disorders, and ability to speak Persian. Eligible participants were selected through purposive sampling and with maximum variation in terms of age, gender, education level, and kinship with patient.

### Data collection

Data were collected through in-depth semi-structured face-to-face interviews held in either the study setting or participants’ homes – depending on participants’

preferences. The authorities of the study setting were consulted in order to identify and select family caregivers with rich experiences of caregiving. An interview guide with general and specific questions was used for interviews. Examples of interview questions were, “Can you please explain your experience of the discharge of your patient from hospital?” “What problems did you have during hospital discharge and afterwards?” “What did you do in that period?” If needed, participants were asked to elaborate on their statements. Data collection lasted up to data saturation, i.e., when no new conceptual codes were obtained from interviews and all aspects of the study subject matter were adequately explored. Saturation was achieved after 15 interviews with 15 family caregivers. Yet, two more interviews were conducted to ensure data saturation. The interviews lasted 22–60 min. All interviews were audio-recorded and transcribed verbatim.

### Data analysis

Data were analyzed concurrently with data collection using conventional content analysis. Interview transcripts were read to grasp participants’ perceptions and then, meaning units were identified and coded with conceptual labels. Then, codes were constantly compared in terms of their similarities and differences and were grouped into subcategories. Similar subcategories were also grouped into larger categories.<sup>[14]</sup> Table 1 shows an example of data analysis.

### Data trustworthiness

The four criteria of credibility, confirmability, dependability, and transferability were used to ensure trustworthiness. Credibility was established via member checking, peer checking, prolonged engagement with the data over 9 months, and sampling with maximum variation. For member checking, four participants were invited to verify whether our generated codes and categories were consistent with their experiences. During peer checking, the second and the third authors of the article reviewed study findings and approved the accuracy of data analysis. To ensure the dependability and the confirmability of the findings, the whole process of the study was documented with as much details as possible. Transferability was also ensured through providing rich descriptions about the data collection and analysis processes and the findings. Moreover, study findings were provided to two additional family caregivers of patients with SCI who confirmed the congruence between their experiences and the findings.

### Ethical considerations

The Ethics Committee of the University of Social Welfare and Rehabilitation Sciences, Tehran, Iran, approved this study (code: IR.USWR.REC.1397.011). All participants

**Table 1: An example of data analysis**

Meaning units	Codes	Subcategories	Category
My husband could not move at all after the accident. It was very difficult to move him. We had to frequently change his position to prevent bed sore	Patient immobility Difficulty in moving the patient	Heavy burden of daily caregiving	Excruciating care
My husband had urinary incontinence. We cleaned him regularly, bathed him, and fed him through a gastric tube with difficulty	Great need for care Difficult feeding		
When we took my husband home, he had a tracheostomy and needed regular suctioning. When he was discharged from hospital, he had bed sores. I dressed his wounds with the help of relatives, but the wounds worsened	Need for suctioning at home Wound dressing at home by lay people	Need for providing professional care at home	

were informed about the aim of the study, voluntariness of participation, confidentiality of their data, and their right to withdraw from the study at will. All of them signed the informed consent form of the study.

## RESULTS

Participants were 17 family caregivers of patients with SCI (13 females and four males). The mean of their age was 39.7 years. Table 2 shows their characteristics.

Participants' experiences of care transition from hospital to home were categorized into four main categories, namely lack of knowledge, excruciating care, emotional burden, and need for support [Table 3].

### Lack of knowledge

The participants reported lack of knowledge about SCI and postdischarge patient care, which consequently caused them problems in the process of caregiving. The subcategories of this category were lack of medical and care-related information and seeking for information.

### Lack of medical and care-related information

The participants could not give quality care and support to their patients due to having limited knowledge about SCI and SCI-related care and receiving limited education, if any, from health-care providers. Therefore, they had a feeling of uncertainty during caregiving to their patients.

*Nobody gave me information in the hospital about the kind of care my patient needed at home. Moreover, nobody taught me about wound care, how to contact health care providers, and where I should take my patient in case of any serious problem. After ten months of caregiving at home, I learned how to take care of him. It was better if hospital authorities gave me an educational pamphlet (P. 6).*

*At the time of hospital discharge, no one gave use any information. Returning to home was the beginning of our problems. We were not familiar with the disease and didn't know anything about the consequences of SCI (P. 12).*

Some participants noted that information provided to them by health-care providers was insufficient and unclear and believed that health-care providers avoided telling them the truths. Unclear information had made them more worried.

