

# Family-Centered Empowerment Process in Individuals with Traumatic Spinal Cord Injury Living in Iran: A Grounded Theory Study

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**Running title:** Family-Centered Empowerment Process in Individuals with SCI

## ABSTRACT

**Study Design:** This was a qualitative study using Grounded Theory Method. **Objectives:** To explain the process of family-centered empowerment in a population of individuals with SCI living in Iran. **Setting:** Brain and SCI Research Center, Social Welfare Center, and SCI Association of Tehran; Iran. **Methods:** Participants were 19 persons with traumatic SCI, 13 family member caregivers, and 11 health care providers selected through purposeful sampling. Data were collected using face-to-face, semi-structured interviews which were continued until data saturation. The interview data were methodically collected and analyzed using Strauss and Corbin's (1998) recommended method for grounded theory. Constant comparative analysis was simultaneously conducted through reviews of the interview statements, observations of behavior, interviewer field notes, and interviewer memos. The analysis was managed in MAXQDA software version 10. **Results:** The process of family-centered empowerment following SCI included 5 categories: 1) disruption in the existential integrity of the individual; 2) constructive life recovery; 3) inhibitors of family-centered empowerment; 4) facilitators of family-centered empowerment, and 5) back on Track. Constructive life recovery was selected as the core variable using the Grounded Theory Method. This core variable identified the strategies most frequently used by the participants to cope with the challenges of SCI related impairment, disability, and overall life management. **Conclusions:** Family-centered empowerment process in individuals with SCI living in Iran emerged from the data. The model includes early disruptions in the bio-psycho-social and vocational lives of individuals with SCI and their families, strategies for recovery post-injury, inhibitors and facilitators of family-centered empowerment, the gradual return to work and daily activities, and the expected social roles for individuals with SCI.

**Keywords:** spinal cord injury, family-centered, empowerment

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31 **Sponsorship:** not applicable

## 32 INTRODUCTION

33 Spinal cord injury (SCI) is among the most devastating problems of the central nervous system  
34 [1], afflicting patients not only with sensory-motor problems, but often with numerous physical  
35 complications for the remainder of their lives. Autonomic dysreflexia, urinary tract stones,  
36 urinary infections, anal sphincter dysfunction, decubiti ulcers, heterotopic ossification,  
37 osteoporosis, stiff joints, and sexual problems are some of the complications that may add to the  
38 impairment [2, 3].

39 The World Health Organization reported that worldwide, 250,000 to 500,000 people suffer from  
40 SCI which is associated with considerable costs for individuals and societies [4]. In Iran, the  
41 prevalence of traumatic spinal injury in Tehran was reported as 1.2 to 11.4 injuries for every  
42 10,000 people from 2008 to 2009[5].

43 Costs of care for SCI and its secondary conditions may impose a heavy financial burden on all  
44 involved [6, 7]. Persons with SCI often face multiple challenges that extend beyond physical  
45 impairment and disability, including the absence of financial, emotional, psychological, and  
46 social support. Moreover, their families often are the primary source of care [8].

47 Families are the most valuable, yet most vulnerable, source of care and support for their family  
48 member with chronic healthcare needs [9]. If they accept the responsibility of providing care,  
49 they often are exposed to numerous psychological and social issues, themselves [10]. In fact, the  
50 management of a chronic condition at home can be a very complex and time consuming activity,  
51 that far surpass mere medical treatment [11]. Many of the social and psychological complexities  
52 associated with having SCI are often ignored by professional healthcare providers making family

support even more challenging. Yet, management for these devastating injuries are next to impossible without the involvement of families [11]. Strategies for helping both individuals and families play an active healthcare role must emphasize empowerment that extends beyond the provision of traditional medical services [12].

In this way financial, social, and emotional dimensions of the lives of patients, their families, and societies can better be addressed. For example, caregivers can assist patients in enhancing their quality of life and can play a role in decreasing social and psychological impairment that often comes with chronic illness [13]. Moreover, to be most effective, healthcare providers need to leverage family caregivers and engage both patients and families in the process of empowerment to promote everyone's long term health and well-being [9].

Family-centered care for persons with SCI may be more challenging than care for other chronic health problems. The management of SCI is a multi-dimensional (physical, psychological, social, cognitive, cultural, and economic) process, which is influenced by various underlying factors [14]. Understanding this process-which starts from the moment of hospital admission and goes through discharge to home and return to society-depends on socio-cultural factors, multi-disciplinary interactions in dynamic contexts that occur between healthcare providers, individuals with SCI and their family caregivers.

Grounded theory method (GTM) is a systematic research methodology used in the social sciences that involves the construction of theory through methodical gathering and analysis of data[15]. GTM works inductively, often beginning with a question or with the collection of qualitative data to study social interactions, structures, and processes. GTM was employed in the current study to examine persons with SCI, their families, and their healthcare providers in their



respective lives and roles. Thus, for the first time in Iran, we aim to explain the process of family-centered empowerment for individuals with SCI using GTM.

## METHODS AND PARTICIPANTS

### *Study design*

This study was a qualitative study using GTM, to investigate the process of family-centered empowerment in individuals with SCI in Iran[16].

### *-Methodology*

Family-centered empowerment is a complex and multidimensional phenomenon, and there is little information about it available in scientific literature. GTM was useful to gather information to improve our understanding of social processes and human interactions by collecting free expression of emotions, reported behaviors, and the participants' life experiences [17].

### *- Ethical Considerations*

This study was approved by Institutional review Board (IRB) at Tehran University of Medical Sciences (No. IR.TUMS.REC.1394.1493). Participants voluntarily participated in this study and could refuse to participate or withdraw at any time for any reason. Furthermore, participants were informed that all identifying information and responses would be kept confidential. The participants who agreed to join in the study were asked to sign an informed consent document.

### *- Sampling and Data Collection*

Participants were recruited from three centers in Tehran: Brain and SCI Research Center, Social Welfare Center, and SCI Association of Tehran using a purposeful sampling technique with a maximum variation sampling strategy to ensure maximum variation among those selected to participate [17]. For example, we collected information on gender, marital status, socio-economic level, cultural background, clinical context, and healthcare profession to ensure the sample included a wide breath of participants. Forty-three people agreed to participate: 11 were healthcare providers, 19 were persons with traumatic SCI, and 13 were family caregivers. Recruitment was from November 2015 to October 2017.

The inclusion/exclusion criteria were as follows:

Healthcare providers: willing to participate in the study and share information and experiences; at least 3 years of clinical experience with SCI; and Iranian and Farsi/Persian speaking. Persons with SCI: over 18 years of age; traumatic SCI at least one-year post; diagnosed paraplegia or tetraplegia; without cognitive impairment or head injury; without extremity fractures; not pregnant; and literate.

Family caregivers: any member of a family (sibling, parent, spouse, or child) of a person with SCI for at least one year; literate; physically and mentally healthy; responsible for the care of an individual with SCI (caregiver approved by the individual with SCI), and not a member of the healthcare treatment team.

Data were collected by using semi-structured, face-to-face interviews until data saturation (i.e., to the state when data review creates no new codes and the extracted categories are considered coherent and logical) [17]. The interviews were performed at a convenient time and place for the participants which included participants' homes, private interview rooms in the research center, or in private areas of the hospital.

Interviews were 30 to 90 minutes in length. Interview questions are presented in Table 1.

121

### ***Data analysis***

The first author (MS), experienced in qualitative research, employed the analysis strategy recommended by Strauss and Corbin (1998) in which constant comparative analysis is used simultaneously with data collection. In this method, interviews are continuously reviewed, along with observations during the interviews, field notes (written records produced by fieldwork) and memos (records of the researcher's developing ideas about codes and their interconnections). Furthermore, this method has three basic steps: open coding, axial coding, and selective coding [17].

All interviews were transcribed and the responses were reviewed and read several times to get a sense of the general concepts and themes that could be identified and coded (i.e., open coding). Next, these codes were compared with each other and overlapping concepts were combined into specified categories and assigned proper descriptive titles (i.e., axial coding) [17]. Field notes were collected in participants' homes and during occupational therapy sessions in which were the families of individuals with SCI or healthcare providers in order to understand the actions, interactions, verbal, and nonverbal behaviors. These notes were also entered into the software for analysis. The number of initial codes was 2,300. Eventually, these codes were organized into five main categories and seventeen axial categories. This analysis was managed in MAXQDA software version 10.