*When I asked nurses about my patient's conditions and the duration of his conditions, they did not answer properly and told me to trust in God's will (P. 1).*

### Seeking for information

In order to resolve their uncertainties about caregiving, the participants attempted to seek SCI-related information and improve their knowledge about SCI and caregiving.

*Sometimes, I go to doctor's office to ask my questions and sometimes I call a doctor or a nurse in our relatives (P. 5).*

Some participants searched and found their necessary information on the Internet.

*Through searching the Internet for SCI, I could find information about its symptoms and necessary care measures. In this way, I got familiar with the situation (P. 6).*

### Excruciating care

Patients with SCI have a wide range of needs, the fulfillment of which is difficult and beyond the abilities of family caregivers, particularly those who are alone in caregiving. Therefore, caregivers experience fatigue and strain due to the necessity of fulfilling many different needs of their patients. The two subcategories of this main category were heavy burden of daily caregiving and need for providing professional care at home.

### Heavy burden of daily caregiving

The participants reported that they needed to perform heavy care-related activities such as moving their patients, changing their position, feeding them, and performing activities related to their personal hygiene. The heavy burden of daily caregiving affected caregivers' physical well-being, quality of life, and

**Table 2: Participants' and their patients' characteristics**

Number	Age (years)	Gender	Kinship with patient	Patients' SCI type
1	56	Female	Mother	Thoracic (at T12)
2	35	Female	Sister	Lumbar (at L1)
3	38	Male	Husband	Lumbar (at L1)
4	57	Female	Mother	Thoracic (at T8)
5	31	Female	Wife	Cervical (at C4)
6	28	Female	Wife	Thoracic (at T8)
7	55	Male	Brother	Cervical (at C4)
8	38	Female	Wife	Cervical (at C4)
9	29	Female	Wife	Cervical (at C5)
10	42	Female	Wife	Cervical (at C4)
11	25	Female	Wife	Lumbar (at L1)
12	49	Male	Father	Cervical (at C4)
13	28	Female	Wife	Cervical (at C5)
14	35	Male	Husband	Thoracic (at T12)
15	50	Female	Mother	Lumbar (at L1)
16	35	Female	Wife	Lumbar (at L1)
17	45	Female	Wife	Thoracic (at T12)

SCI: Spinal cord injury

**Table 3: Categories and subcategories of the experiences of care transition from hospital to home among the family caregivers of patients with spinal cord injury**

Subcategories	Categories
Lack of medical and care-related information	Lack of knowledge
Seeking for information	
Heavy burden of daily caregiving	Excruciating care
Need for providing professional care at home	
Feelings of sadness and sorrow	Emotional burden of caregiving
Feeling of insufficiency	
Restriction of life	
Limited support by family members and relatives	Need for support
Limited financial support by the government	

quality of patient care. Participants with lower social support reported heavier caregiving burden.

*My main problem was related to moving him because it was very difficult. I was alone while needed two persons for bathing him. Moreover, I had to put food in his mouth while he couldn't sit and I needed two persons for help (P. 8).*

Besides caregiving to a patient with SCI, most participants had responsibilities such as housekeeping, shopping, cooking, and childrearing. Managing and performing all these responsibilities put huge pressure on them.

*I took care for my husband day and night for the first six months after his hospital discharge. I was under high pressure. At the same time, I had to perform*

*household chores, shopping, cooking, and looking after my two-year-old child. I didn't sleep and stayed awake all night (P. 13).*

### Need for providing professional care at home

Most participants had challenges and difficulties in performing professional care measures at home because they did not have the necessary skills for professional care and did not have access to professional services due to financial problems.

*In the beginning, we asked a homecare nurse for wound care. But, as we couldn't afford the costs of professional care, we had to watch, learn, and do procedures such as wound care and urinary catheterization ourselves. These are very difficult procedures (P. 9).*

### Emotional burden of caregiving

This category reflects family caregivers' emotional reactions and feelings respecting their patients' SCI. Participants were very upset by their patients' sudden loss of functionality. Moreover, SCI had affected all aspects of their lives. The three subcategories of this category were feelings of sadness and sorrow, feeling of insufficiency, and restriction of life.

### Feelings of sadness and sorrow

SCI of participants' family members had caused them sadness and sorrow. They felt deep sadness and sorrow at finding their SCI-afflicted family member in a bedridden state with physical and motor disabilities and dependence on others for doing their activities.