140

### ***- Rigor***

The researchers worked to establish trusting relationships and credibility with the participants with the goal of data enrichment and optimal understanding of the experiences being described. Most participants were interviewed once; three were interviewed multiple times to get enough information. Furthermore, a number of participants (7%) reviewed summary themes and interpretations of the data being collected to validate that researcher's coding/interpretations accurately represented their experiences (member checking). Maximum variation also increased the study's credibility. In order to enhance the reliability of the coding of the participant's statements (confirmability), the interviews and extracted categories were reviewed and verified by two impartial faculty members to confirm agreement on the codes and themes identified. Their perspectives were included. All steps of the study process were described to these two external reviewers and captured for future auditing of the research. Direct quotes, specific examples, and precise descriptions gathered from the participants are provided to assist potential generalization (i.e., transferability) to other situations and patients with SCI [18].

## RESULTS

Demographic characteristics of the participants are presented in Table 2. Five main categories emerged from the data analysis: 1) disruption in existential integrity of the individual; 2) constructive life recovery; 3) inhibitors of family-centered empowerment; 4) facilitators of family-centered empowerment and 5) back on Track. Constructive life recovery was selected as the core variable and was a set of strategies participants most frequently used to deal with the injury and its consequences. The categories and sub-categories are fully described below:

(There are two appendixes; Appendix 1: Categories/ sub-categories and quotes from participants, Appendix 2:

165 Theory diagram: towards constructive life recovery.)

## 166 **1- Disruption in Existential Integrity of the Individual**

167 Participants reported that several dimensions of their lives are affected following SCI. Sub-  
168 categories that emerged from the analysis are described below:

### 169 **1-1 Potentially harmful emotional reactions**

170 Negative emotions such as, denial, anger, and depression are themes included in this sub-  
171 category.

### 172 **1-2 Poor social interactions and isolation**

173 Most of the families and individuals with SCI prefer to stay at home and isolated from others.  
174 They cite their reasons as shame over physical impairments, pain and/or muscle spasm, and fear  
175 of frustration. Social isolation was somewhat more common than “fear of frustration” which  
176 included two themes: "restrictive concerns about employment or an educational situation" and  
177 "concerns about the impossibility of marriage”.

### 178 **1-3 Family structure transformation**

179 This sub-category included themes such as "changes in interpersonal relationships," "changes in  
180 the role of family members," and "dealing with family deprivations." Changes in interpersonal  
181 relationships included such concepts as harmony of relationships, distressed relationships, and  
182 total relationship breakdown. Some of the identified causes of interpersonal relationship  
183 disruption were lack of sexual activity with the spouse, blaming a family member for the  
184 accident that caused the SCI, and poor financial situations as a result of increased healthcare  
185 expenses.

186 Changes in the role of family members included additional sub-categories of "increased  
187 workload” followed by “increase in the responsibilities" and "long-term involvement in the role





188 of caregiver." We found that in most cases, one family member assumes the burden of care for  
189 the injured person.

190 Dealing with loss is another problem area for families. This includes loss of work and  
191 educational opportunities, loss of comfort, loss of emotional support for spouse and children,  
192 financial damage, physical and psychological damage, and loss of dignity in the family.

193 1-4 Difficulties caused by physical problems

194 Restricted mobility (e.g., paraplegia and tetraplegia), bowel disorders, sexual disorders, pain  
195 and/or muscle spasms, immobilization caused by problems such as decubitus ulcers,  
196 osteoporosis, and heterotopic ossification were frequently mentioned themes.

## 197 **2- Constructive Life Recovery**

198 This concept was revealed in the data as the core variable and described the strategies most  
199 frequently used to deal with participants' greatest concerns about SCI-related impairment,  
200 disability, and life management post-injury. This core category emerged from three big sub-  
201 categories, including the following:

### 202 **2-1 Active coping with disability**

203 This sub-category was comprised of several themes including positive emotions such as  
204 exploration, recovery of hope and motivation, establishing social communications, reaffirming  
205 spirituality, correcting faulty thinking, and reforming attitude.

#### 206 **2-1-1 Exploration**

207 Most individuals with SCI and their families, especially in the first year post injury, did not have  
208 sufficient information about SCI. They obtained knowledge through the Internet, healthcare  
209 providers, peers, relatives, workshops presented by SCI associations, and occasionally through

210 TV programming. Health information, governmental and non-governmental support networks  
211 were part of this theme.

#### 212 2-1-2 Recovery of hope and motivation

213 Within this theme, some participants reported hope and motivation by comparing their own  
214 situations to those of other patients and families dealing with more complicated physical  
215 impairments (e.g., the loss of a hand or complete quadriplegia), noticing the return of physical  
216 sensation and mobility, and a sense of responsibility for the family.

#### 217 2-1-3 Establishing social relationships

218 Individuals with SCI and their families were trying to re-connect with their social communities,  
219 as they may have become isolated post-injury. These communications included re-establishing  
220 relationships with non-injured peers (i.e., friends and relatives), and building relationships with  
221 peers in the patient associations, health centers, research centers, and/or through the Internet  
222 (e.g., responding to others with SCI through social media such as Telegram or WhatsApp). Most  
223 of those who were in contact with others using social media were young and those with  
224 paraplegia.

#### 225 2-1-4 Reaffirming spirituality

226 This concept emerged from themes such as trust in God, pilgrimage, prayer, and vows. Most of  
227 the individuals with SCI and their families used the term "trust in God" in their interviews. In the  
228 Iranian culture, people become closer to God and pray more when they are in trouble. Also, most  
229 individuals with SCI consider their disability as the will of God. In the Islamic-Iranian culture,  
230 the belief in the "divine test" makes facing challenges easier.

231 Participants reported using their faith and spirituality to reduce stress and anxiety, and to cope.

232 The religious practice of the pilgrimage of Imams was another coping strategy.

233 The other themes in this category were resorting to prayer and vows. Some individuals with  
234 SCI and their families vow to do good deeds for the sake of God, if they can overcome current  
235 difficulties or improve circumstances. These vows typically include charitable acts, such as  
236 giving food or money to those who are in need.

#### 237 2-1-5 Correcting faulty thinking

238 Cognitive re-framing was another theme that emerged from the data. When attitudes and  
239 cognitions change, behavior change often follows. Interview data suggested that positive  
240 attitudes helped the participants to more effectively cope with daily struggles. This theme  
241 included "correcting thinking" and "optimism."

#### 242 2-1-6 Reforming attitude

243 A number of participants also tried to be more positive about those around them. Interview data  
244 suggested that an attitudinal shift makes them less anxious.

#### 245 2-2 Efforts to achieve and promote physical function

246 Many persons with SCI, with the support of family caregivers and the rehabilitation team, make  
247 efforts to reach physical and functional independence. This sub-category included physical  
248 rehabilitation and assistive devices, complementary medicine methods, and achieving self-  
249 reliance.

#### 250 2-2-1 Using physical rehabilitation and assistive devices

251 Strengthening exercises, and the use of assistive devices, such as canes, walkers, AFO's and  
252 KFO's, and wheelchairs are included in this category. Rehabilitation services (i.e., occupational  
253 therapy and physiotherapy) and home modifications to ensure accessibility also were described.  
254 A small number of individuals with SCI with greater financial resources purchased elevators and  
255 electric wheelchairs.

## 2-2-2 Using Complementary medicine

Some study participants used complementary medicine and expressed an open attitude toward energy therapy (e.g., using physical touch for stress reduction and health), homeopathy, traditional medicine (e.g., treatment based on the body's temperament and individual characteristics, and beliefs related to herbal, animal and mineral medicines), acupuncture, water therapy, and cell therapy.

## 2-2-3 Achieving self-reliance

Most of the participants described significant attempts to become independent. There were two themes: "innovation in building rehabilitation assistance tools by the family" and "efforts for becoming independent in personal affairs." A small number of participants and their families had invented creative devices to assist rehabilitation; some of the participants also tried to do more to take care of their personal affairs. Some families were described as playing an important role in helping the individual with SCI to become more independent.