*I was very upset at seeing my husband's inability to walk and having a disordered life. My husband was a very active man who turned into a disabled person confined at home (P. 6).*

### Feeling of insufficiency

Family caregivers have pivotal role in SCI rehabilitation and are the major source of support for patients with SCI after hospital discharge. However, the participants felt insufficiency in caregiving due to facing challenges and feeling inability to provide necessary care and support to their patients. This feeling was more prevalent among caregivers who were alone in caregiving and had inadequate physical strength.

*I tell my husband I wish I was injured in the accident and he was healthy to carry me around and take me to the doctor (P. 9).*

The critical conditions of patients further complicate caregiving and thereby, worsen the feeling of insufficiency among family caregivers.

*I was very concerned about my husband's respiration during airway suctioning. I feared I might incorrectly*



*perform suctioning and thereby cause him suffocation or pulmonary infection (P. 10).*

### Restriction of life

Most participants had devoted all of their time to caregiving to their SCI patients at home and hence, had no free time for themselves. They noted that having a family member with disability had disrupted their activities and social relationships with friends and relatives. This problem was specifically prevalent among caregivers who did not receive support from other family members or close relatives.

*We used to travel a lot with my husband; but we haven't traveled since his injury. I even can't go to my friends' homes because he needs care and there is no one else to care for him except me (P. 9).*

### Need for support

The participants reported receiving limited support from family members and healthcare system and hence, had problems in caregiving to their patients. The two subcategories of this main category were limited support by family members and relatives and limited financial support by the government.

### Limited support by family members and relatives

The participants received limited support from their family members and relatives for caregiving to their patients and hence, felt inability to give care and could not receive some rehabilitation services. Most of them felt alone and abandoned due to receiving limited support.

*My husband's family provided no support at all. There was nobody to help me take him to bathroom and hence, I asked neighbors for help. I took a private taxi for taking him to physiotherapist several times; but I couldn't take him to the taxi and the taxi driver didn't help me (P. 11).*

The participants also had experienced lack of support due to their family members' and relatives' limited empathy and encouragement for them.

*Instead of offering hope and showing empathy, my mother-in-law often blamed me for his son's conditions (P. 5).*

### Limited financial support by the government

The majority of participants had experienced different problems respecting health insurance payments and inadequate insurance coverage of some medical tests, medical visits, prescriptions, and rehabilitation services. They also had problems with delayed payments by supplemental insurance companies.

*The supplemental insurance company doesn't cover many medications and medical visits. During the past*

*ten months, I had a physiotherapist to come to my house which cost me around ten million Iranian Rials per month. Moreover, I've spent about 500 million Rials for medications and equipment. But, they just paid me twenty million Rials. The government should provide us with more financial support (P. 10).*

## DISCUSSION

Caregivers' experiences of care transition from hospital to home for patients with SCI fell into the four main categories of lack of knowledge, excruciating care, emotional burden of caregiving, and need for support.

Lack of knowledge about SCI and its treatment and prognosis was one of the main categories developed based on the experiences of care transition from hospital to home among the family caregivers of patients with SCI. Family caregivers need information about the process of treatment and its outcomes. In some countries, patients with SCI are admitted to rehabilitation settings after the acute phase of SCI, where they receive care services from professional health-care providers.<sup>[1,15]</sup> However, patients with SCI in Iran are discharged from hospital directly to their homes to receive care from their family caregivers. Consequently, family caregivers clearly need information about the different aspects of caregiving. Such information should be provided by health-care providers throughout the course of treatment and rehabilitation and should be compatible with caregivers' needs. Otherwise, they may experience uncertainties about caregiving. Recognizing the needs of family caregivers is the first step in developing plans for care transition.<sup>[16]</sup> Different studies reported the significance of information exchange among health-care providers, patients, and family caregivers.<sup>[1,15,17]</sup> Family caregivers' lack of information and poor preparation for caregiving can cause them anxiety and dissatisfaction, place heavy caregiving burden on them,<sup>[18]</sup> and thereby, negatively affect care quality. Health-care providers, particularly nurses, need to have effective communication skills and an empathetic attitude in order to establish close relationships with patients and family caregivers and encourage them to express their needs.<sup>[9,17]</sup> Adequate preparation of family caregivers by nurses in hospital settings can enhance their satisfaction with health-care services and with their own caregiving experience at home and help them balance their old and new roles.<sup>[17]</sup> Nurses should provide family members with necessary information about the available options for treatment and care, collect relevant scientific evidence, summarize them, make them understandable for family caregivers, provide them to family caregivers, and thereby help them make informed decisions about care transition.<sup>[4]</sup>