## 2-3 Efforts for life management

This sub-category includes concepts of self-awareness, self-control and life balance.

### 2-3-1 Thinking and self-awareness

Some individuals with SCI and their families have thought about the ramifications of ongoing physical impairment and have become aware that SCI is a life-long condition that may require alterations in life plans.

### 2-3-2 Self-control

A number of participants explained taking control over themselves and their behavior.

### 2-3-3 Life balance

A number of participants worked to restore a sense of balance to their lives.



### 3- Inhibitors of Family-Centered Empowerment

Several variables that inhibit empowerment of individuals with SCI and their families were identified. The main category of inhibitors of empowerment consist of 5 sub-categories which are described below:

#### 3-1 Lack of family and patient education

One of the most frequently mentioned needs of persons with SCI, their families, and healthcare providers was training and education in the comprehensive management of SCI. Themes included the following:

3-1-1 Lack of proper training programs: Participants described a failure to educate patients and families about basic primary health issues associated with SCI.

3-1-2 Independence vs. dependence on others: During the interviews, many families expressed the desire to help their injured member as much as possible and seemed unaware of the potential of encouraging greater dependence and furthering unnecessary disability.

#### 3-2 Being in problem-oriented healthcare system

Some participants believed that a portion of the barriers to family-centered empowerment are associated with the healthcare system, itself, and its acute care emphasis. These were identified in themes of:

3-2-1 Lack of professional competence: A number of participants cited negative interactions, lack of communication skills, and lack of SCI knowledge in healthcare providers.

3-2-2 Poor teamwork: Teamwork among providers was described as weak.

3-2-3 Lack of patient follow-up system: Participants noted a lack of follow-up services or systems to ensure ongoing care.

301 3-2-4 Lack of government-sponsored home care services: Most participants noted the high costs  
302 of care without insurance benefits, travel difficulties for rehabilitation therapists, and a lack of  
303 SCI awareness in the community.

304 3-2-5 Lack of shared decision making: Most participants and many of the healthcare providers  
305 described the need for more shared decisions about SCI care.

306 3-3 Failure to support transition back into the community

307 The themes that created this sub-category included the following:

308 3-3-1 Lack of social facilities: The primary codes such as "lack of accessible entertainment  
309 places in the community," inaccessible streets and sidewalks," and "inadequate insurance  
310 coverage" (which was noted most frequently) created this category.

311 3-3-2 Lack of financial resources: One of the most concerning issues described by the majority  
312 of participants was the lack of state funding and the low economic status of many patients.

313 Some participants said that inadequate financial allocation of resources in our country has  
314 significantly affected urban planning, legislation, adaptation, and disability focused services.

315 3-3-3 Lack of employment opportunities: Participants noted the shortage of jobs and a failure to  
316 comply with employment laws for disabled people.

317 3-4 Hurtful reactions from others

318 Many participants expressed distress with the responses of people in their communities. They  
319 described reactions to their physical impairment made them feel socially isolated. Two themes  
320 were identified:

321 3-4-1 Humiliating reactions: Many individuals with SCI and some of their families mentioned  
322 that the reactions of others felt demeaning and discouraged them from being out in the world.

3-4-2 Pitiful reactions: Many participants perceived that others felt sorry for, or stared at them inappropriately.

3-5 Secondary impairment:

Some participants described increasing dependence on others, post-injury, due to the development of secondary physical impairments. Physical complications, such as carpal tunnel syndrome and pressure ulcers, were specifically identified as playing a role in limiting independence in patients with SCI.

3-6 Nonadherence to recommendations for independence

Nonadherence to recommendations was another sub-category that described barriers to becoming independent in activities of daily living and activities outside the home. The following themes emerged:

3-6-1 Lack of cooperation with family and the healthcare team: Family members described the lack of willingness for the injured person to do anything to take care of themselves or work toward independence.

3-6-2 Discounting the experiences of peers with SCI: Some individuals with SCI didn't care to learn about or use the experiences of injured peers.

#### 4- Facilitators of Family-Centered empowerment

A number of factors facilitated the family-centered empowerment process. The sub-categories described below were identified as enhancing empowerment:

4-1 Personal characteristics

The sub-category of personal characteristics included themes around "religious beliefs," "supportive family," and "disability benefits." Religious beliefs were described as extremely helpful for individuals with SCI and their families. In addition, a family psychological support



seemed to facilitate empowerment. Finally, a small number of individuals with SCI received disability income post-injury, which partly helped them to pay for costs of care.

#### 4-2 High quality rehabilitation services

The quality of healthcare and the available rehabilitation services were a source of empowerment for patients and their families.

#### 4-3 Benefiting from NGOs and charities

Participants spoke positively about organizations that provide rehabilitation services at low prices and offer free transportation.

### 5- Back on Track

A number of participants reported their lives returned to some sense of normalcy post injury. Some returned to work; some married and had children. This category consisted of two sub-categories:

#### 5-1 Gradual return to society

Some individuals with SCI were able to return to their previous jobs or find new jobs with support of their families. Others were able to continue their education.

#### 5-2 Recovery of normal life

Marriage and having children were included in this category.

## DISCUSSION

This qualitative study was an exploration of the process of family-centered empowerment in individuals with traumatic SCI living in Iran. GTM was used to develop our model. The analysis for the present study was based on five main categories, entitled, “disruption in



369 existential integrity of the individual,” “constructive life recovery,” “inhibitors of family-  
370 centered empowerment,” “facilitators of family-centered empowerment,” and “back on track”  
371 The process of family-centered empowerment in individuals with SCI starts with a  
372 Disruption in the Existential Integrity of the injured person. This main category included changes  
373 in physical and psychological function, along with alterations in family and social interactions.  
374 Egnew stated that the absence of health threatens the existential integrity of the individual  
375 as comprehended within a whole related to physical (i.e., body function), mental (i.e.,  
376 psychological wellbeing), and social (i.e., interpersonal and family relationship) [19].  
377 The analysis of the interviews conducted with this study population identified content  
378 reflective of Egnew’s concepts.

379 Constructive Life Recovery was identified as the core variable in this study. This core variable  
380 identified the strategies most frequently used by the participants to cope with the challenges of  
381 SCI related impairment, disability, and overall life management. The findings were that SCI  
382 affected the injured person and his /her family, alike. As a result, families and individuals  
383 with SCI struggled to cope with issues of a devastating injury and the subsequent  
384 physical impairment, while they simultaneously worked toward functional recovery,  
385 independence and successful management of a lifelong condition.

386 The first sub-category under Constructive Life Recovery was active coping with  
387 disability which included themes of coping with injury such as exploration, recovery of  
388 hope and motivation, re-establishing social relationships, reaffirming spirituality, and a  
389 reforming attitude. The existing literature on persons with SCI supports similar findings.  
390 Matter et al. reported that people with SCI typically seek information from a variety of  
391 resources to learn more about their condition or related issues [20]. Dorsett reported that

392 increasing sensations and movement in paralyzed limbs after a period of time boosted  
393 hope in individuals with SCI [21]. Kennedy et al. reported that most individual with SCI  
394 eventually reintegrate with their family, friends, and expanded social networks similar to  
395 the participants in the current study[22]. Furthermore, reaffirming spirituality in the  
396 present findings was similar to Marini et al.'s results. They noted that the majority of  
397 persons with SCI used spirituality to cope with their injury and that some patients  
398 believed that SCI made them more spiritual, in general [23]. In addition, Kennedy et al.  
399 found a correlation between optimism and functional independence in the SCI population  
400 [24].

401 The second sub-category under Constructive Life Recovery included efforts to achieve  
402 and promote physical function. Three themes were identified: physical rehabilitation and  
403 use of assistive devices, complementary medicine, and achieving self-reliance.