The findings showed that lack of knowledge and its associated uncertainty among family caregivers made them search different sources for information about SCI and its treatment and care. This finding is consistent with the results of previous studies.<sup>[9,17]</sup> Information seeking reflects family caregivers' need for information unmet by health-care providers. Nurses need to establish close relationships with family caregivers during the course of their patients' hospital stay in order to provide them with necessary information<sup>[17]</sup> and facilitate their informed decision-making.<sup>[16]</sup>

Excruciating care was another main category of the study. Most participants were married homemakers who had to simultaneously meet the needs of their disabled and dependent husbands (such as feeding and moving) and perform their household activities (such as housekeeping and cooking). Performing all these tasks was beyond their physical strength and capacity. Most Iranian family caregivers like to give quality care to their patients due to their cultural and religious beliefs and strong familial relationships.<sup>[19]</sup> However, in line with several earlier studies,<sup>[9,17,18]</sup> our findings showed that active involvement in caregiving during care transition from hospital to home caused family caregivers many difficulties in caregiving. Therefore, our participants needed health-care providers to help and support them in caregiving at home. Similarly, two former studies showed that health-care providers' professional support for family caregivers is essential for empowering them in caregiving and promoting their patients' health and independence.<sup>[20,21]</sup> Home-based professional support for family caregivers is routinely provided in Western countries;<sup>[13]</sup> however, home-based services, such as home visit, support, and counseling, are not available for family caregivers in Iran.

The third main category of the study was emotional burden of caregiving. Caregiving-related difficulties as well as sadness and sorrow over their patients' conditions had imposed heavy emotional burden on our participants, made them feel insufficiency in caregiving, and restricted their lives. Hospital to home care transition is associated with intense stress for family caregivers due to their lack of knowledge, skills, and equipment for confidently and effectively managing caregiving situation.<sup>[6]</sup> Similarly, former studies reported that heavy caregiving-related responsibilities impose heavy burden on family caregivers and cause them depression, social isolation, and financial problems.<sup>[13,22]</sup> Family caregivers' heavy emotional burden highlights their great need for strong psychological support by health-care providers, family

members, and support groups. Evidence shows that support groups can give caregivers the opportunity to express their emotions and understand the positive aspects of their situations and thereby, are effective in reducing caregivers' feelings of loneliness and social isolation.<sup>[1]</sup>

The last main category of the study was the need for support. Most participants had experienced feelings of hopelessness and abandonment during care transition from hospital to home. Similarly, former studies reported limited support for family caregivers by relatives, society, and health-care providers.<sup>[13,17]</sup> Social support can significantly reduce caregiving burden among the family caregivers of patients with SCI.<sup>[23]</sup> In Iran, patients and their families usually receive considerable support during the first days after the diagnosis of a chronic condition; however, this support gradually reduces over time, causing families to lose hope over the future.<sup>[24]</sup>

High treatment costs and inadequate insurance coverage were the main sources of concern for participants. Financial problems had restricted participants' access to proper professional care and services. Iranian families need to pay out of pocket most treatment- and care-related costs due to coverage problems in insurance plans.<sup>[25]</sup> Similarly, families in some developed countries have financial and insurance-related problems in caregiving to their patients.<sup>[26]</sup> As low income and inadequate financial support impose heavy burdens on families,<sup>[13]</sup> formal support and adequate financial resources can reduce their caregiving burden.<sup>[17,23]</sup>

Despite sampling with maximum variation, the findings of the present study may have limited generalizability due to the small sample of the study. Further studies on larger samples of family caregivers are recommended to more extensively explore the experiences of care transition from hospital to home among family caregivers.

## CONCLUSION

This study concludes that during care transition from hospital to home, the family caregivers of patients with SCI experience different challenges and problems, bear heavy physical and emotional burden, and receive limited family and social support. These problems can adversely affect the quality of their care services for their patients. The findings of this study can be used by health-care providers, such as nurses, to develop discharge education programs for patients with SCI and their family caregivers based on their literacy level and needs.

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## Conflicts of interest

There are no conflicts of interest.

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