404 Kehn and Kroll, in a qualitative study, found that individuals with SCI desire to  
405 participate in activities, but face a number of obstacles, such as the lack of financial  
406 means for rehabilitation equipment [25]. Van Buyten et al. reported that people with SCI  
407 used various complementary therapies including massage, acupuncture, and percutaneous  
408 electrical therapies to reduce the pain often associated with injury [26]. Lam et al. found that  
409 individuals with SCI try to walk with the aid of assistive devices (such as prostheses, orthoses,  
410 canes or walkers) [27]. The theme of achieving self-reliance found in the current analysis  
411 included leveraging rehabilitation assistance and working toward independence in personal  
412 affairs. Gowan and Roth reported that strong family functioning was related to independence in  
413 persons with SCI which was similarly noted in our findings [28].

414 Efforts for life management was the third sub-category in the core category of Constructive Life  
415 Recovery which included themes of thinking and self-awareness, self-control, and life balance.  
416 Boschen et al. evaluated coping strategies in persons with SCI and indicated that individuals  
417 sometimes modified their life goals and altered their expectations toward goals they perceived as  
418 more achievable. They noted that family members, friends, or rehabilitation professionals could  
419 help in this regard, and conversely, that negative attitudes of others could lead to limited choices  
420 and a reduced sense of self-control, thus compromising the independence of the individual with  
421 SCI [29].

422 The third main category was entitled, Inhibitors of Family-Centered Empowerment, and  
423 addressed barriers to the care and management of persons with SCI. Inhibitors to empowerment  
424 were lack of family and patient education, a problem-oriented healthcare system, lack of social  
425 facilities, poor financial support, hurtful reactions from others, and unintended dependence.  
426 Lack of family and patient education was a broad sub-category including lack of proper patient  
427 and family training programs, misconceptions about disability, and lack of family participation  
428 and patient in care-related decision-making. Juguera et al. noted that both the patient and family  
429 need information, training throughout the process of suffering, and the creation of informal  
430 groups of mutual aid[30]. Shields et al. investigated children with physical disabilities and found  
431 that barriers for activity included parental behavior, negative attitudes about disability, lack of  
432 disability knowledge and inadequate community facilities[31]. These barriers were similar to  
433 those identified by adults with SCI in the present study.

434 Problem-oriented healthcare systems that focus on acute problems at the expense of chronic care  
435 management were seen as inhibitors to empowerment. Some of the issues identified were lack of  
436 comprehensive services, lack of professional expertise, poor healthcare teamwork, lack of a

437 patient follow-up system, and lack of government-sponsored home care services. The lack of  
438 professional competence and expertise was similar to the concerns raised by Chang who was  
439 working to develop a successful rehabilitation model. Chang described the importance of  
440 specialized training for the members of the rehabilitation team which included not only technical  
441 skills, but also communication competencies to provide appropriate care to the SCI population  
442 [32]. Furthermore, home care in Iran is not government supported. Nikbakht-Nasrabadi and  
443 Shabany-Hamedan have called for the establishment of a home healthcare system for helping  
444 this population [33].

445 Lack of social facilities, low socio-economic status, hurtful reactions from others, unintended  
446 dependence and nonadherence to recommendations for independence were sub-categories and  
447 viewed as barriers to family-centered empowerment. Physical and financial dependence on one  
448 or more family members is an obstacle; moreover, inadequate social facilities, restricted access  
449 to healthcare services, and limited social support networks can impair the empowerment of  
450 people with physical impairment and disability [34]. Hurtful reactions from others was a sub-  
451 category of the inhibitors. Hosseinigolafshani et al. found that individuals with SCI believed  
452 people that do not have any experience with or exposure to SCI, and often expressed hurtful,  
453 negative, and misinformed attitudes toward injured persons. These reactions were described by  
454 persons with SCI as extremely painful, undermining, and in some cases were described as being  
455 more difficult to cope with than the actual SCI event. Importantly, the negative attitudes of  
456 others were reported to worsen the injured persons' sense of hope and confidence [35].

457 Nonadherence to recommendations for independence was another sub-category of barriers to  
458 empowerment. This sub-category captured persons with SCI who were unwilling to engage in  
459 their care and develop independence in functioning. It seemed that some participants struggled



to come to terms with the fact that they have sustained a life changing injury that requires them to modify almost everything in their lives. Olney et al. found that one of the consequences of such denial is poor psychosocial adjustment which makes the follow-up and treatment of patients difficult [36].

The fourth main category of family centered empowerment was called Facilitators of Family-Centered Empowerment. Personal characteristics and benefiting from quality services were sub categories. Personal characteristics included religious beliefs, a supportive family, and a professional position before injury. Löfvenmark et al. conducted a qualitative study on individuals with SCI and reported findings which emphasized strong family support, adequate source of income, and faith as strong empowerment facilitators [37]. High quality rehabilitation services were another sub-category in the fourth main category. According to a World Health Organization report, deficient rehabilitation care for people with physical impairments and disabilities is an obstacle to full societal integration and that this is a problem not just in acute care, but across one's lifespan. Therefore, quality services may be a facilitator in the family empowerment path [38]. Benefiting from NGOs and charities was another sub-category. Khan et al. stated that NGOs and charities have been essential in funding rehabilitation services to help empower affected people [39].

back on Track was the final main category in the present study. It had two sub categories including gradual return to society and recovery of normal life. Lidal et al. found that return to work rates following SCI ranged from 11.5% to 74% [40]. In a qualitative study conducted by Pashaei Sabet et al., findings included that people with disability seek return to normal conditions and gradually adapt to their problems over time [41]. The themes of marriage and having children were included in the sub-category of return to normal life. Zahra Khazaeipour et

al.'s study noted that childbearing after SCI makes individuals feel that they have returned to the life they expected prior to injury [42] and this finding was similar to the sentiments expressed in the present study.

#### **- Limitations**

One of the limitations of the current study was the variability in the study population of level of SCI. Because different types of SCI might be associated with different challenges and experiences, some of the findings might not be generalizable to a larger SCI population. Furthermore, the cause of injury was a result of trauma for all of the participants and their families. As a result, the findings in this study population might not generalize to the broader population of persons with SCI. Finally, there are geographic constraints. Because participants were recruited from care centers in Tehran province, results might not be generalizable to other countries.

#### **CONCLUSION**

Our investigation of family-centered empowerment in individuals with traumatic SCI found the process to be dynamic, complex, multifaceted, and ongoing. We generated a conceptual model of these processes through the methodical gathering and analysis of interview data from individuals with SCI, their family caregivers, and their healthcare providers. Numerous changes across several dimensions in the lives of patients with SCI and their families were identified, including the significant challenges of coping with impairment and disability, while simultaneously working toward functional independence and management of life following injury. Factors inhibiting empowerment were categorized as deficiencies in patient education and

specialized rehabilitation services, acute focused healthcare, and negative reactions from others about SCI-associated impairment. Factors determined to facilitate empowerment were categorized as psycho-social-vocational characteristics of the patient, high quality rehabilitation care, and support through NGOs and charities. According to the barriers mentioned, further research is needed to provide a prescriptive model that can improve the overall health and independence of the SCI population.

### Clinical messages

- Education and communication need to be improved in healthcare systems and in providers' work practices to achieve integrated rehabilitation and family centered empowerment for persons with SCI.
- Self-care education is needed for individuals with SCI and their families.
- SCI awareness is necessary in Iranian society for both individuals with SCI as well as the larger population.

### Data Archiving

The datasets generated and/or analyzed during the current study are not publicly available due to confidentiality and privacy of the participants but are available from the corresponding author on reasonable request.

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There is no acknowledgement.

### Statement of Ethics

We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research.



## Conflict of interest

The Author(s) declare(s) that there is no conflict of interest

## Author Contributions

MS responsible for suggesting topic, performing and typing interviews, analyzing and interpreting the interviews, writing the manuscript. ANN was responsible for interpreting the interviews, helping to acquiring data, drafting and revising the article. NM analyzing the interviews, drafting and revising the article. SP helping to translation, critical revise and drafting the article.

ANN and NM assessed the accuracy of analysis and extracted themes, and their perspectives were applied.

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## Legend for Supplementary Material

Supplementary information in this article is directly relevant to "Result" included Appendix 1: Categories/ sub-categories and quotes from participants, Appendix 2: Theory diagram: towards constructive life recovery.





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